Appendix A:

Assisted Dying in Jersey Phase 2 Consultation Feedback:

Organisation responses

The list of organisations and their full responses to the Assisted Dying consultation are presented below. The responses include written submissions made by organisation representatives and/or their responses to the online survey.

1. All-Party Parliamentary Group for Choice at the End of life
2. The Anscombe Bioethics Centre
3. Association for Palliative Medicine of Great Britain and Ireland
4. CARE (Christian Action Research and Education)
5. Care Not killing and Our Duty of Care
6. Catholic Union of Great Britain
7. Channel Islands Humanists
8. Christian Medical Fellowship (CMF)
9. Compassion & Choices
10. DIGNITAS
11. Dignity in Dying
12. End of Life Choices Jersey
13. European Institute of Bioethics
14. General Medical Council
15. Go Gentle Australia
16. Humanists Against Assisted Suicide and Euthanasia
17. Jersey Dying Well Group
18. Jersey Evangelical Alliance
19. Lives Worth Living
20. Living and Dying Well
21. Medical Ethics Alliance
22. My Death, My Decision
23. National Secular Society
24. Quennevais Evangelical Church
25. Royal College of Psychiatrists
26. The Christian Institute
27. The Nursing and Midwifery Council (NMC)
28. Tōtara Hospice

1. All-Party Parliamentary Group for Choice at the End of life

Submission to the Government of Jersey Consultation on Assisted Dying

The All-Party Parliamentary Group for Choice at the End of Life

From Karin Smyth MP and Rt Hon Kit Malthouse MP, Co-Chairs of the Group

The All-Party Parliamentary Group for Choice at the End of Life is a group of MPs and Peers who meet to support the aim of promoting greater patient choice at the end of life, particularly over where, when and how one dies. The APPG's purpose is:

> To improve the experience of dying in the UK by promoting and expanding people's choices at the end of life. To promote a change in the law to allow the choice of assisted dying for terminally ill, mentally competent adults.

Since it was established, the APPG has worked proactively and purposefully to gather evidence from a range of experts, nationally and from overseas, on the practice of assisted dying and the impact of the blanket ban in the UK. We focus on lived experience rather than speculation. These efforts have prompted targeted actions in support of law change - for example, the then Secretary of State for Health and Social Care, the Rt Hon Matt Hancock MP's request to the Office of National Statistics for more data on suicides by terminally ill people in 2021. We also heard from supporters of Dignity in Dying's Compassion is Not a Crime campaign who called on the then Justice Secretary to launch an inquiry into the impact of the current law.

The evidence submitted below is a brief summary of the information the APPG has gathered from people who have been impacted by the blanket ban on assisted dying. These stories support our conclusion that the status quo is unjust, unsafe and unacceptable and that government time must necessarily be devoted to addressing this issue in a comprehensive and evidence-based manner.

The APPG endorses the submission by Dignity in Dying on the detailed policy questions.

The blanket ban on assisted dying has resulted in unacceptable failings in patient safety

Our outdated law on assisted dying discriminates between those who can and cannot afford an assisted death in Switzerland; criminalises grieving relatives who support their loved ones to exercise control over their deaths; and forces a small but significant number of dying people to end their lives before they are ready in lonely and sometimes violent ways.

Dying people in this country are the biggest victims of the ban and its unequal effects. Financial and logistical challenges make travelling abroad a 'business class' option for only a small number of people. In addition to the substantial cost, the process of arranging an assisted death abroad can be extremely difficult and time-consuming, meaning people often need the help of friends and family to make arrangements. Yet providing any assistance is against the law.

Ann Whaley told the APPG how she was investigated by police after an anonymous call alerted social services of her plan to accompany her terminally ill husband Geoffrey, 80, to Dignitas in February 2019.

> *"Geoffrey had been by my side for over 50 years and I was determined to be by his until the very end. But in supporting his final wish to die with dignity, I became a criminal under British law. It was utterly devastating to think that I might be arrested or that Geoffrey might be stopped from travelling to Dignitas"*

The requirement to be physically able to travel to Switzerland to have an assisted death also means people are ending their lives much sooner than they might otherwise choose to. An NHS clinician, speaking anonymously to the APPG in order to protect her loved ones, explained the realities that she has been forced to face in order to have a dignified death:

> *"I am 45 and until my diagnosis of secondary breast cancer last September I was a senior mental health professional in the NHS. (She died at Dignitas in Nov 2020). Like many of the people who have succumbed to Covid-19 this year, I am being forced to die in the presence of strangers, in unfamiliar surroundings, without my husband, family or friends to comfort me. In my case, however, it is the result of the antiquated laws on assisted dying in the UK, which have compelled me to travel to a foreign country to die alone."*

The disparity between the choices available to dying people in the UK and those in jurisdictions which offer more meaningful choice at the end of life through a safeguarded assisted dying law was brought home to the APPG by Sher and Joy's stories. Sher Safran explained:

> *"In 2017, the year both my parents turned 88 years old, each one of them was diagnosed as terminally ill, and each was given 6 months or fewer to live. Dad Charlie was failing from advanced Parkinson's and prostate cancer, and mum Francie was declining from advanced coronary disease, heart attacks and small strokes. They lived in Oregon state which 20 years before had passed the death with dignity law. My parents always believed that there should be the choice of peaceful dying wherever possible. The week before they died they had arranged for all of us in the family to come together and celebrate their life. On April 20th, at 10 am that morning, mum and dad each drank their medicine, and then they laid down together on their bed as they had done for nearly every night for 66 years. And they held hands, and closed their eyes and they fell asleep. My mum passed very peacefully in 15 minutes, and my dad passed very peacefully 45 minutes later. Their death reflected so beautifully the intent and grace of their lives."*

Meanwhile, Joy Munns told us about how her mother, Mavis Eccleston, 80, from Staffordshire, was charged with the murder and manslaughter of her husband Dennis, 81, after he ended his own life at home in February 2018 while dying of bowel cancer. Mavis, who had attempted to overdose at the same time, was resuscitated and later charged. A jury unanimously found her not guilty on both counts following a trial at Stafford Crown Court in September 2019. Joy explained:

> *"My mom would have done anything for her husband, but she had no idea that her actions, motivated purely by love, would land her in the dock. On top of losing Dad, we were terrified we would lose Mom to life in prison. Under an assisted dying law, this would never have happened. Politicians have to face facts – a law is clearly not working if it makes criminals of innocent great-grandmothers."*

In 2021 Dignity in Dying published a report, Last Resort, which tells the stories of the dying people who took their own lives in the absence of an assisted dying law. The report estimated that up to 650 terminally ill people take their own lives every year in the UK in the absence of the safe, legal choice of assisted dying. In April 2022, the Office of National Statistics published data, commissioned by the former Secretary of State for Health and Social Care, the Rt Hon Matt Hancock MP, indicating that people with severe and potentially terminal health conditions are more than twice as likely to take their own lives than the general population.

The devastating impact that the current law has on individuals and their families was revealed to the APPG by loved ones left behind. Irene explained to us that:

> *"My son Gavin was diagnosed with throat cancer in 2014 at just 50 years old. The throat cancer was rapidly advancing, he couldn't swallow anything - we were told that the tumour would grow daily and, in effect, would slowly but surely strangle him. An assisted dying law could have eased so much of his suffering, knowing that when it became too much he could choose to die when and how he wanted. Without this choice, Gavin felt he was out of options. A few days before he died he attempted to end his life at home and was admitted to hospital. But his choices - or lack of choices - remained the same.*

> *It is a measure of his desperation that he walked out of the hospital Emergency Department onto a nearby main road and threw himself in the path of a passing lorry. The effect of the manner of Gavin's death on me and my family is ongoing and unforgettable. I feel I failed him and grieve every day. How much easier it would have been for all of us if Gavin had been given the choice of an assisted death. My family and I could now have an image of him of dying peacefully surrounded by those whom he loved and who loved him. We wouldn't have his violent end constantly hanging over us."*

Palliative care and assisted dying are not mutually exclusive.

The APPG supports greater investment in palliative care alongside the development of a safeguarded assisted dying law. Overseas evidence demonstrates that even with access to the highest quality of palliative care services, some people still suffer and wish to have control over the timing and manner of their death. There is evidence that palliative care can flourish alongside the introduction of assisted dying legislation.

Addressing the APPG in 2021, Dr Bill Crawley, former GP, practising palliative care lead and experienced palliative care physician, acknowledged that while the majority of people are able to have "what might be termed 'good' deaths" with access to palliative care, his own professional experiences have shown him that a significant minority of patients still die without adequate symptom control or pain relief. Dr Crawley said that he had often been asked by patients for more choice at the end of their lives, and that on many occasions he had witnessed suffering beyond the reach of the current options available. This included patients with motor neurone disease experiencing 'air hunger' when removing a ventilator in order to hasten death, and cancer patients being strangled by tumours wrapped around their trachea or vomiting faeces due to bowel obstructions. He added that:

> *"choice at the end of life, to have an assuredly dignified death in skilled hands, is the only way we can be sure that patients do not have to tolerate subjectively intolerable symptoms."*

Professor Sir Paul Cosford, Emeritus Medical Director at Public Health England, who died of lung cancer in April 2021, shared his experiences of living with a terminal illness with the APPG in November 2020 and wrote about assisted dying in the British Medical Journal. He said:

> *"My biggest fear around dying is the lack of control…The lack of ability, if all becomes too much, to advance the end a little, to take some control in my final days. I might have a diamorphine pump at that time, and the idea of having an extra vial in the fridge for me to use if I need it is appealing. Despite helpful conversations with excellent palliative care specialists, this final element of choice and self-determination seems to evade me."*

Overseas evidence demonstrates that legislation which balances individual autonomy and the protection of vulnerable people is possible and preferable to the status quo

Assisted dying, as supported by the APPG, describes the process of prescribing on request, life-ending medication to an individual with mental capacity who is already dying, in order to give them the means to control the manner and timing of their own death. This is the eligibility criteria which underpins the legislative models adopted in 11 US states, all six Australian States and in New Zealand.

The evidence we gathered from parliamentarians and frontline clinicians from these jurisdictions, confirms that such an approach successfully balances the importance of promoting individual autonomy at the end of life while protecting those who may be vulnerable.

The Rt Hon Helen Clark, former Prime Minister of New Zealand, said at an APPG meeting in November 2020:

> *"The central objective of the End of Life Choice Act is to offer the option of assisted dying to terminally ill New Zealanders who meet the criteria set out in the Act. You cannot access this Act if you have a mental illness. You cannot access this Act if you have a disability alone. You must have a terminal*

> *illness which is likely to end your life in the next six months….it is about enabling people to live better as they are dying – whether or not they choose this option – in addition to easing the deaths of those who do and providing protection to the most vulnerable in our society."*

Dr Catherine Forest M.D., M.P.H., is a clinical associate professor of community and family medicine as well as a public health specialist. In 2021, her spouse, Will Forest, who was terminally ill with motor neurone disease, requested and received the aid-in-dying law Catherine had championed in their home state of California. She explained what the law looks like in practice when she supports patients at the end of life:

> *"Several times, I have had tough conversations with people who do not qualify. The law requires that patients are terminal with less than six months to live, can take the medication on their own, and have the capacity to make their own medical decision Therefore, people with diagnoses like Alzheimer's disease and other dementias do not qualify. I regret that better options aren't available for these patients. However, I believe that learning from current legally defined conditions is important. We need to make sure no one is coerced or chooses assisted dying when they don't have the capacity to make the decision for themselves."*

Jill Hennessy, who was the Australian minister in charge of Victoria's Voluntary Assisted Dying Bill explained how the Government collaborated with eminent specialists, from neurologists to leaders in palliative care, as well as legal experts, in order to ensure protection and clarity through their law and clinical protocols. . She explained that while the passage of the legislation was hard-fought, once passed, politicians quickly accepted the new status quo:

> *"The sky hasn't fallen in. In fact, the highlight of my day is getting letters from people who have been with their family when their choice has been exercised and where their end of life has been achieved with dignity."*

Time and time again, British citizens have testified to the APPG that the choices at the end of life available to citizens in the US and Australia for example are the same choices they wish to have here. Kit explained:

> **"***In 2017 I was diagnosed with secondary breast cancer, but since I was born I have also lived with a mobility impairment which makes walking very painful. I know my cancer cannot be cured, but I want to explore every possible treatment to prolong my life. But the further I go, I know the drugs will become less effective and the side effects get worse. Eventually my options will run out. I've already had adverse reactions to pain meds like morphine; doctors can't guarantee they can keep me pain-free. When I reach that stage, I just want the ability to go out as 'me'. I don't want to be drugged out of my mind, not knowing what's going on, or unable to express myself. I don't want to put my death in someone else's hands, I want to go on my own terms. It feels unfair that people who don't have terminal illnesses are deciding things for people who do."*

She concluded:

> *"I don't want to die, but if I have to, then I want to die 'free' and I want to die 'me'."*

Dr Stephen Duckworth OBE, a veteran disability rights campaigner who has been a wheelchair-user for 40 years, highlighted the important distinction that needs to be made between disabled people and those who are terminally ill in debates on assisted dying. In addition to talking about his own strong support for greater end-of-life choice which is shared by 86% of disabled people, Dr Duckworth criticised non-disabled opponents who "exploit the experiences of disabled people and the inequalities and fears we endure in our daily lives", using this "as a smokescreen for their own agenda to block progress on this issue". He added that:

> *"There is no hierarchy of rights. Equality for disabled people cannot be addressed by denying dying people the autonomy, choice and control that they want and deserve over their lives."*

Conclusion

Former Health Minister in Victoria, Australia, Jill Hennessy, who was the Minister in charge of Victoria's Voluntary Assisted Dying Bill summarised what legislators in the UK now need to do:

> *"The Victorian laws have been used safely, they've been used compassionately and all of the risks and reasons that people have used as objections, none of those fears, none of the fearmongering that we've seen during the debates on assisted dying has materialised. The Parliamentary Committee had made some recommendations and we used the resources of government to help develop the model. We took those recommendations and we established a panel of eminent people in the medical and legal world. With the use of the experts, we were able to, with political consensus, work through each of these issues and we developed our model of assisted dying.*
>
> *"We should never let our political leaders get away with saying that the status quo is acceptable. When people are engaged in a debate about the reasons not to embrace law reform, they must engage in why the status quo is unacceptable. An important part of the debate in Australia was evidence from the coroner about these tragic stories. Evidence from our judiciary who were having to preside and prosecutors who were having to look at these cases they didn't want to prosecute. Nurses who were working in an unregulated area with some patients having the privileged access to terminal sedation while others did not. Others had to die lonely private deaths, with paramedics and police officers discovering them. Others who were given no legal choice, made a choice of their own. We've got to continue to highlight the complete unacceptability of the status quo. But we must build models of assisted dying that have the backing of expertise."*

Similarly, the Rt Hon Helen Clark, former Prime Minister of New Zealand, shared that:

> *"Having examined the evidence and looked back on my 27.5 years of parliamentary experience, I am confident that enacting this [assisted dying] law is the safe, compassionate and right thing to do."*

The APPG for Choice at the End of Life looks forward to colleagues and Parliamentarians in British jurisdictions taking steps towards the legalisation of choice at the end of life. By doing so they will be following the example of other free-thinking, liberal and compassionate democracies around the world. Those countries have shown that assisted dying is safe, fair and compassionate for dying people and offers protection to those who are potentially vulnerable. Our own experiences demonstrate that the blanket ban on assisted dying is no longer fit for purpose, providing neither compassion nor protection.

We would be delighted to discuss this further with colleagues from other jurisdictions and help where we can to ensure that the rights of the Crown Dependencies to legislate in this area are upheld.

2. The Anscombe Bioethics Centre

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
The Anscombe Bioethics Centre

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should not be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No

Please tell us the reason for your response
Among the many reasons to object to this practice, it is worth noting that the drawing up of eligibility criteria inevitably signals that some disabilities can or ought to be considered reasons for not living. This is a very serious affront to disabled communities, and erodes the affirming attitude towards those in need of care that our society needs. See Pia Matthews, ‘Dignity in Living: Addressing Euthanasia by

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Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

Affirming Patient Personhood in Dementia', https://bioethics.org.uk/media/hvnfyc0i/dignity-in-living-addressing-euthanasia-by- affirming-patient-personhood-in-dementia-dr-pia-matthews.pdf

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note 'Jersey resident' on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid 'death tourism". It is proposed that a person will only be considered 'resident' if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Don't know

Please tell us the reasons for your response
In addition to residents, non-residents should not be allowed access to euthanasia or assisted suicide either.

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note 'Age limit' on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

Don't know

Please tell us the reasons for your response
Euthanasia legislation has been (or is seriously being considered to be) extended to children under the age of 18 (e.g. Belgium, the Netherlands, Canada). This is one of many examples of how the passing into law of euthanasia and/or assisted suicide leads to further liberalising of restrictions. For an up-to-date

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

survey of the latest peer-reviewed evidence see: https://bioethics.org.uk/about-us/showcase/euthanasia-and-assisted- suicide-a-guide-to-the-evidence/

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Don't know

Please tell us the reasons for your response
Although the Anscombe Bioethics Centre opposes all forms of euthanasia and assisted suicide, to offer the service for free would add an additional stress for those nearing the end of their lives to accept the service.

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as ‘Coordinating Doctor’ or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person’s prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person’s eligibility for an assisted death?

Yes - they should have the right to refuse

Please tell us the reasons for your response
No healthcare professional should be expected to be involved in an assessment, and additionally, they should not be expected to refer to someone who would make such an assessment. Such expectations would place an unacceptable moral burden on healthcare professionals, and would deny them their right to refuse participation on the grounds of conscience. This issue was recently considered by the World Medical Association in revising its International Code of Medical Ethics, and an open letter signed

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Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

by over 250 professors, directors of research centres, physicians, and others concerned with medical ethics, urged the WMA not to impose an obligation to refer patients for procedures that the physician sincerely and reasonably considers unethical, see: https://bioethics.org.uk/news-events/news-from-the-centre/open-letter-to-the-world- medical-association-on-conscientious-objection/

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes - they should have the right to refuse

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they 'opt-in' to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Yes

Please tell us the reasons for your response
In the unfortunate event that assisted suicide becomes legal, it is important that data be available to allow for transparency and scrutiny.

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

Don't know

Please tell us the reasons for your response
It is not possible to commend the proposed steps due to the Centre's opposition in principle to euthanasia and assisted suicide. Moreover, evidence from other jurisdictions shows that proposed safeguards do not provide the safety they purport to offer. On the issue of the extension of legislation once passed, see John Keown, 'Voluntary Euthanasia & Physician-assisted Suicide: The Two 'Slippery Slope' Arguments', https://bioethics.org.uk/media/vrkdjlgu/voluntary-euthanasia-physician-assisted-suicide-the-two-slippery-slope-arguments-prof-john-keown.pdf

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

No

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

No - I do not agree

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Don't know

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

No - I do not agree

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

Don't know

Please tell us the reasons for your response
The question presupposes support for euthanasia/assisted suicide, which the Centre does not.

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a 'confirmation of consent to proceed form', allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

No - I do not agree

Please tell us the reasons for your response
It is not clear how consent can be legitimately confirmed when the reasons for consenting to the process are themselves tied to the interests and concerns of others. This is clear in jurisdictions where assisted suicide is legal. The idea of autonomous consent in this area is a dangerous falsehood. See: Xavier Symons, 'The Principle of Autonomy: Does it Support the Legalisation of Euthanasia and Assisted Suicide?', https://bioethics.org.uk/media/ugannjkp/the-principle-of-autonomy-does-it-support- the-legalisation-of-euthanasia-and-assisted-suicide-dr-xavier-symons.pdf

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a 'waiver of final consent'.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

No - the law should not allow for a waiver of final consent

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Don't know

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

Yes

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person’s wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

No

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

No– I do not agree, there should be a time period longer than 48-hours

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Don't know

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

No - I disagree, there should be an expiry date

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

Don't know

Please tell us the reasons for your response
It is important to note that the proposed role of an Administering Practitioner blurs the distinction between assisted

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

suicide (self-administration) and euthanasia (administration by another). On this issue see Christopher M. Wojtulewicz, 'Analysing the Assisted Dying [HL] Debate 2021', The New Bioethics 28, no. 4 (2022): 350-67.

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance?
substance?

No

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Please tell us the reasons for your response
It is absolutely necessary that there be no obfuscation of the cause of death in such cases, and that such information should be readily and easily accessible to the public. Clarity and precision in language is indispensable, and 'assisted dying' is itself already
euphemistic. Not only should the records show the means of death (e.g. ingestion or injection of lethal drugs) but also whether this was self-administered or administered by someone else. On the reasons why such clarity is necessary, see David Albert Jones, 'Defining the Terms of the Debate: Euthanasia and Euphemism', https://bioethics.org.uk/media/t0yhyej4/defining-the-terms-of-the-debate-euthanasia- and-euphemism-prof-david-albert-jones.pdf. In jurisdictions where euthanasia and/or assisted suicide is legal, the data that is available to researchers (including the cause of death) allows us to see that rates of euthanasia/assisted suicide increase significantly over time, as do rates of self-initiated deaths (euthanasia/assisted suicide and non-assisted suicide). The latest data therefore shows that legalising euthanasia or assisted suicide is a threat to suicide prevention, despite arguments which seek to distinguish 'assisted dying' from suicide. See David Albert Jones, 'Suicide Prevention: Does Legalising Assisted Suicide Make Things Better or Worse?', https://bioethics.org.uk/media/mhrka5f3/suicide-prevention-does-legalising-assisted- suicide-make-things-better-or-worse-prof-david-albert-jones.pdf

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Don't know

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

Yes - I agree, it should not be considered an essential service

Please tell us the reasons for your response
Assisted Dying, that is, euthanasia or assisted suicide, are not part of palliative care, they are not part of end-of-life care, they are not part of healthcare. If it is deemed to be ‘essential’ healthcare for those who request then it will be ‘essential’ to provide it to people who do not request, on the basis of best interest (which is how essential healthcare decisions are made in all other cases). Furthermore, if it is an ‘essential’ service and is more cost effective than palliative care or assisted living at reducing suffering (as it eliminates the one suffering and has no further costs) then it will gain priority in allocation over palliative care and assisted living. Deeming euthanasia and assisted suicide as essential services is also likely to lead to coercion of healthcare professionals and others who regard these interventions as harmful and do not wish to participate. Euthanasia and assisted suicide are essentially elective and, even if they are tolerated by law, they should not be deemed essential services that others have a duty to provide.

3. Association for Palliative Medicine of Great Britain and Ireland

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
Association for Palliative Medicine of Great Britain and Ireland

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should not be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No

Please tell us the reason for your response
This example illustrates that the proposed legislation does not fulfil its intended purpose and is subject to the possibility of repeated adjustment and expansion –which could mean incorporation of an increasing number of eligibility scenarios.

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

Once this legislation is enacted it would take a simple court proceeding on the basis of equality to expand the scope further. This opens the opportunity for expansion of eligibility to include minors, people with dementia or a disability and the potential for ever widening the criteria. This can be an example of the slippery slope nature of assisted dying legislation and this occurring in practice is evidenced for example by changes with Canadian practices for Medical Assistance in Dying. We are concerned about the impact of this for the most vulnerable in society.

"Laws are like nation states. They are more secure when their boundaries rest on natural frontiers. The law that we have rests on just such a frontier. It rests on the principle that we do not involve ourselves in deliberately bringing about other people's deaths. Once exceptions are introduced, based on arbitrary criteria such as terminal illness, those frontiers get blurred. They become no more than lines in the sand, hard to define and easily crossed"
(Baroness Elizabeth Butler-Sloss, former President of the Family Division of the High Court, The Times 5 January 2012)

Canada no longer requires a patient to be terminally ill and they there are debates about whether to allow Medical Assistance in Dying to those with mental illness, learning disability and autism.

Reference: Select committee on the evolution of the Act respecting end- of-life care. Assemblée Nationale du Quebec. Special consultations and public hearings on the Evolution of the Act respecting end-of-life care - National Assembly of Québec (assnat.qc.ca)

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism". It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes

Please tell us the reasons for your response
This question is leading with no option to disagree with the fundamental process and to proceed in the survey you must select one.

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

Don't know

Please tell us the reasons for your response
The Association for Palliative Medicine opposes any change in the law to license doctors to supply or administer lethal drugs to a patient to enable them to take their own life -this includes people of any age.

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

No, it should be paid for

Please tell us the reasons for your response
This question is leading with no option to disagree with the fundamental process and to proceed in the survey you must select one.

The Association for Palliative Medicine have answered 'no' it should be paid for because this question is leading and there is no option to disagree with the process and proceed with the survey.

Palliative care remains substantially funded by charity. We strongly feel that an adequately resourced

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

palliative care service is required. We would have grave concerns if the state were to fund assisted suicide but does not adequately fund palliative care for all.

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes - they should have the right to refuse

Please tell us the reasons for your response
The Association for Palliative Medicine position is that if assisted dying is legislated, it should be outside healthcare.

We believe that individuals should have the right to refuse to undertake a supporting assessment about assisted dying. Conscientious objection is considered in detail in the article by Prof Derek Willis and Prof Rob George. https://apmonline.org/wp-content/uploads/2019/01/conscience-willis-george-bmjspc-2018.pdf

There is evidence that for some practitioners, participation in assisted dying has a significant emotional impact on them, including moral distress and psychological harm. If assisted dying does go ahead, it is our view that a conscientious objection clause would be absolutely essential to maintain the wellbeing of staff who do not wish to participate in assisted dying or who are harmed by doing so. Not allowing conscientious objection risks imposing harm on health or social care practitioners, violating their autonomy and risking an exodus of skilled and valuable health and social care practitioners.
https://bmjopen.bmj.com/content/12/7/e058523

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes - they should have the right to refuse

Please tell us the reasons for your response
There should be complete conscientious objection to being involved at any level including ongoing referral. Conscientious objection should be for both individuals and organisations. This is essential to avoid inflicting direct harm on people who do not wish to participate in assisted dying. We also think that it would also be important for trust –for example for people to know that assisted dying does not happen within an organisation will be reassuring to those who are vulnerable and/or who fear pressure or coercion about assisted dying.

There is also evidence that for some practitioners, participation in assisted dying has a significant emotional impact on them, including moral distress and psychological harm. If assisted dying does go ahead, it is our view that a conscientious objection clause would be absolutely essential to maintain the wellbeing of staff who do not wish to participate in assisted dying or who are harmed by doing so. Not allowing s conscientious objection risks imposing harm on health or social care practitioners, violating their autonomy and risking an exodus of skilled and valuable health and social care practitioners. https://bmjopen.bmj.com/content/12/7/e058523

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Yes

Please tell us the reasons for your response
Full transparency of process is important.

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

Yes

Please tell us the reasons for your response
We have answered yes because this is the only way to indicate the inadequacy of safeguards.

The APM believe the existing law provides extensive safeguards for our population.

Despite safeguards in Canada, 40% of patients who had Medical Assistance in Dying (MAiD) had no Palliative care involvement before death. (1) 85% of Canadians do not have access to publicly funded palliative care and many areas have none (2).

Should assisted dying be legalised and involve doctors, this could then imply the acceptability or even desirability of assisted dying. This could create a burden especially upon the vulnerable members of the population.

Ref:
1) Munro C, et al. Can Fam Physician. 2020 66(11): 833-842.
2) Access to Palliative Care in Canada. Ottowa: Canadian Institute for Health Information, 2018, p6.

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

Yes

If yes, please detail the further steps or actions you think should be included.
This question is leading with no option to disagree with the fundamental process and to proceed in the survey you must select one. The APM opposes any change in the law to license doctors to supply or administer lethal drugs to a patient to enable them to take their own life

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

No - I do not agree

Please tell us the reasons for your response
This question is leading with no option to disagree with the fundamental process and to proceed in the survey you must select one.

It does not seem that 14 days is sufficient time to address factors which can change a person's desire to die.

In patients with progressive neurological disease, a wish to die is not related to cognitive or behavioural impairment but is strongly related to depression. (1)

Most of those people who express a wish to die report being lonely and had symptoms of depression. (2)

In the UK, loneliness is associated with long-lasting depressive symptoms (3) and loneliness predicts pain, fatigue and depression. (4).

Clinical depression can take at least 6 weeks to treat successfully.

14 days seems insufficient time the for the opportunity to appeal.

1) Rabkin J, Goetz R, Murphy JM, Mitsumoto H. Neurology, 2016; 87(13): 1320-8.
2) Hartog ID, Zomers ML, van Thiel GJ, Leget C et al. BMC Geriatrics, 2020; 20: 342-356;
3) Lee SL et al. Lancet Psychiatry, 2021; 8: 48-57
4) Powell VD et al. Journal of the American Geriatrics Society, 2022
https://agsjournals.onlinelibrary.wiley.com/doi/epdf/10.1111/jgs.17796

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

No - I do not agree

Please tell us the reasons for your response
Half of 'unbearable suffering' is psychological and social and does not predict a wish to die. (1, 2) Self-defined 'suffering' is variable and highly influenced by a personal and societal narrative. We do not think it is possible to develop a clear and consistent understanding of the term 'unbearable suffering.' Legislation should not be using an undefinable entity as a criterion to determine eligibility for assisted dying.

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

1) Ruis CDM et al. BMC Palliative Care, 2012; 11: 12.
2) Ruis CDM et al.. BMC Palliative Care, 2014; 13: 62.

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Don't know

Please tell us the reasons for your response
A doctor raising the subject of assisted dying could place a burden upon on the patients receiving this information. Canadian press reports in 2022 describe the impact that occurred when health or social care professionals raising assisted dying as an option with veterans -these illustrate the distress that can be caused in practice when professionals raise assisted dying.

People have highly interconnected lives; there are burdens, spoken and unspoken, coercion and pressure that could arise if health care professionals could raise assisted dying.

In Europe suicide rates have not decreased after the legalisation of assisted suicide. Dutch non-assisted suicides have increased compared with Germany and Belgium now has the highest non-assisted suicide rate in women in Europe. (1) In Canada non-assisted suicide rates increased 2016-19 (11-12.2/100k) then reduced in 2020 (10.1/100k) (2). This phenomenon of increasing suicide rates (excluding assisted suicide) could be because suicide becomes culturally an accepted means to manage suffering.

1) Jones DA, et al. Journal of Ethics in Mental Health, 2022; 11:1.
2) Centre for Suicide Prevention https://www.suicideinfo.ca/resource/ suicide-stats-canada-provinces/

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Please tell us the reasons for your response
This would be against any form of conscientious objection if healthcare staff were forced to tell people about it.

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

No - I do not agree

Please tell us the reasons for your response
This question is leading with no option to disagree with the fundamental process and to proceed in the survey you must select one.

The APM position is that doctor involvement in assisted suicide risks damaging patient and societal trust in doctors. The APM position is that decisions on assisting suicide and administering euthanasia, were it to be legalised, should be made by judges and the procedures carried out by competent operatives outside healthcare.

If assisted dying is legislated and there is non-agreement, because it is person’s life is at stake, there may need to be many different opinions.

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

Yes - I agree

Please tell us the reasons for your response
If there is no ‘active confirmation’ to proceed there is removal of the autonomy of the person which is the major premise that this legislation is based upon. Thus, there must be active confirmation to proceed.

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

No - the law should not allow for a waiver of final consent

Please tell us the reasons for your response
If the law is based upon autonomy being the fundamental principle of course there should be no capacity to waiver this consent.

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Other (please specify):
It should be made by judges and the procedures carried out by competent operatives outside healthcare

Please tell us the reasons for your response
Decisions on assisting suicide and administering euthanasia, were it to be legalised, should be made by judges and the procedures carried out by competent operatives outside healthcare

The APM position is that experience over 15 years with the Mental Capacity Act demonstrates a persisting problem with implementing safeguarding legislation by healthcare staff (including doctors) and organisations and that therefore doctors and organisations cannot exclude undue influence and implement safeguarding law.

Heslop P BP, Fleming P, Hoghton M, Marriott A, Russ L. Confidential Enquiry into the Premature Deaths of People with Learning Disabilities (CIPOLD). Norah Fry Research Centre: Bristol: University of Bristol 2013. See http://www.bristol.ac.uk/cipold/ (Checked 7 Sep20)

Mental Capacity Act 2005: post-legislative scrutiny. House of Lords Select committee on the Mental Capacity Act 2005. London: The Stationery Office, 2014. See:

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/139.pdf (Checked 14Sep20)
6 Marshall M, Sprung S. The Mental Capacity Act: 10 years on – the key learning areas for healthcare professionals Nursing: Research and Reviews, 2018; 8; 29-38

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

No

Please tell us the reasons for your response
Tribunal should be the fundamental decision-maker in all cases, removing healthcare professionals completely.

Doctors are ill positioned to be judges, certainly in regard to familial pressures, coercion, financial strains etc. Decisions on assisting suicide and administering euthanasia, were it to be legalised, should be made by judges and the procedures carried out by competent operatives outside healthcare

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

Yes

Please tell us the reasons for your response
Decision, including appeal, should be made by judges

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person’s wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

No

Please tell us the reasons for your response
There should be no restrictive criteria for appeal. Appeal should be possible on any aspect of the process. All cases should go through the courts.

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

No– I do not agree, there should be a time period longer than 48-hours

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

No

Please tell us the reasons for your response
A doctor is not placed well to uncover coercion, unseen burdens, financial strains, and internal and external pressures. Thus, there is a wide range of people who will have insight into the reasons why a person could be requesting assisted dying and who should therefore be able to object. The proposed legislation does not adequately consider reasons 'why' people request assisted dying and lacks consideration of mental health, or social pressures, or familial burdens or even coercion.

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

No - I disagree, there should be an expiry date

Please tell us the reasons for your response
This suggestion eliminates the proposed prognostic safeguard.

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

No

Please tell us the reasons for your response
This then becomes Active Euthanasia which is not how this legislation is described or set up.

It may also be an acknowledgement that assisted dying does not guarantee a 'good death'

Smith KA et al Quality of death and dying in patients who request physician-assisted death. J Pall Med. 2011; 14(4): 445-50. https://www.ncbi.nlm.nih.gov/pubmed/21417741

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

No

Please tell us the reasons for your response
This could traumatise and place a burden on the families to be involved. This also raises concerns about safeguards, for example if the family were coercive and placing the burden on the patient to take it.

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Please tell us the reasons for your response
This is essential for transparency and monitoring.

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Please tell us the reasons for your response
This is essential for transparency and monitoring.

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Please tell us the reasons for your response
This is essential for transparency and monitoring.

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Yes

Please tell us the reasons for your response
This is essential for transparency and monitoring.

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

Yes - I agree, it should not be considered an essential service

Please tell us the reasons for your response
It should not be an essential service. Access for all to good palliative care should be an essential service.

4. CARE (Christian Action Research and Education)

CARE Response | January 2023

Consultation: Assisted Dying in Jersey

by email to AssistedDying@gov.je

INTRODUCTION

1. CARE (Christian Action Research and Education) is a well-established mainstream charity providing resources and Christian insight and experience to matters of public policy and practical caring initiatives. We have supporters resident on Jersey, and give permission for this response to be quoted (Question 1).

2. We note that the consultation document says on page 7 that this consultation is not about whether assisted dying should be permitted on Jersey, but we wish to be clear that **CARE believes the law should not change** to allow any assisted dying measures for any patient (Questions 2-4). We also believe that the Assembly should continue to keep this issue under review in the light of evidence since the vote in November 2021.

3. CARE's guiding principle is that we affirm the **inherent value of every human life – regardless of age; physical, mental or emotional health; or disability.** A principle recognised during the pandemic when the elderly and infirm were prioritised for vaccination and protection. **This principle is undermined by legislation that permits the terminally ill (or others) to end their lives prematurely.** Physician assisted suicide (PAS) and euthanasia are not private acts. They involve a person(s) bringing about the death of another. The societal implications of such a law change have serious implications. We agree with the 1999 Council of Europe Recommendation that "*recognising that a terminally ill or dying person's wish to die never constitutes any legal claim to die at the hand of another person … (and) cannot of itself* ***constitute a legal justification to carry out actions intended to bring about death***".[1]

4. **It is essential that with an ageing population, all those who need it can access physical and mental healthcare, including palliative care, social care and support**. Services should be signposted and readily available. However, palliative care and so-called assisted dying are not complementary in nature. Palliative care is about holistically enhancing the quality of life of a patient. Assisted dying involves extinguishing a life.

5. CARE believes that **medical professionals should not be involved in assisting someone to end their life; nor should anyone else.** The current law does not restrict open or honest conversations, it restricts doctors from suggesting to a patient that they may be better off dead, or a patient inferring the same. Those struggling with depression, rely on doctors to dissuade them from suicidal thoughts. Endorsing a medical route to ending a person's life undermines fundamental ethics; endorses the belief that certain lives are no longer worth living; and radically alters the nature of the doctor-patient relationship by undermining the Hippocratic Oath to first "do no harm".

6. Furthermore, if we enshrine in law the principle that a person should have control over the manner and timing of their death, why should that not be extended to the person suffering from a devastating mental illness? Or someone simply tired of life? If the personal autonomy argument forms the basis for legislative change, it would unavoidably open the door to incremental extension of the law.

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[1] Council of Europe Recommendation 1418 (1999), Protection of the human rights and dignity of the terminally ill and the dying. Para 9.3.2 and 9.3.3

EVIDENCE FROM OTHER COUNTRIES

7. Canada is a Commonwealth country which has demonstrated both changes in scope and pressure on individuals to choose an assisted death.

    7.1. In June 2016 their law came into effect allowing patients to receive "MAID" (Medical Assistance in Dying) when death was "*reasonably foreseeable*".[2]

    7.2. In September 2019 a court deemed this criterion "*too restrictive*";[3] and was supported by the Canadian Government, giving credence to the view that restricting access to a legalised 'right' to assisted suicide **only to terminally ill people was discriminatory.**[4]

    7.3. In 2021, a further Bill passed which enables people who are not terminally ill to die by MAID and permits administration of lethal drugs to someone incapable of consenting if they had previously been approved for assisted death; as well as provisionally allowing MAID for someone experiencing mental illness[5] (although implementation of this has been delayed).[6]

    7.4. In July 2022, the latest annual report revealed a 32.4% increase in deaths from 2020 (7,603) to 2021 (10,064); 3.3% of all deaths in Canada.[7] In comparison, in California, similar in population size to Canada, 486 people died in 2021 under the PAS legislation for terminal illness.[8]

    7.5. Articles, including from the *Spectator* and the *Lancet*, are reporting that Canadians who meet the medical eligibility for MAID, are choosing MAID because of poverty or lack of support.[8] [9]

    7.6. Campaigners are seeking extension of MAID to "mature minors"[11] and potentially to younger children too.[10]

8. In the US states where access to PAS only is restricted to terminal illness, Bills are being debated/passed to ensure "*barriers*" (previously termed 'safeguards') are removed, including changing residency requirements, telemedicine, elimination of waiting periods, allowing nurses to prescribe lethal drugs, and changes in the freedom of conscience provisions.[11] [12]

9. In August 2022, in California, the most populous US state and an economy larger than many countries, a new campaign began to allow individuals with non-terminal illnesses to use the end-of-life law.[13] In

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[2] https://www.parl.ca/DocumentViewer/en/42-1/bill/C-14/royal-assent

[3] The Court's ruling comes into effect on 11 March 2020. Truchon c. Procureur 3eneral du Canada, 2019 QCCS 3792

[4] See also Sleeman K, Chalmers I. Assisted dying: restricting access to people with fewer than six months to live is discriminatory *BMJ* 2019; 367 :l6093 doi:10.1136/bmj.l6093

[5] Bill C-7, An Act to Amend the Criminal Code (Medical Assistance in Dying), Second Session, Forty-third Parliament, 17 March 2021

[6] https://www.theglobeandmail.com/canada/article-maid-expansion-delay-mental-disorders/

[7] Third Annual Report on Medical Assistance in Dying in Canada 2021, July 2022,
pages 5 and 18 [8] California End of Life Option Act 2021 Data Report

[8] https://www.spectator.co.uk/article/why-is-canada-euthanising-the-poor- 30 April 2022
Webster P, Worries grow about medically assisted dying in Canada, The Lancet, Vol 400, 10 September 2022, pages 801-2

[9] Alexander Raikin, "No Other Options," The New Atlantis, Number 71, Winter 2023,
December 16, 2022 [11] https://www.dyingwithdignity.ca/blog/pr_mature_minors/

[10] https://nationalpost.com/news/quebec-college-of-physicians-slammed-for-suggesting-maid-for-severely-ill-newborns

[11] In Oregon as of 2020, there is an exemption to the requirement to have a cooling off period of 15 days if the patient is expected to live for fewer than 15 days from the time of the first oral request for medication See 127.840 s.3.06. In 2023, there are expected to be changes in residency requirements after a court case dismissed the residency requirement. Written and oral requests; In Washington – debated but not passed SHB 2419 and HB1141. Plans are being made to bring these back in 2023. In California in effect from 1 Jan 2022 Text as amended from Bill SB-380 End of Life; In Vermont in effect from 27 April 2022 from S74; In Hawaii HB1823 not passed. In California, https://broadenchoice.org/our-proposed-changes

[12] Concerns about the balance between safety and access are raised in McDougall R, Pratt B, Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation, *BMC Med Ethics* 21, 38 (2020)

[13] https://medicalfutility.blogspot.com/2022/08/broadening-end-of-life-choices-in.html; https://broadenchoice.org/our-proposed-changes

November 2022, on the anniversary of the New Zealand law coming into effect, the author of the Bill called for the law to be extended beyond individuals with a terminal illness.[14]

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10. Assisted dying is frequently portrayed as a peaceful option amid suffering. However, the evidence is clear that taking these lethal drugs is not always associated with a peaceful, dignified death but can result in complications including regurgitation of the medicine, regaining consciousness and seizures; and that death can take a long time, up to 3 or 4 days in some cases.[15] A 2018 journal article reported on the experience of a caregiver who was advised by the patient's doctor to give the patient all the morphine in the house after a delayed death during which time the patient stopped breathing twice and turned purple.[16] One person ingested lethal medication intended for another.[17] Research conducted in the Netherlands showed that in 114 cases of assisted suicide, **complications occurred in 7% of cases** – such as vomiting the drugs – and **problems with completion occurred in 16% of cases** (a longer time to death; failure to induce coma or the patient regaining consciousness). [18]

11. There is evidence to suggest that where assisted dying is legal, there is an increase in the total suicide rate (aside from those that would come within the scope of the legislation), possibly because of "*a reduction in societal taboos associated with suicide*"[19] and "*no evidence that it would be beneficial in relation to suicide prevention overall*."[20]

THE IMPLEMENTATION OF AN ASSISTED DYING LAW IN JERSEY

12. CARE disagrees that the law should be changed but were it to do so:

    12.1. None of the proposed extended definitions on pages 13-15 should be accepted (Question 4).

    12.2. It should be restricted to adult Jersey residents (Questions 5 and 6)

    12.3. It should be funded by individuals who want to use the system (Question 7) but should not be seen as a cost-effective way to reduce health care costs.

        12.3.1. The Nuffield Trust has stated that "*the cost of hospital care at the end of life is substantial*".[21] The cost of an adult staying in a UK hospital specialist palliative care is estimated at £447 per day.[22] The Sue Ryder website states that inpatient hospice care costs £500 per day and a hospice nurse £3,000 a month.[25] In 2017, the cost of drugs for the Canadian Medical Assistance in Dying (MAID) was estimated to be between CAD$25.40-$326 (£15.57£199.87).[23] [24] Figures published in Canada in 2020 for the reduction in health care costs under the Canadian MAID regime estimated that for 2021

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[14] https://www.nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/
6 November 2022

[15] Oregon Death with Dignity Annual; Reports 1998-2019, quoting data from 2010, 2007, 2009, 2015-2020, and 2021 pages 14 and 17
Washington Death with Dignity Annual Reports 2009-2018, including 2018 Table 4, page 13. Complications and length of time to death were not reported for 2019 and 2020

[16] Buchbinder M et al, Caregivers' Experiences With Medical Aid-In-Dying in Vermont: A Qualitative Study, Journal of Pain and Symptom Management, December 2018, Vol 56(6), pages 936-943, Tables 2 and 5 and page 940

[17] https://www.jems.com/patient-care/death-with-dignity-when-the-medical-aid-in-dying-cocktail-gets-into-the-wrong-hands/ 29 November 2022

[18] Groenewoud JH et al, Clinical problems with the performance of Euthanasia and Physician –Assisted Suicide in the Netherlands, *New England Journal of Medicine*, Volume 342, Number 8, Feb 2000, Pages 551-556
http://www.nejm.org/doi/pdf/10.1056/NEJM200002243420805

[19] Girma S, Paton D, Assisted suicide laws increase suicide rates, especially among women, Vox EU, 29 April 2022

[20] Jones DA, Euthanasia, Assisted Suicide and Suicide Rates in Europe, *Journal of Ethics in Mental Health*, Open Volume 11, February 2022

[21] The Nuffield Trust, 'Exploring the cost of care at the end of life' September 2014, page 17

[22] Curtis, Lesley A. and Burns, Amanda (2020) Unit Costs of Health & Social Care 2020. PSSRU, University of Kent, page 87. Translates to £3,129 per week [25] https://www.sueryder.org/support-us/make-a-donation/how-we-spend-your-donations Accessed 4 October 2021

[23] Trachtenberg AJ, Manns B, Cost analysis of medical assistance in dying in Canada, CMAJ, 2017 Jan 23;189(3):E101-E105. Figures referred to are in Table 1 doi: 10.1503/cmaj.160650

[24] Using Financial Times currency conversation rate of 1 CAD=0.6131 GBP of as 11 January 2023

alone it would equate to CAD$149m (£91.35) and a reduction of 0.08% in health care budgets.[25] [26]

12.4. medical professionals, hospices, care homes, and hospitals should have a robust right to conscience

12.4.1. We believe that the current proposal set out on page 23 is insufficient to protect medical professionals. We firmly believe that doctors should not have to provide supporting assessments or provide their professional opinion in cases where a medical professional wishes to exercise their right to conscience (Question 8). CARE also believes that institutions like care homes and hospices should not be required to allow assisted deaths if that is against their policy (Question 9).

12.4.2. However, even if the right to conscience was initially protected, evidence suggests that there will be pressure for change to ensure that access to assisted dying is not restricted.[27] California's 2015 legislations initially ensured that no doctor would be "*required to take any action in support of an individual's decision*". The doctor was under no threat of penalty for not giving a patient information nor referring to another doctor. [28] In October 2021, this position significantly changed. Provision of information is no longer included under protection of conscience and doctors must record the first request.[29] In requiring the doctor to document the first request, they become part of the process. In September 2022, a court ruled *"The ultimate outcome of this requirement is that non-participating providers are compelled to participate in the Act through this documentation requirement, despite their objections to assisted suicide."* The court also ordered that California should not enforce the requirement.[33]

12.5. There should be open transparency about the impact of the law:

12.5.1. any register of doctors should be made public (Question 10);

12.5.2. with a full annual report with reporting of prescriptions, deaths, complications and reasons for an assisted death

12.5.3. assisted death reported as the cause of death (Question 29); and

12.5.4. a post-death administrative review (Question 31).

12.6. Medical professionals must not be able to initiate discussions on assisted dying with patients (Question 15) and no explicit requirement should be placed on professionals to discuss assisted dying either (Question 16 – this answer relates to our earlier comments on right to conscience).

12.7. There should be no option for a waiver of final consent (Question 19) as there is too much ambiguity about the wishes of the individual if not consenting is to be judged by "sounds or gestures" (para 290, page 79). We also believe that there should be clear verbal communication for the first request and for confirmation of capacity and that gestures are insufficient (para 91, page 37 and para 24, page 101).

13. CARE's opposition to the proposed changes in Jersey includes the concern that **no safeguard nor extra step will prevent undue pressure for someone to 'choose' assisted dying** (Questions 11 and 12).

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[25] Cost Estimate for Bill C-7 "Medical Assistance In Dying", Office of the Parliamentary Budge Officer, 20 October 2020, Tables 1 and 2, pages 1 and 2

[26] Based on 2021 data, the population of Canada is less than two thirds of the population of England and Wales see data from the ONS (mid-year population for England and Wales was 59,641,829) and Statistics Canada as of July 1 2022 was 38,226,498.

[27] Concerns about the balance between safety and access are raised in McDougall R, Pratt B, Too much safety? Safeguards and equal access in the context of voluntary assisted dying legislation, *BMC Med Ethics* 21, 38 (2020)

[28] Section 443.14(e)(1) and (2) of the California Health and Safety Code, as passed in 2015

[29] Section 443.14(e)(1) and (2)and 443.15(3)(B), Health and Safety Code of California. Text as amended from Bill SB-380 End of Life

[33] Court Ruling, 2 September 2022, pages 20-21 and page 26

13.1. While for some a change in the law may be perceived as granting choice, disability campaigners are concerned that it will lead to many others seeing the option as a duty to end their lives.[30]

13.2. For others struggling to access high quality health or social care, it may seem to be the only choice open to them. There is a huge risk that this lack of choice combined with the provision of a state sanctioned/state regulated assisted dying regime will result in some patients reluctantly opting for an assisted death when they would have preferred to live their life to completion with appropriate symptom management.

13.3. CARE believes that the pressure will be subtle but difficult to resist: the choice to die will be seen by some as a duty. Data from Washington and Oregon highlights the number of people who cited being a "burden on family, friends/caregivers" as one of their reasons for choosing to due. In Canada in 2021, 35.7% cited being a burden and 17.3% said isolation or loneliness was a factor in their decision.[31] Research on cancer patients in England *"shows that self-perceived burden affects patients' well-being…associated with hopelessness and depression…in end-of-life care situations has been found to underlie…request for euthanasia".*[32][33]

Year	**Oregon**[37]	**Washington**[38]
2019	59%	57.6%
2020	53.1%	58.6%
2021	54.2%	56%

Table: *End of life concerns of participants who died: "burden on family, friends/caregivers"*

13.4. Marie Curie reports on another pressure: that "*being diagnosed with a terminal illness and reaching the end of life increases a person's risk of falling below the poverty line. Even those who were previously getting by can be forced into poverty, when they are already at the most vulnerable time in their lives, by the financial impact of a terminal illness*."[34] This could lead to a person choosing an assisted death for financial reasons.

13.5. **To deny the risk to the vulnerable is to dismiss the assessment by UN human rights experts** that *"even when access to medical assistance in dying is restricted to those at the end of life or with a terminal illness, people with disabilities, older persons, and especially older persons with disabilities, may feel subtly pressured to end their lives prematurely due to attitudinal barriers as well as the lack of appropriate services and support"*.[35]

13.6. It would be an extraordinarily difficult task for a doctor or tribunal to ensure that someone choosing to end their life would be doing so voluntarily. For this reason, **we believe that there is no legal protection, beyond the current law which makes it an offence to assist suicide, that could prevent coercion.** Instead, the "*self-perceived burden by patients and its detrimental consequences will need to be addressed by better support for family carers and better home care*."[36]

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[30] Campbell, J, 'Disabled people like me fear legal assisted suicide: it suggests that some lives are less worth living', British Medical Journal, 6 February 2019

[31] Third Annual Report, *Op Cit*, Chart 4.3, page 26

[32] Bausewein et al, 'Burden to others' as a public concern in advanced cancer: a comparative study in seven European countries BMC Cancer 2013, 13:105 http://www.biomedcentral.com/content/pdf/1471-2407-13-105.pdf [37] Oregon Death with Dignity Act Annual Reports

[33] Washington Death with Dignity Act Annual Reports, Table 3 for 2019 and 2020, Table 2 for 2021 (Note: there are two Table 1 in 2021)

[34] Dying in poverty, Exploring poverty at the end of life in the UK, Marie Curie, May 2022, page 4

[35] 'Disability is not a reason to sanction medically assisted dying – UN experts', United Nations Human Rights, Office of the High Commissioner, 25 January 2021

[36] Bausewein et al, 'Burden to others' as a public concern in advanced cancer, *Op Cit*

14. Our concerns about safeguards are also based on the difficulties of diagnoses, the definitions of suffering and the identification of capacity and judgement to make a decision to end one's life.

15. The difficulties of determining prognosis are well documented even for those with specialist knowledge:

    15.1. At the start of the Oregon Act, 1 in 4 doctors were not confident in determining 6-month life expectancy. [37] Those who die from the prescribed drugs in Oregon are judged likely to die within six months. In 2021, the range of days from first request to death was 0 to 1095 days (3 years). Prior to 2020, the range has been 15 to 1503 days (4.12 years). Since the Act was enacted, 4% of participants have outlived their prognosis.[38]

    15.2. A 2022 Australian article said, "*Modern medicine … has not made predicting the life expectancy of an individual any easier…..The reality of such predictions is that it is simply impossible to know with certainty how much longer a complex system like a human can continue to function, but someone has to make the call*."[39] Another Australian journal article said, "*We predict that many doctors will find it difficult to answer whether they expect individual patients to die within 6 months….Assessing a person's eligibility for VAD is difficult because prognostication is difficult, prognosis is inherently uncertain…*"[40]

    15.3. In July 2013 Lady Neuberger's independent review of the Liverpool Care Pathway underscored the problems of prognoses of death even within 48 hours saying, '*diagnosing imminent death is a far more imprecise science than people realise. And accurate prediction in non-cancer patients is particularly difficult. There are no precise ways of telling accurately when a patient is in the last days of life*'.[41]

16. We are further concerned that there can be no clear definition related to an "incurable physical medical condition" which is leading to "unbearable suffering" since the definition of "unbearable suffering" and what is "deemed tolerable" are exceptionally difficult. The Western Australia Guidance recognises, "*Suffering is a subjective experience*."[42] Tasmania's law has come into effect and includes expected suffering that *"might arise"*.[43] Canada's law allows assisted dying for non-terminal conditions and there have been multiple articles raising concerns about individuals with non-terminal conditions choosing an assisted death because there are health and social care needs have not been met (as referred to above). In May 2022, the Canadian Human Rights Commission said, "*Medical Assistance in Dying is intended to allow people the ability to die with dignity when science and medicine can offer no better alternative to alleviate unbearable suffering. Leaving people to make this choice because the state is failing to fulfil their fundamental human rights is unacceptable…In an era where we recognize the right to die with dignity, we must do more to guarantee the right to live with dignity.*"[44] The description on page 34 of the consultation document does not assume that the exploration for "other services" have been provided or indeed could be provided.

17. Were the law to change, an **expert assessment of capacity and judgement is essential for determination of eligibility and just before death.**[45] [46] Lord Falconer's Commission said, "*in the context*

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[37] Ganzini L, Nelson HD, Lee MA et al, Oregon Physicians' Attitudes About and Experiences with End-of-Life Care Since Passage of the Death with Dignity Act, *Journal of the American Medical Association*, 2001, 285(18), 2363-2369

[38] Oregon Death with Dignity Act Report 2021, Table 1, page 14

[39] Life expectancy: questions to ask yourself, 10 October 2022, Insight Plus.

[40] Nahm, HS, Stockler MR, Keily BE, Voluntary assisted dying: estimating life expectancy to determine eligibility, Med J Aust 2022; 217 (4): 178-179, doi: 10.5694/mja2.51648, Published online 25 July 2022

[41] More Care, Less Pathway, A Review of the Liverpool Care Pathway, 2013, page 19

[42] Western Australian Voluntary Assisted Dying Guidelines, Western Australia, Dept of Health, 2022, para 8.2.5, page 36

[43] Section 14, https://www.legislation.tas.gov.au/view/whole/html/asmade/act-2021-001

[44] MAiD cannot be an answer to systemic inequality, Canadian Human Rights Commission, 10 May 2022

[45] Response to the Assisted Dying for the Terminally Ill Bill, 24 April 2006, Statement from the Royal College of Psychiatrists on Physician Assisted Suicide

[46] This option was recommended for consideration by the House of Lords Select Committee on the Assisted Dying for the Terminally Bill, April 2005, Paper

*of such a serious decision as requesting an assisted death…**a formal assessment would be needed to ensure that the person concerned had capacity**."*[47] Studies have shown 30% of people with terminal illnesses display psychiatric illnesses (particularly depression).[48] It is essential that if dementia is to be included as a physical condition considered to be in scope that the person has capacity and judgement to make a decision for assisted death and should not be able to make an advanced decision (pages 14 and 47).

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chris.buttenshaw@care.org.uk

86-I, paras 252-254

[47] Commission on Assisted Dying, *Op Cit*, pages 28-29

[48] Lloyd Williams M., Screening for depression in patients with advanced cancer, European Journal of Cancer Care, 2001, 10:31-35
Bowers L., Boyle D.A., Depression in patients with advanced cancer, Clinical Journal of Oncological Nursing, 2003, 7:281-288
Stiefel et al, Depression in palliative care: a pragmatic report from the Expert Working Group of the European Association for Palliative Care, Support Cancer Care 2001, 9:477-488

5. Care Not Killing and Our Duty of Care

Response to the “Assisted Dying in Jersey Consultation” on behalf of Care Not Killing (CNK Alliance Ltd) and Our Duty of Care

January 2023

Introductory remarks

A number of issues arise in the report which are not addressed by the questions.

The Government of Jersey‘s 121-page consultation report states that:

> *“the purpose of this consultation is not to consider whether assisted dying should be permitted in Jersey - as the Assembly have already determined, in principle, that it should be permitted - but instead to understand peoples’ response to how an assisted dying service should work.”* (p7)

This approach neglects the constitutional principle (cf Dicey) that no parliament can bind its successor; Jersey elected a new States Assembly in June 2022, following the earlier vote in November 2021. It also fails to recognise that citizens may for whatever reason have been unable to respond to the earlier consultation, and that members and citizens may decide having considered these proposals that regardless of their view on the principle, “assisted dying” cannot be safely legalised. The States Assembly passed the Proposition in question subject to adequate safeguards being drawn up by officials: our view is that the safeguards proposed are far from adequate and that no system of euthanasia can ever be truly safe for vulnerable people. The current law is the safeguard.

The consultation asserts that:

> *“assisted dying is not suicide or assisted suicide – the decision to commit suicide and the taking of your own life are lonely acts, often accompanied by mental and physical pain and fear. Suicide invariably leaves behind a legacy of irresolvable grief for loved ones. Assisted dying can be the exact opposite, it provides a safe, calm and considered environment in which a person – most often with the support of their loved ones – can end their life and associated suffering.”* (p11)

This denies reality: “suicide” is “the act… of taking one's own life voluntarily and intentionally.”[49] The Jersey Government’s definition of “assisted dying” is misleading and repeats the euphemistic campaign messaging of those seeking a change in the law. The Government of Jersey is proposing both assisted suicide and euthanasia, for terminally and chronically ill people.
However, a July 2021 survey in the UK found that more than half of respondents thought the term ‘assisted dying’ meant “providing hospice-type care to people who are dying” or “giving people who are dying the right to stop life-prolonging treatment.”[50] Only 42% realised that it refers to giving lethal drugs to a patient to end their life intentionally. The consultation is only accurate in its statement above in the sense that euthanasia is not assisted suicide and the likelihood is that the overwhelming majority of deaths under the proposed legislation will be acts of euthanasia (as is the case in Canada where over 99% of Medical Assistance in Dying (“MAiD”) deaths are by euthanasia). In such deaths, lethal drugs are administered by a doctor or nurse rather than selfadministered by a person committing an assisted suicide.

The consultation report states that:

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[49] merriam-webster.com/dictionary/suicide

[50] dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf

> *"any person seeking an assisted death should be making a real choice. They should not choose an assisted death on the basis that they cannot access – or believe they cannot access – high quality end-of-life or palliative care services. Hence, it is envisaged that the report and proposition which be presented to the Assembly in early 2023 will ask Members to agree, in principle, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that all Islanders can access good palliative and end-of-life services."* (p11)

This conclusion is the wrong way around: the States Assembly should not consider passing "assisted dying" legislation before they can guarantee access to not just *"high quality end-of-life or palliative care services"* but also social support (including affordable housing) for people with chronic illnesses and disabilities. Canada has seen many examples of medically eligible people applying for euthanasia or assisted suicide not because of their condition but because of a lack of support. One recent example was that of 54-year-old Amir Farsoud who hit the headlines in November 2022 when he applied for MAiD because he was in danger of losing his housing and feared being made homeless.[51] Another of the many examples is that of Roger Foley who recorded a hospital employee offering him a MAiD death, citing the financial cost of his care and being unwilling to provide the care package Mr Foley desired.[52]

Questions on us

Q. 1 Do you give permission for your comments to be quoted?

No ☐ Yes, anonymously ☐ Yes, attributed ☑

Name to attribute comments to: (N/A)

Organisation to attribute comments to, if applicable: Care Not Killing, and Our Duty of Care

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes ☑ No ☐ Prefer not to say ☐

Q.3 If yes, do you think assisted dying:

should be permitted ☐ should not be permitted ☑

Questions on the proposals

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy or 12 months or less?

Yes ☐ No ☑ Don't know ☐

Please tell us the reasons for your response: It is very disturbing that the consultation document proposes different terminology from that approved by the States Assembly, especially since the Proposition was only approved subject to adequate safeguards being drafted. In fact, the new terminology is less safe than the previous language used. The reference to "tolerable" alleviation is entirely subjective, providing no objective criteria by which doctors can be expected to judge whether the suffering is at a degree to qualify for an

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[51] toronto.citynews.ca/2022/10/13/medical-assistance-death-maid-canada/

[52] https://www.dyingwell.co.uk/stories/roger-foley/

assisted suicide or euthanasia death. The Netherlands' law uses similar language, requiring that "there was no reasonable alternative solution for the situation in which he [the applicant] found himself."[53] This broad criterion has not only seen the numbers of deaths rise year on year, but has also seen the rate of increase accelerate. The latest regulatory report states that: "In 2021, the number of notifications of euthanasia (7,666) was 10.5% higher than in the previous year and was also higher as a percentage of the total number of deaths (170,839): 4.5% compared to 4.1% in 2020."[54] Belgian law also uses similar terminology and specifically the concept of 'unbearable' suffering. As in the Netherlands, the number of deaths by euthanasia has risen over time in Belgium from just 24 in 2004 to 2,699 in 2021. The Belgian Federal Control Committee itself has stated: "The unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values."[7]

The reliance on the two routes brings us to the precedent in Oregon where without any amendment to the statute, which only allows assisted suicide for terminally ill people with a 6month prognosis for death, health officials now interpret the law as including chronically ill people who forego "administration of life-sustaining treatment".[55] In Oregon, illnesses prompting assisted suicide include anorexia, arthritis, arteritis and complications from a fall.[56]

The process proposed in the Jersey Government's consultation supposedly allows

> *"time to ensure that all other options for the person have been explored in terms of treatment, pain relief and the provision of any other services that may be able to alleviate the person's suffering"* (p34)

The term "explore" is not defined and indeed is mainly used in conjunction with "dialogue" (p39): applicants need not try such options to find out if they would make a difference.

The framing of the prognosis requirement ("reasonably expected") concedes the well-known fact that prognostication, especially many months from death, is far from an exact science: a 2017 UCL study found that over half (54%) of those predicted to die within a specified time period lived longer than expected.[57]

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes ☐ No ☐ Don't know ☐

Other, please state ☑ ___

Please tell us the reasons for your response: We agree that non-residents shouldn't be allowed to access euthanasia or assisted suicide, but we also note that other jurisdictions have seen such restrictions successfully overturned. The report notes (p16) that while most earlier consultation respondents were averse to "death tourism", some "noted the potential financial benefits of providing assisted dying to non-residents." Just last year, the same campaign group which co-wrote Oregon's assisted suicide law forced the state, through the courts, to abandon its residency requirement[58], and is now engaged in similar action against Vermont[59]. It is to be expected that similar pressures will be brought to bear in Jersey and that legal challenges to the any new law may ensue.

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[53] wetten.overheid.nl/BWBR0012410/2021-10-01/0

[54] euthanasiecommissie.nl/de-toetsingscommissies/uitspraken/jaarverslagen/2021/maart/31/jaarverslag-2021

[7] Federal Control Committee, First Report, 2004, p.16

[55] carenotkilling.org.uk/articles/six-months-redefined/

[56] Oregon Death with Dignity Act Data Summary 2021, Footnote 3, Page 14. https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[57] carenotkilling.org.uk/articles/longer-than-expected/

[58] npr.org/2022/03/30/1089647368/oregon-physician-assisted-death-state-residents

[59] cbsnews.com/news/woman-sues-over-residency-requirement-for-assisted-suicide-vermont/

Q.6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes ☐ No ☐ Don't know ☐

Please tell us the reasons for your response: We believe children should not be included, but both "yes" or "no" indicate acceptance of euthanasia and assisted suicide for adults and so we decline to answer. Noting that the earlier consultation process had seen a degree of support for under-18s having access, the report states that:

> *"it is proposed that the law should only provide for assisted dying for people aged 18 or over. It is recognised, however, that the law should allow for the Assembly, by Regulation, to lower the age limit if, at some point in the future, they determine it was the correct course of action."* (p16)

Canada's law is barely six years old and they are considering such a move to include children – having already extended from terminal illnesses to chronic illnesses, and with a further extension to mental illnesses in 2023 only "temporarily" paused in December. Belgium extended its law to children in 2014 by primary legislation, but politicians in the Netherlands – where the current laws already apply to children as young as 12 and disabled infants aged under 12 months – are considering a similar move also by regulation. Notably the Groningen Protocol in the Netherlands, applying to disabled infants, has never been written into law by the Dutch Parliament. It highlights the dangers of incremental extension, without Parliamentary scrutiny, of euthanasia to include those who cannot give informed consent once it becomes accepted medical practice.

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?

Yes, it should be free ☐ No, it should be paid for ☑ Don't know ☐

Please tell us the reasons for your response: While emergency treatment is free in Jersey, everyone has to pay for access to doctors (GPs), dentists, pharmacists and ante-natal clinics. Aside from there being no logical basis to provide euthanasia and assisted suicide freely in that context, to do so would also send a worrying message about the value of those who are nearing the end of their lives, or are severely disabled.

Prior to the extension of Canada's MAiD law beyond terminal illnesses, the Parliamentary Budget Office there produced a report which estimated that under the then-law, 6,465 people would die by MAiD in 2021 - 2.2% of all deaths - with net healthcare savings of $86.9m. The PBO expected amending the law to add 1,164 deaths to that figure in the first year alone, leading to increased healthcare savings in 2021 of $149m - almost £87m.

Earlier that same year (2020), the journal Clinical Ethics published a controversial paper in which, as The Times reported:

> 'David Shaw, an ethicist, and Alec Morton, a health economist, argue that granting terminally-ill patients help to die would save money and potentially release organs for transplant.'
>
> 'Dr Shaw, who is based in Glasgow… described the potential savings of allowing assisted dying as "the elephant in the room". He said: "We are simply arguing that the economic costs of denying assisted dying should not be ignored; they should not be the key driver of any legal change, but it would be irresponsible not to consider them."'[60]

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[60] https://www.carenotkilling.org.uk/articles/widening-canadas-euthanasia-law-set-to-save-149m/

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes, they should have the right to refuse ☑ No, they should not have the right to refuse ☐

Don't know ☐

Please tell us the reasons for your response: We read in the report:

> *"It is proposed that the assisted dying law provides for a conscientious objection clause which relates to directly participating in the assisted dying assessment and delivery process… any objection clause that is cast too 'wide' could potentially have the effect of negating the underlying policy intent."* (p23)

Reflecting movements in Canada (where courts have required doctors with conscientious objections to involve themselves in the process by making "effective referrals"[61]), staff and service providers could not (p24) refuse tasks including *"delivery of equipment or medical supplies that may be used for… the delivery of an assisted death", "booking appointments for additional assessments, undertaking residency checks" or "financial planning tasks associated with the delivery of the service."* They must also (p25) provide people who want information with *"contact details of the Care Navigators."* The consultation report leaves open the possibility of requiring objecting staff to provide *"supporting opinions or assessments requested by an Assessing Doctor to help support their determine [sic] of whether a person is eligible for an assisted death."*

To be clear, the conscience rights of doctors and nurses will be seriously undermined if this proposal goes ahead. This may well lead to professionals being unwilling to work in Jersey under such conditions, adding to existing recruitment pressures. The World Medical Association is clear that doctors should not be required to participate in assisted suicides and euthanasia deaths and *"nor should any physician be obliged to make referral decisions to this end"*.[62]

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes, they should have the right to refuse ☑

No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises ☐

Don't know ☐

Please tell us the reasons for your response: The report says a location for an "assisted death":

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[61] theglobeandmail.com/canada/article-religious-doctors-must-make-referrals-for-assisted-dying-abortion/

[62] https://www.wma.net/policy-tags/euthanasia/#:~:text=The%20WMA%20reiterates%20its%20strong,euthanasia%20and%20physician%2Dassisted%20suicide.

> *"cannot be approved unless permission has been given… for example, if the person wishes to die in their residential care home (or similar) the consent of the care home manager or provider will be required."* (p75)

Belgium passed a new law in 2020, prohibiting bans on euthanasia in institutional care settings (and forcing objecting physicians to make effective referrals.)[63] The report says that:

> *"if the assisted death is to take place in a care facility, there will need to be consideration of other individuals that may be present or close by during the assisted death (for example, patients and staff in the same hospital ward, even if the assisted death takes place in a private room)."* (p75)

How meaningful would "consideration" for patients who don't want to live in a setting where the practice is permitted be?

Would state funding be in question for homes and hospices which refused such permission?[64] At least one hospice in Canada has lost funding owing to its unwillingness to provide euthanasia deaths on its premises.[65]

Q.10 Do you agree that the assisted dying register should be public?

Yes ☑ No ☐ Don't know ☐

Please tell us the reasons for your response: The possibility of making that register public means that determined patients would be able to contact healthcare professionals predisposed to view assisted suicide and euthanasia as acceptable responses to distress. In Oregon, doctor shopping has become a standard feature of the practice of assisted suicide. Oregon Health Authority reports on assisted suicide show patents often being approved by doctors they have only known for a few days.[66] While conscious of the risk of doctor-shopping, transparency is important. The extent of involvement in the euthanasia and assisted suicide process by particular individuals must be open to scrutiny. These factors present a significant tension.

Q. 11 Do you agree that the nine proposed steps are all necessary?

Yes ☐ No ☐ Don't know ☐

Please tell us the reasons for your response: The more steps that are involved in the process, the greater potential opportunity for the detection of coercion, abuse, depression or undue pressure. However, experience in other jurisdictions shows that often, these steps are technical formalities which are insufficient to protect those who are vulnerable.

A survey in England and Wales conducted by the charity SafeLives found that on average, victims at high risk of serious harm or murder live with domestic abuse for 2-3 years before getting help. 85% of victims sought help five times on average from professionals in the year before they got effective help to stop the abuse.[67] If this is the degree of difficulty in seeking assistance for and detection of high-risk abuse, it is not clear how the current steps would provide sufficient protection for those in abusive or coercive relationships. However, since we do not agree with the proposal to legalise euthanasia and assisted suicide, we would not wish to recommend any process.

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[63] ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-lawhttps://www.ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-law-on-euthanasia-2086.html?backto=searchon-euthanasia-2086.html?backto=search

[64] scoop.co.nz/stories/AK2006/S00673/euthanasia-referendum-threat-to-hospice-movement.htm

[65] https://toronto.citynews.ca/2020/02/25/b-c-hospice-loses-funding-after-refusing-to-provide-assistance-in-dying/

[66] carenotkilling.org.uk/articles/oregon-2021-anorexia-hernias-feeling-a-burden/

[67] SafeLives (2015), Insights Idva National Dataset 2013-14. Bristol: SafeLives. Available at: https://safelives.org.uk/policy-evidence/about-domesticabuse#top%2010

Q. 12 Do you think there are any further steps / actions that should be included?

Yes ☑ No ☐ Don’t know ☐

Please tell us the reasons for your response: Since we do not agree with the proposal to legalise euthanasia and assisted suicide, we cannot suggest any further steps/actions except that of dropping the proposals to change the law.

Q.13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes – I agree ☐ No – I do not agree ☐ Don’t know ☐

Please tell us the reasons for your response: Since we do not agree with the proposal to legalise euthanasia and assisted suicide, we would not endorse any arbitrary deadlines.

Q.14 Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Yes – I agree ☐ No – I do not agree ☐ Don’t know ☐

Please tell us the reasons for your response: Since we do not agree with the proposal to legalise euthanasia and assisted suicide, we would not endorse any arbitrary deadlines.

Q. 15 Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes – I agree ☐ No – I do not agree ☑ Don’t know ☐

Please tell us the reasons for your response: We note, first, that the wording of this question is unhelpfully complex: our chosen answer includes a triple negative, and it seems likely that many respondents will have been confused. Conscious especially of the statement in the report (p36) that *“the law will not prohibit health and care professionals from talking to their client / patient about assisted dying, even where the client / patient did not raise the subject in the first instance,”* we make clear that healthcare professionals should not be permitted to do this.

The GMC’s guidance in Good Medical Practice states that:

> “You must work in partnership with patients, sharing with them the information they will need to make decisions about their care, including: their condition, its likely progression and the **options for treatment**, including associated risks and uncertainties.”

It is not currently clear where the ‘Assisted Dying’ Service will sit in terms of it being a treatment option. Normally, doctors are expected to inform patients of all available options, even if they have a conscientious objection to taking part. Will this apply to the Assisted Dying Service?

Consider the impact of this proposal on patients, and on the trust they have in all healthcare professionals from that point on. If a doctor raises the issue of euthanasia or assisted suicide, it may well be perceived by a vulnerable patient to be a suggestion or recommendation. Combined with the inevitable pressures of the cost of treatment and lack of resources, this may well lead to people seeking death by assisted suicide or euthanasia owing to external pressures.

Canada’s law states that no healthcare professional commits an offence “if they provide information to a person on the lawful provision of medical assistance in dying,” paving the way for a 2019 document issued by the Canadian Association of MAID Assessors and Providers which asserts that “physicians and nurse practitioners… involved in care planning and consent processes have a professional obligation to initiate a discussion about MAiD if a patient might be eligible for MAiD."[68]

Q. 16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes – I agree ☑ No – I do not agree ☐ Don't know ☐

Please tell us the reasons for your response: Our comments in response to Q15 apply here also.

The report mentions the "Jersey Assisted Dying Service" making leaflets available, but have States Assembly members considered the danger that the people of Jersey might soon be confronted with this "choice" in far starker terms? An assisted suicide group in Switzerland has advertised on public transport[69] and in Canada, there have even been adverts in hospital emergency rooms[70]. No person with an eligible illness would be able to avoid considering the "choice" on offer and may well feel a public duty to die in order to avoid being a burden on family, friends and care services. This is increasingly the case in Oregon with over 50% of those having an assisted suicide now regularly citing this reason for seeking death.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

Yes ☐ No ☐ Don't know ☑

Please tell us the reasons for your response: The phrasing of the question means that answering yes means one supports allowing one second opinion, while answering no means one supports allowing more than one. We feel that allowing any second opinions opens the door (further) to doctor-shopping.

Q. 18 Should the law allow for confirmation of consent to proceed?

Yes ☐ No ☑ Don't know ☐

Please tell us the reasons for your response: Any system allowing third parties to act to cause death when the individual is unconscious (or similarly incapacitated) would be ripe for abuse, as well as placing an additional burden upon healthcare professionals.

Q. 19 Should the law allow for the option of a waiver of final consent?

Yes– the law should allow for a waiver of final consent ☐

No – the law should not allow for a waiver of final consent ☑

Don't know ☐

Please tell us the reasons for your response: Where some earlier respondents had favoured advance decisions, the report's authors have settled on waivers of final consent being available for Route 1 applicants who lose decision-making ability after final approval:

> *"The rational for 'waiver of final consent' is that it ensures a person, who has been approved as eligible for an assisted death, will not be prevented from having their request fulfilled (in accordance with previously agreed arrangements) if their health condition deteriorates rapidly to the point which they lose their decision-making capacity before the assisted death takes place."* (p48)

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[68] https://nationalpost.com/news/canada/canada-maid-medical-aid-in-dying-consent-doctors

[69] worldradio.ch/news/bitesize-news/suicide-group-advertises-on-trams/

[70] nationalreview.com/corner/canadian-hospital-waiting-room-promotes-euthanasia/

Later, we read that:

> *"even if the person has in place a waiver of final consent in place the process will not proceed if, during the final review or in the lead up to the assisted dying substance being administered, the person demonstrates a refusal or resistance to the administration of the substance by words, sounds or gestures."* (p79)

It is very dangerous to give doctors and nurses the legal power to end life where there is no explicit consent from the patient. Where doctors or nurses become used to ending their lives of their patients without consent, the boundaries of the law will be blurred. In 2013 in Belgium, 1.7% of all deaths were of physician administered without the explicit consent of the patient which represents over 1,000 deaths that year.[71] Similarly in 2010 in one survey in Belgium, 50% of nurses involved in administering euthanasia admitted to cases where no consent from the patient was obtained.[72]

The plan for final consent waivers also creates a contradiction: if an applicant signs a waiver, could indications of a change of mind be ignored? Where do those present at the end draw the line before disregarding the waiver itself? The question raises the example of a Dutch woman with dementia whose family restrained her to allow a doctor to euthanise her in line with an advance directive.[73] However, when the doctor and the family sought to conduct the euthanasia procedure, the patient resisted and said no three times. The doctor put a sedative in the patient's coffee and she was held down by her son-in-law whilst the doctor administered the lethal drugs to end her life. At a subsequent trial, the doctor was acquitted and later the Supreme Court of the Netherlands confirmed that doctors acting in this way is compatible with the Dutch euthanasia law. The courts ruled that the doctor "did not have to verify the current desire to die."[74]

It is proposed that there are two different approval routes:

a) ***Route 1 (terminal illness)*** *which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (i.e. two doctor assessments),*

b) ***Route 2 (unbearable suffering)****, which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal*

Q. 20 Do you agree with the two different approval routes as proposed?

Yes ☐

No – all approvals should be by the Coordinating Doctor based their assessment and that of the Independent Assessing Doctor only (i.e. no requirement for a Tribunal) ☐

No – all approvals by the Coordinating Doctor should be confirmation by a Tribunal (i.e. a Tribunal involved in all cases ☑

Don't know ☐

Other, please state ☐ ___

Please tell us the reasons for your response: With regard to the viability of any such tribunal: while the report (p58) indicates significant support from the Citizens' Jury for a tribunal as an *"additional safeguard"*, it also lists a number of concerns raised against it by some (including added costs and time), and it is foreseeable that, the legislation having passed on the strength of such an additional "safeguard", it could be stripped out in relatively short order. Just one year after New Zealand's law came into effect, the politician who

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[71] https://lozierinstitute.org/study-more-than-1000-deaths-hastened-without-patients-explicit-request-in-belgium/
[72] https://www.dailymail.co.uk/news/article-1285423/Half-Belgiums-euthanasia-nurses-admit-killing-consent.html
[73] bbc.co.uk/news/world-europe-52367644
[74] apnews.com/article/europe-health-courts-dementia-euthanasia-1ed45f0819e788708da51d161b48e9f8
apnews.com/article/a041563e55204279bfb8e335a19c2802

championed its passage has called for one of its defining "safeguards" – a six-month prognosis being required – to be excised[75]. Jersey's draft law is already set to admit a far wider range of people than New Zealand's; it is easy to imagine efforts to suppress the tribunal after legalisation, especially given the *"inherent difficulties in ensuring the Tribunal has the skills and knowledge necessary to make assisted dying determinations"* noted later (p66) in the report.

It is proposed that the Tribunal:

- *always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard)*
- *does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).*

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Yes ☑ No ☐ Don't know ☐

Please tell us the reasons for your response: These proposals concern deliberately ending citizens' lives: if activists and campaigners truly only wish it for those in extremis, no application where eligibility is found to be lacking or in doubt should be able to be reanimated.

Q22. Do you agree that the Law should provide for appeals to the Royal Court?

Yes ☑ No ☐ Don't know ☐

Please tell us the reasons for your response: ____

Q23. Do you agree with proposed grounds for appeal?

Yes ☐ No ☑ Don't know ☐

Please tell us the reasons for your response: The report envisages allowing second opinions to ease the path to euthanasia and assisted suicide earlier in the process; it cannot then provide an appeals process which is not allowed to question diagnoses and prognoses.

Q.24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Yes – I agree ☐

No– I do not agree, there should be no minimum time period for appeals ☐

No– I do not agree, there should be a time period longer than 48-hours ☑

Don't know ☐

Please tell us the reasons for your response: If the appeals process is to have value, it requires time and transparency. The freedom to exclude family members runs great risks, as seen in the case of Godelieva de

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[75] nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymour-says/AEC6XMXQRJG35CAAZ42KDU7Y5M/

Troyer, a Belgian woman with long-term depression who was euthanised by the co-chair of the euthanasia review body, to whose pro-euthanasia organisation she had donated money, with her son only finding out the day after she had died.[76]

Q.25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Yes ☑ No ☐ Don’t know ☐

Please tell us the reasons for your response: ___

Q.26 Do you agree that there should be no expiry date for the approval of an assisted death?

Yes – I agree, there should be no expiry date ☐

No - I disagree, I think there should be an expiry date ☑

Other, please state ☐ ___

Don’t know ☐

Please tell us the reasons for your response: The consultation document makes multiple references to considering whether a wish to die is fluctuating. Suicidality is transient and without an expiry date being set on an approval, an individual may act upon an unsettled wish to die during a period of particular strain.

Q.27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes ☐ No ☐ Don’t know ☐

Please tell us the reasons for your response: Advocates paint euthanasia and assisted suicide as forms of healthcare, but they are not. A 2019 joint statement issued by the Canadian Hospice Palliative Care Association and Canadian Society of Palliative Care Physicians stated that:

> “MAiD is not part of hospice palliative care; it is not an “extension” of palliative care nor is it one of the tools “in the palliative care basket”. National and international hospice palliative care organizations are unified in the position that MAiD is not part of the practice of hospice palliative care. Hospice palliative care and MAiD substantially differ in multiple areas including in philosophy, intention and approach.”[77]

While this question could be approached from several angles, we decline to support the medicalisation of causing death, and so decline to answer.

We do note, with respect to the final acts of euthanasia and assisted suicide, the report’s claim that:

> *“detailed protocols will be developed should an unexpected medical event occur, such as complications with the administration of the assisted dying substance. This could include the person taking longer to die than expected or issues with the administration of the substance.”* (p81)

“Unexpected” is an odd description to use, partly because assessing doctors are required (p99) to discuss *“the potential risks of self-administering or being administered the assisted dying substance”* with applicants, and partly because there is a growing body of research on complications in assisted suicide and euthanasia. Research published in the journal Anaesthesia suggested that a relatively high incidence of vomiting,

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[76] adfinternational.org/tom-mortier/

[77] https://www.cspcp.ca/wp-content/uploads/2019/11/CHPCA-and-CSPCP-Statement-on-HPC-and-MAiD-Final.pdf [31] carenotkilling.org.uk/articles/assisted-dying-inhumane/

prolongation of death and reawakening from coma could render such deaths “inhumane,”[31] while Dr Joel Zivot, writing in the Spectator, has observed that “paralytic drugs are used [in euthanasia]. These drugs, given in high enough doses, mean that a patient cannot move a muscle, cannot express any outward or visible sign of pain. But that doesn’t mean that he or she is free from suffering.”[78]

Q.28 Do you agree that a loved one should be able to support the person to self-administer the substance?

Yes ☐ No ☑ Don’t know ☐

Please tell us the reasons for your response: The new “service” could not guard against coercion while allowing this.

Q.29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes ☑ No ☐ Don’t know ☐

Please tell us the reasons for your response: While we object to use of the euphemism “assisted dying”, many proposals for euthanasia and assisted suicide seek to obscure the real nature of such deaths on death certificates, instead listing underlying illnesses only. We would agree that the real cause of death – ingestion or injection of lethal drugs – should be listed as the cause of death in such circumstances.

Q.30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes ☑ No ☐ Don’t know ☐

Please tell us the reasons for your response: At present, there is no regulation at all of community or hospital services. They are only just constructing an independent board to oversee health and community services. There is no CQC or regulator that oversees any services except care homes and a few day care facilities. Regulation is desperately needed to bring assurance to all areas of healthcare so a board to oversee the service would be welcome, but we urge members of the States Assembly to give particular consideration to whether a brand new, complex, life-ending service could be safely inspected and regulated in such a context.

Q.31 Do you agree that post-death administrative review of each assisted death is required?

Yes ☑ No ☐ Don’t know ☐

Please tell us the reasons for your response: We recommend careful examination of the European Court of Human Rights' ruling in the case of Tom Mortier (whose mother’s euthanasia death we cited in our response to Q24) when considering the immense difficulties of developing a meaningfully robust system of post-mortem review. The Government must be held accountable concerning its ECHR Article Two responsibilities.

Q.32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service?

Yes ☐ No ☐ Don’t know ☑

Please tell us the reasons for your response: We might be inclined to answer “yes”, but the JCC has no experience of regulating any community services in Jersey or even the hospital at the moment, so it is going

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[78] spectator.co.uk/article/last-rights-assisted-suicide-is-neither-painless-nor-dignified/

to be a steep learning curve to be able to regulate all these things and an assisted dying service. They are due to begin inspecting hospital wards in 2023, but community services and GPs will be after this. Would they really be ready by 2025 to inspect the assisted dying service?

Q.33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)

Yes – I agree, it should not be considered an essential service ☑

No– I disagree, it should be considered an essential service ☐

Don’t know ☐

Please tell us the reasons for your response: ___

6. Catholic Union of Great Britain

Assisted dying public consultation
Government of Jersey
Ground floor
19-21 Broad Street
St Helier
Jersey, JE2 3RR

Sent by email only

13 January 2023

Dear Consultation Team

Please accept this letter as the response from the Catholic Union of Great Britain to the consultation on assisted suicide proposals in Jersey. We note that the consultation uses the term “assisted dying” but we consider that the more realistic term is “assisted suicide” and will use that term in our response.

We are happy for the contents of this letter to be quoted. A copy of this letter will be made available to members and supporters of the Catholic Union.

Background

The Catholic Union is a membership organisation that works with others to represent the views and interests of the 4.5 million Catholics in Britain and advance the common good. We bring the experience and expertise of Catholic laity from all walks of life into the public sphere.

While Jersey is not part of the United Kingdom, it is part of the Roman Catholic Diocese of Portsmouth, and we fully support the statements made by Bishop Philip Egan on this matter. We strongly encourage you to listen to the views expressed by the Catholic community of the island as part of this consultation.

As part of the British Isles, and one of the Crown Dependencies, there are close social, political and cultural ties between Jersey and Great Britain. Developments on the island of Jersey are watched closely by Catholics in Britain, especially where questions of morality and human dignity are concerned.

The prospect of Jersey becoming the first territory within the British Isles to legalise assisted suicide is a matter of great concern to Catholics in Britain. Given the deep links between Jersey and Great Britain, there are clear practical implications of any decision, especially in the provision of health and social care, as well as the prospect of setting a precedent for other parts of the British Isles.

Church teaching

The Catholic Union is resolutely opposed to the introduction of assisted suicide in any form, including the proposals set out by the Government of Jersey. This position is based on the clear imperative in natural law, which is reflected in the teaching of the Catholic Church. *Samaritanus Bonus* (The Good Samaritan), a letter published in September 2020 by the Congregation for the Doctrine of the Faith, approved by Pope Francis, states:

> *“Assisting in a suicide is an unjustified collaboration in an unlawful act that contradicts the theologal relationship with God and the moral relationship that unites us with others who share the gift of life and the meaning of existence.”* [79]

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[79] https://press.vatican.va/content/salastampa/en/bollettino/pubblico/2020/09/22/200922a.html

This teaching is the product of two thousand years of careful thought and deliberation on human flourishing. It forms part of the wider body of work known as Catholic Social Teaching, which has at its heart the understanding that human beings are created in the image and likeness of God and possess intrinsic value.

Consultation proposals

We appreciate that these proposals are at an advanced stage, and this consultation deals with many of the practical challenges of introducing assisted suicide. In confronting these challenges, we hope that the Government of Jersey will pause and reflect on the right course of action before pushing ahead with changes to the law.

For the purposes of this consultation, we will limit our response to those areas where our expertise allows us to comment – including conscientious objection for medical professionals and premises, the requirement to inform people about assisted suicide, making appeals and recording cause of death.

We will include results and comments from a recent online survey of our members and supporters on assisted suicide, which ran from 9 December 2022 – 9 January 2023. [80]

Q. 8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes – they should have the right to refuse.

The importance of service to others instilled by our Catholic schools has encouraged many Catholics to pursue a career in heath or social care. The reason many people, not only Catholics, choose to work in healthcare is the ability to help others and support them when they are most in need.

In the Catholic Union's recent survey on assisted suicide, 88 per cent of responders said that introducing assisted suicide would make it harder for Catholics and other people of faith to enter the medical profession.

A number of responders pointed to the pressures faced by medical professionals in Canada, which recently introduced assisted suicide. Other responders said that certain areas of the medical profession in Great Britain were already becoming "no go" areas for Catholics, such as obstetrics and gynaecology, on account of deficiencies in conscientious objection policy and practice. One responder said:

> *"It is already difficult for Catholics to enter the medical/ nursing profession. Any move to make assisted suicide easier would make it much harder, and some areas of medicine impossible to work in. Furthermore it would be a barrier to accessing care for those millions of patients who care about this issue and would be concerned about their medical professionals' commitment to their care knowing that assisted suicide were possible."*

It is vital that any new law contains a clear and robust right for medical professionals not to be involved with any aspect of assisted dying, and that such a right be effective in practice. The proposed requirement that no one should be required to "directly participate" in the assessment, approval or delivery of an assisted death should be broadened to "any involvement" in such tasks.

Any new law that made it harder for Catholics to enter the healthcare profession would be an extremely regrettable step, and risk exasperating problems with staff shortages in health and social care.

Q. 9 Do you think that a conscientious objection clause should provide a premise owner/operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)?

Yes – they should have the right to refuse.

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[80] https://catholicunion.org.uk/2022/12/assisted-suicide-survey/

The Catholic Church has a long tradition of providing social and palliative care, and of supporting the work of others in this area. This work was summarised in a document published in December 2019 by the Caritas Social Action Network. [81]

We are aware of at least one Catholic care provider on the island of Jersey, and there may be others. It is vital that the values and ethos of such places are protected by a specific conscientious objection clause for premises. This right should not only be for care homes where there is a religious background, but for any premise owner/operator that wishes not to allow assisted suicide.

In the Catholic Union's recent survey on assisted suicide, 87% of responders said there was not enough palliative care support for people in England and Wales. One responder commented:

> *"Good Palliative care is a feature of our health care system but there is never enough. People fear that their symptoms will not be managed or controlled. Palliative care clinicians are far more creative in finding solutions to intractable symptoms. General clinicians lack expertise in this area. Community support provided by hospice is high quality but largely funded by charitable donations."*

We appreciate this may not reflect the situation in Jersey, and strongly encourage the Government to commission its own research into people's experience of palliative care on the island before moving forward with proposals for assisted suicide.

Q. 15 Do you agree that the law should not prohibit professionals from raising the subject of assisted dying?

No – we do not agree.

According to the consultation document, *"It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so."*

We believe this approach could create a grey area in which expectations and understanding may change over time. It would be preferable to include a requirement in law for health and care professionals not to raise assisted suicide with those in their care. This would make it clear that any suggestion of assisted suicide would need to come from the patient.

Q.16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about assisted dying service?

Yes – we agree.

This is vital if conscientious objection is to be properly understood and upheld as part of any new law.

We have already commented on the concern amongst Catholics in Britain at the impact that assisted suicide would have on Catholic medical professionals. We strongly encourage the Government of Jersey to work with the Catholic community on the island and medical bodies in exploring these concerns further.

The fear of a culture developing in which assisted suicide becomes the norm or even expected outcome in certain situations, is felt strongly by Catholics working in health and social care. In response to the Catholic Union's recent survey on assisted suicide, one person commented:

> *"I'm a carer at a care home. If they introduce assisted suicide I would find it very difficult and upsetting since all life is sacred. I would not like to be part of the process and if I had to give advice about this, I could lose my job for sharing my beliefs. I would not be promoted."*

Q.19 Should the law allow for the option of a waiver of final consent?

No – the law should not allow for the waiver of final consent.

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[81] https://www.csan.org.uk/wp-content/uploads/2019/11/Care_in_Time_Web.pdf

Allowing a waiver of final consent presents the terrible prospect of a person being deemed to have lost their decision-making capacity and being ‘assisted to die’ while in fact resisting the administration of the lethal medication. A doctor in the Netherlands was prosecuted for murder in these circumstances and the risks are simply too great.[82]

Q. 22 Do you agree that the law should provide for appeals to the Royal Court?

Yes.

Given the seriousness of the proposals being considered, there should be the right of appeal available to both patients and family and close friends.

Q. 29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes.

It is vital that in circumstances in which someone was helped to end their life, that this is recorded on their death certificate.

We would be happy to provide further information to any of these questions or meet representatives from the Government of Jersey to provide evidence in person.

Thank you for considering our response to this consultation.

Yours faithfully

Nigel Parker
Director
Catholic Union of Great Britain
director@catholicunion.org.uk

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[82] https://www.catholicnewsagency.com/news/44875/dutch-doctor-who-euthanized-woman-without-final-consent-defends-decision

7. Channel Islands Humanists

JERSEY GOVERNMENT: ASSISTED DYING

Response from Channel Islands Humanists, January 2023

Channel Islands Humanists

ABOUT CHANNEL ISLANDS HUMANISTS

Channel Islands Humanists is a part of Humanists UK. At Humanists UK, we want a tolerant world where rational thinking and kindness prevail. We work to support lasting change for a better society, championing ideas for the one life we have. Our work helps people be happier and more fulfilled, and by bringing non-religious people together we help them develop their own views and an understanding of the world around them. Founded in 1896, we are trusted to promote humanism by 100,000 members and supporters, over 100 members of the All-Party Parliamentary Humanist Group, and humanist members of the Jersey and Guernsey States Assemblies. Through our ceremonies, pastoral support, education services, and campaigning work, we advance free thinking and freedom of choice so everyone can live in a fair and equal society.

We have long supported attempts to legalise assisted dying and voluntary euthanasia in the UK and crown dependencies for those who have made a clear decision, free from coercion, to end their lives and who are physically unable to do so themselves. We gave oral evidence to Jersey's citizens' jury into assisted dying, as well as responding to previous consultations on the matter. We also gave oral evidence to the UK Parliament's last assisted dying inquiry in 2005. In recent years, we have been part of the UK and Welsh Department of Health and Social Cares' Moral and Ethical Advisory Groups, and the equivalent group in Northern Ireland.

SUMMARY

In many cases, those wanting an assisted death will be terminally ill. However, we do not think that there is a strong moral case to limit assistance to terminally ill people alone and campaign for a change in the law that would be responsive to the needs of other people who are permanently and incurably suffering. Humanists defend the right of each individual to live by their own personal values, and the freedom to make decisions about their own life so long as this does not result in harm to others. Humanists do not share the attitudes to death and dying held by some religious believers, in particular that the manner and time of death are for a deity to decide, and that interference in the course of nature is unacceptable. We firmly uphold the right to life but we recognise that this right carries with it the right of each individual to make his or her own judgement about whether his or her life should be prolonged in the face of pointless suffering.

We recognise that any assisted dying law must contain strong safeguards, but the international evidence from countries where assisted dying is legal shows that safeguards can be effective. We also believe that the choice of assisted dying should not be considered an alternative to palliative care, but should be offered together as in many other countries.

We have only answered questions where we believe there is a specific perspective relevant to humanists or we have specific expertise we can contribute.

RESPONSE TO CONSULTATION QUESTIONS

Q. 1 Do you give permission for your comments to be quoted?

Yes, attributed to Channel Islands Humanists

Q.2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?
Yes

Q.3 If yes, do you think assisted dying:
Should be permitted

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?
Yes

We believe it is morally right and more compassionate to change the eligibility criteria for people with neurodegenerative diseases from a life expectancy of six months to 12 months.

Firstly, people with neurodegenerative conditions have the potential to be in pain for considerably longer periods of time. Extending the timeframe may give individuals the option of an assisted death earlier, reducing the amount of pain and suffering they are likely to live through.

Extending the eligibility criteria for people with a neurodegenerative disease from six months to 12 will give them more time to act before mental capacity is lost. A person with a neurodegenerative disease may not have full mental capacity when a healthcare professional deems they have six months left to live, so some individuals may never have the option for an assisted death by default. This could act as a de-facto barrier for some individuals with neurodegenerative diseases. It would be wrong to deny these people the right to make decisions at the end of their lives.

However, while we support a change in the criteria, we would like to note that a person with a neurodegenerative disease could also fall under the consultation's proposed 'Route 2' for people with incurable, intolerable conditions with no time limit. We believe that if the Government chooses to continue with the proposed two routes, then clear guidance needs to be created for people who could fall into both categories, or for people who may start down 'Route 2' but then become eligible for 'Route 1'.

Later in the consultation, we will argue that the two separate routes are unnecessary and discriminatory. If the proposed plan for two routes were to be replaced by a single route, then the extension of the time criteria would be unnecessary.

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?
Yes

We understand the need for Jersey to limit eligibility criteria to those ordinarily resident in Jersey for 12 months and believe in this instance it is appropriate. Making sure the service is only available to residents will keep the service Jersey-centric and will mean that it is tailor-made to suit islanders' needs.

Q.7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?
Yes, it should be free

We believe it would be unjustifiable for those without the means to be forced to suffer and die a painful, undignified death. A core argument in favour of the legalisation of assisted dying is that the current circumstances lead to intrinsically unfair and unequal situations. At the current moment in time, the only route for an assisted death for a resident of Jersey that is legal in the jurisdiction in which it is carried out would be for them to travel to one of the assisted dying centres in Switzerland. The minimum cost for this service is over £9,000 which is prohibitive for many. This creates a thoroughly unequal system where only the wealthy can access an assisted death. Through this same reasoning, the Jersey Assisted Dying Service should be free in order to provide equal access to all those who need it.

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes, they should have the right to refuse

Humanists strongly believe in freedom of religion and belief and this should include the freedom for religious healthcare professionals to refuse to take part in activities that go against their conscience, as long as it does not impact the rights and freedoms of others. We believe it is right in this instance that conscientious objection should be framed to mirror the existing termination of pregnancy law.

However, we are concerned that in some cases, both in the UK and internationally, conscientious objection has been misinterpreted and abused so as to allow people with religious convictions to not fully comply with the requirements of their employment or to disrupt public health and safety. On such occasions, an individual's freedom of conscience can and should be balanced against the rights of others.

We recommend that steps are taken to make sure that conscientious objection does not impact the health and healthcare options of others. People have the right to make choices about their treatment and the end of their lives and conscientious objection should not hinder that. This could mean, for example, that where a healthcare professional refuses to take part in conversations around assisted dying, they have to refer the patient to another healthcare professional that will.

We agree with the consultation report that the law will require the minister to bring forward clear guidance.

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

We are concerned that allowing premise owners and operators the right to conscientiously object could be misinterpreted and abused so as to allow people with religious convictions to block access to the Jersey Assisted Dying Service. We believe it is right that all public premises (such as Jersey General Hospital) would not have the option to conscientiously object.

The consultation report states that possible locations for an assisted death include individuals' private homes, provided they are approved by the Administering Practitioner. Care homes are homes. An individual may have lived in a care home for years, it will be the location they feel most comfortable and they should have the right to have their assisted death there. By extension, a landlord shouldn't be able to block an assisted death from someone who rents from them.

We believe that an individual's freedom of conscience can and should be balanced against the rights of others and if this level of conscientious objection were allowed many people could be denied their right to make choices at the end of their lives.

There is a difference between an individual, acting on an issue of conscientiousness and personal belief, compared to an entity, business, or operator denying people the right to access a service to which individuals are legally entitled.

As we have previously mentioned, freedom of choice and bodily autonomy are important parts of our support for the legalisation of assisted dying. If multiple religious-owned and operated premises were to refuse access to the service, then many citizens of Jersey could have their choices severely reduced. We note that it is common for hospices to be owned, managed or linked to religious organisations. For individuals who are severely disabled, or close to death, moving from a care home to a hospital can be physically difficult, distressing and against their own wishes.

We believe premise owners and operators should take responsibility to make sure that their care and service are not compromised because of personal values and beliefs. Access to the assisted dying service should be equal for all citizens, including those citizens who are in the care of people with different values and beliefs. Assisted dying should be patient-centric and as much as reasonably possible it should be led by the individual themselves. Just as people have the right to make decisions about their own treatment, people have the right to make decisions about the end of their lives. It should not be for premise owners to make decisions for others.

Q.11 Do you agree that the nine proposed steps are all necessary?

Yes

We believe that the nine-step process appears practical and safe, however, we note in a response to a later question that we believe the second route to be unnecessary.

It is important that safety is a large factor, not only for the individual who is embarking on the process but for public confidence in the system. International evidence shows that safeguards around assisted dying are effective and safe. The US state of Oregon, Belgium, the Netherlands, and Switzerland have had assisted dying legislation for over twenty years that has been shown to be safe, accessible, and trusted by the public.

The nine-step process would introduce important safeguards that do not exist in the current system. A study by the Office of National Statistics shows that a diagnosis of a serious health condition is associated with an elevated rate of death due to suicide. Individuals with terminal, intolerable, and incurable conditions are already taking their lives into their own hands, but without support or the involvement of any healthcare professionals.

While safeguards are critical when considering assisted dying legislation, they shouldn't act as a barrier to access for patients and more safeguards don't necessarily make a safer system.

We suggest amending the assisted death plan in Step 6 to remove the reference for 'their family'. Currently, Step 6 states: 'The assisted death plan will set out:… any cultural considerations and rituals that are important to the patient and their family'. An individual's cultural considerations may be very different to their family's. We therefore think it's important that all cultural considerations are centred around the individual, not their family. The individual may include family, friends, and loved ones in their decision-making if they so wish, but it is not for the Assisted Dying Service to automatically include family members in the process.

Q. 12 Do you think there are any further steps / actions that should be included?

No

We understand from both the citizens' jury and international evidence that it is important that the process isn't too long and arduous. People who apply for an assisted death are often in serious pain, suffering, and indignity and it would be cruel to force them to remain in that situation for longer than is necessary to create a safe and fair system.

David Seymour, an MP in New Zealand, recently expressed concern that one in six applicants for an assisted death there had died of underlying conditions before they were able to get an assisted death. 'Given applicants need to have a terminal illness to apply, there will always be some people in this position… it can take two months to get through the entire process, and that is longer than necessary to observe all the safeguards in the law.'[83][84] We therefore believe that it is vital that the entire process is as short as it needs to be in order to be fair and safe. A core argument in support of assisted dying is the reduction of pain, misery, and suffering. By extension, it's important that the process does not maintain a situation of suffering longer than necessary.

We agree with the decision not to include the courts in the process. We believe that the need for a High Court order, as suggested in the most recent proposed legislation in England and Wales, would be unworkable. In Canada, in the case of *Y v. Swinemar*, the judgement found that the courts cannot play any role in reviewing

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[83] NZ Herald, 'Euthanasia laws too strict and should be relaxed, Act leader David Seymour says', 6 Nov 2022 https://www.nzherald.co.nz/nz/euthanasia-laws-too-strict-and-should-be-relaxed-act-leader-david-seymo ur-says/

[84] NSCA 62 (CanLII), Sorenson v. Swinemar, 02 Oct 2020

assessments. It would place unnecessary strain on the courts in Jersey to play a leading role in every single application.[2]

Q.13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

No – I do not agree

While we believe the 14-day minimum timeframe is an important safeguard, we would strongly suggest introducing a caveat for extreme cases. We are concerned that the 14-day minimum could lead to unnecessary pain and suffering, and could even be a barrier to some individuals accessing an assisted death.

There are cases when the diagnosis of a terminal illness is sudden and the timeframe is incredibly short. As previously mentioned, there have been concerns in New Zealand about the number of individuals who have died after making a request for an assisted death: one in six applicants died of underlying conditions before they were able to have an assisted death. In 2020 in California of the 677 individuals who were prescribed life-ending drugs, 112 died from an underlying illness or other causes and did not have an assisted death.[85] California requires two verbal requests to their physicians at least 15 days apart.

In Canada, the 10-day waiting period can be waived if both assessing doctors agree and the patient is at imminent risk of either losing capacity or dying. In Ontario, the waiting period was waived for 24% of patients in 2019.[86]

Furthermore, page 34 of the consultation report states rightly that it is important that the person dictates the pace at which they move through the process.

Evidence from abroad shows that when an individual applies for assisted death, they have already thought about it extensively. This can also be reflected by the low rate of individuals who change their minds. In 2021 in Canada less than 2% of people who were approved decided not to go ahead in the end.[87]

Q.14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

No – I do not agree

We strongly believe that 90 days is an excessive amount of time for those with incurable diseases to live with pain, suffering, and indignity. We believe that the approach to people unbearably suffering should be the same as for people with terminal illnesses.

Firstly, this point of view is supported by international evidence from multiple jurisdictions as mentioned previously that show that long waiting periods are unnecessary and can act as a barrier to people accessing an assisted death.

This is further compounded by the nature of ‘unbearable suffering’. We do not believe that anyone who can be classified as unbearably suffering should be forced to suffer for a minimum of 90 days.

For degenerative illnesses, this 90-day waiting period could lead to the loss of mental capacity and would then inhibit the individual from having an assisted death. For aggressive cancers, such as skin cancers, this could mean 90 days of immense and incredible pain. For an individual with a condition like locked-in syndrome, this would mean 90 days of a life of misery and indignity.

Furthermore, the 90-day waiting period could push individuals to apply to the process early in order to make sure that they would not lose mental capacity during the 90-day period.

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[85] CDPH, California End of Life Option Act 2020 Data Report, July 2021

[86] Office of the Chief Coroner, Ontario Forensic Pathology Service MAiD Data, 31 Oct 2019

[87] Health Canada, Third annual report on Medical Assistance in Dying in Canada 2021, July 2022

As previously mentioned, evidence from abroad shows that when an individual applies for assisted death, they have already thought about it extensively and the rate internationally of individuals changing their minds is low.

Q. 15 Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes – I agree

We believe that decisions about healthcare are best made in the open, with honest, frank discussions with medical professionals, friends, and family. In order for someone to make an autonomous decision, they need all the information and options available to them.

Healthcare professionals should be permitted to broach the subject with their patients as part of a wider discussion about their care options, including palliative and hospice care. We believe this could help to reduce health inequalities when it comes to accessing this service, as patients who are more health literate and aware of their rights, in general, are more likely to be aware of their right to assisted death.

Patient trust is incredibly important in the doctor-patient relationship and it's important that assisted dying does not hurt that relationship. There should be guidance for healthcare professionals on how to provide the information in an objective and informative manner. A patient should never feel pressured by a doctor to either have or reject an assisted death. If a patient is strongly against assisted dying then the healthcare professional should not broach the subject again. Similarly, if the patient actively wants to learn more about assisted dying, the doctor should either provide that information or point the patient to a healthcare professional or service that can do so. It is important that if a healthcare professional is found to have broken the guidance and unnecessarily continues to suggest assisted dying that they should be removed from the register.

Q. 16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes – I agree

While we believe there should not be any legal requirement to tell people about the assisted dying service, there should be some explicit guidance given to all healthcare professionals and there should be an offer of training and support for professionals who work closely with patients likely to want an assisted death.

Some of this guidance can be taken from the General Medical Council's Guidance *Personal beliefs and medical practice*[88], namely that all healthcare professionals should treat patients fairly and with respect whatever their life choices and beliefs. Healthcare professionals must explain to patients if they have a conscientious objection to a particular procedure. They must not imply or express disapproval of the patient's choices or beliefs.

Those who conscientiously object should have a duty to refer their patient to another healthcare professional or back to the Jersey Assisted Dying Service which can provide them with advice and guidance.

Nevertheless, assisted dying should never be pushed onto a patient. If a patient decides they do not want an assisted death, the healthcare professional should not suggest it again. Also, caution should be made to not suggest the option of assisted death to patients who may have mental health issues or be incredibly vulnerable.

One of the downsides of not requiring healthcare professionals to tell people about the assisted dying service is that it may reduce the equity of access to information. Medical literacy is different for all people. A strong

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[88] General Medical Council, Guidance on Personal beliefs and medical practice, 25 March 2013
https://www.gmc-uk.org/-/media/documents/personal-beliefs-and-medical-practice-20200217_pdf-58833376.pdf

public awareness campaign, such as the one currently provided by the Jersey States Assembly with town hall meetings, should help negate this.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

Yes

A second opinion is an important part of avoiding human error that may exist. A second opinion may be important to help determine eligibility criteria, such as if a patient counts as a resident of Jersey, or if their medical condition fits the criteria.

We agree with the proposals that if they request a second opinion assessment at Step 2, they cannot request another at Step 3.

Q.18 Should the law allow for confirmation of consent to proceed?

Yes

We believe that the confirmation of consent to proceed is an important step for safety in the very small chance that a self-administered substance does not cause the intended death. We believe that cases where the administering practitioner will need to intervene will be incredibly low.

Q.20 Do you agree with the two different approval routes as proposed?

No – all approvals should be by the Coordinating Doctor based their assessment and that of the Independent Assessing Doctor only (ie. no requirement for a Tribunal)

We believe that the Tribunal is an unnecessary step when evidence from other jurisdictions shows that the assessment from healthcare professionals is appropriate, safe, and best practice. The Tribunal adds little value or safety but could put unnecessary stress on the incurably, intolerably suffering.

The suggested Tribunal would be made up of:

a. 1 x legal member (the Chair) – advocate or solicitor of Royal Court for 5-year minimum
b. 1 x medical member – medical practitioner with relevant experience
c. 1 x lay member.

Firstly, we fear that delays in staffing and holding a Tribunal could be a barrier for people who are not terminally ill. It is unclear how many individuals in Jersey fit the criteria of 'advocate or solicitor of Royal Court for 5-year minimum'. If the assisted dying service is unable to find an individual who meets this criterion, then assisted dying will be de-facto blocked for people who are unbearably suffering.

Furthermore, it is unclear what the lay member and the legal member will contribute that a medical member will not. This is considering that by the time the case has reached the Tribunal, both Assessing Doctors will have already determined that the person requesting an assisted death has an incurable physical medical condition that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable.

The Tribunal will be able to compel any person who has already been involved in the assessment process to provide additional information, evidence, or testimony (in writing, in person, or via video-link) which will support the Tribunal to re-examine the information they have been provided. This again can put unnecessary pressure on the individual requesting the assisted death, who will most likely already be in tremendous pain, suffering, or indignity.

By this step, under the consultation, the individual has already had a right to a second opinion – three more disconnected opinions are unnecessary.

We strongly suggest that the Tribunal is removed from this process, as is the need for two routes. It is widely understood from international evidence that the first route is a clear, safe system for all those involved. If it is deemed safe enough for people with terminal illnesses, there is no reason that it will not be safe for people who are unbearably suffering. We believe it is morally wrong to force people who are unbearably, incurably suffering to be treated differently from others.

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

As detailed in a separate answer, we strongly believe that a Tribunal does not add value or safety to the assisted dying service.

Q22. Do you agree that the Law should provide for appeals to the Royal Court?

No

We are concerned that the process for appeals could allow others (family members and loved ones) to unnecessarily interfere with the assisted dying process. We believe that while it is positive for death and assisted dying to be spoken about openly and publicly, a right to appeal would conflict with the bodily autonomy and the freedom to choose that underpin the reasoning behind assisted dying. Most jurisdictions do not provide appeals. Only Western Australia does so.

We believe that assisted dying should be treated and understood as a healthcare or treatment option. For no other healthcare option would a third party be allowed to interfere. For example, if an individual needed and requested a blood transfusion, a loved one would not be able to appeal that decision based on the loved one's religion or belief.

There have been multiple international cases where a family member has disagreed with an individual's decision to have an assisted death. These family members can occasionally use processes to stall against an individual's wishes and care needs to be taken to ensure this cannot happen.

The Canadian court case *Y v. Swinemar* established that relatives cannot veto an approved assisted death decision in Canada. In this case, as the husband had met all of Canada's eligibility criteria and had made a mentally capable decision to have an assisted death, his wife could not appeal this decision.

There may be some instances where an appeal is important to the person asking for an assisted death. For example, someone appealing on the grounds they weren't considered a Jersey resident even though they considered themselves to be. But with a properly safeguarded and practical law, these appeals should be unnecessary or extremely rare.

Included in the guidance, an individual or family member should be able to flag any potential issues to the Care Navigator, who could raise it with the Assessment Doctors and Coordinating Doctor as a safeguard against any potential abuse.

Q23. Do you agree with proposed grounds for appeal?

No

As detailed in a separate answer, we strongly believe that the proposed grounds for appeal are unnecessary.

Q.24 Do you agree with there should be a 48-hour time period between approval and the assisted death to allow for appeals?

As detailed in a separate answer, we strongly believe that the proposed grounds for appeal are unnecessary. Adding additional waiting periods for individuals who are unbearably suffering or terminally ill is unfair and cruel.

Q.25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

As detailed in a separate answer, we strongly believe that individuals have a right to medical self-determination. While we hope that an assisted dying law will allow friends, family, and loved ones to have more open conversations about end-of-life choices, it is important that individuals come to independent, autonomous decisions.

If an individual has come to the informed, mentally capable decision to pursue an assisted death, as long as they meet the criteria there should not be unnecessary barriers. If a spouse, sibling, or loved one disagrees with an individual's decision to have an assisted death, they should not be allowed to prolong the process or add any degree of difficulty or uncertainty to it.

Q26. Do you agree that there should be no expiry date for the approval of an assisted death?

Yes – I agree, there should be no expiry date

We believe that it is vital that an individual never feels rushed or pressured throughout the assisted dying process. If there were to be an expiry date, an individual could feel pressured into having the assisted death before they are ready to do so. Evidence can show that an assisted death, or potential access to an assisted death, can be more of an insurance policy to ensure that an option becomes available if the pain, suffering and indignity became so much they couldn't bear.

Furthermore, an individual may complete all the steps of the service and then want to spend time with their family, sort out their affairs, or simply want some more time. In these circumstances, they should not feel the pressure of an expiry date that could influence their decision.

Q.27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes

We strongly believe that an important aspect of any assisted dying legislation is safety for all of those involved. Having an experienced, trained professional at close hand during the assisted death may add another layer of safety to this process. The practitioner would be able to step in if the individual was having any issues with the final assisted dying process.

However, requiring an Administering Practitioner to be present for all assisted deaths may put a strain on the number of staff needed to run a safe and equal service. If a lack of Administering Practitioners opted into the service, this could lead to the closure of the entire service.
Furthermore, if certain areas of Jersey lacked available administering practitioners, this could lead to an unequal roll-out of the service, where some islanders had access to the service while others did not. Provisions should be made to allow for travelling practitioners in order for individuals to die in a location of their choosing.

We recommend that while Administering Practitioners should be with the person or nearby, the assisted dying service should take measures to make sure that everyone has equal and continued access to the service.

Q.28 Do you agree that a loved one should be able to support the person to self-administer the substance?

Don't Know

We understand that allowing an individual to help their loved one in this moment is a kind and compassionate approach that may be the expressed will of the individual seeking the assisted death. If a system can be created that allows for a loved one to support an individual in a clear, unambiguous, safe manner then it should be allowed.

However, if a loved one is able to support a person self-administering the substance, then we believe that the administering practitioner must be present to remove any ambiguity.

We recommend that Jersey produces clear guidance on what it would mean to support self-administration. This guidance must be clear on what sort of support is acceptable, such as holding a straw or placing a switch in a person's hand. The guidance must prioritise an individual's autonomy and safety. At present, there is only one paragraph on this (295) in the consultation report, so clarification is recommended before support from a loved one is allowed.

Q.30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?
Yes

Q.31 Do you agree that post-death administrative review of each assisted death is required?
Yes

We believe that the steps outlined from 321 to 325 appear sensible and prudent for the continued safety and quality of the service. Regular review can help make sure that the assisted dying service remains as safe and effective as it can be while making sure that the citizens of Jersey continue to have a compassionate option at the end of their lives.

Q. 32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service
Yes

We understand that public confidence in the assisted dying service is vital. Individuals and their families must have complete trust in the entire process in order for the service to run effectively. The role of the JCC in regulating the service will help the people of Jersey feel that the service is safe.

The annual report on assisted dying is the correct step to keep Jersey in line with international examples and play an important oversight role for safety, monitoring, and research.

The consultation on the regulations of JCC (326) should not hinder the timeline for the legislation of assisted dying in Jersey.

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)
Don't know

We believe that having a choice at the end of your life is essential. People have the right to bodily autonomy and no one should be made to suffer unnecessarily.

We are concerned that if the Jersey Assisted Dying Service was not considered an essential service then, despite it being the will of the people and the Jersey Assembly, people who are in pain, suffering, or indignity may not be able to access the choices they deserve.

However, it is important that the Jersey Assisted Dying Service always complies with all conditions imposed on them. The JCC should be allowed to temporarily suspend the service if it were to find alleged or confirmed breaches of the law or its standards. Not suspending the service in this unlikely scenario could harm public confidence in it, which is paramount.

For more details, information, and evidence, contact Channel Islands Humanists:

Richy Thompson
Director of Public Affairs and Policy

8. Christian Medical Fellowship (CMF)

Assisted dying in Jersey: submission to consultation.

Response from Christian Medical Fellowship, January 2023

Introduction

This submission by Dr Rick Thomas (Rick.Thomas@cmf.org.uk) is on behalf of the Christian Medical Fellowship (CMF). We are happy for the submission to be published and attributed to CMF.
The Christian Medical Fellowship is an association of around 4,500 doctors, medical students, nurses and midwives in the UK that exists to unite and equip them to live and work for Jesus Christ.

Background to Consultation

The consultation document states that "*the purpose of this consultation is not to consider whether assisted dying should be permitted in Jersey - as the Assembly have already determined, in principle, that it should be permitted - but instead to understand peoples' response to how an assisted dying service should work."* (s1.8, p7)

We are concerned that, from the outset, this consultation report assumes the residents and States Assembly of Jersey are still happy with the 'in principle' decision taken in November 2021 and are ready to consult over the proposals for its implementation. We would point out:

a) that a new Assembly was elected in June 2022, and it is a constitutional principle that no government can bind its successor. Has the 2021 decision been tested in the new Assembly?

b) that many citizens, possibly including Assembly members, having considered these proposals, may conclude that they cannot be safely implemented, and that the original 'in principle' decision should therefore be re-visited

c) that the Proposals document makes significant changes in terminology from that approved by the States Assembly. For example, the Final Report of the Citizen's Jury in September 2021 excluded 'mental conditions' from eligibility criteria by a large majority. Discussions at the time considered dementia but excluded it on safety grounds. Yet the current Proposals have excluded dementia from 'mental conditions,' thus including it in the list of eligible criteria. **This is a major change, not approved by the States Assembly**.

   The Proposals refer to 'tolerable' alleviations – a thoroughly subjective notion – without any objective criteria to guide those making eligibility assessments. This is similar to the concept of 'unbearable suffering' used in Belgian law, where it has been associated with a one-hundred-fold increase in deaths by euthanasia between 2004 and 2021. As the Belgian Federal Control Committee has itself stated: *'The unbearable nature of the suffering is largely subjective and depends on the patient's personality, ideas and values.'*[89]

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[89] Federal Control Committee, First Report, 2004, p16.

Section 2. Principles

Definitions

This section begins by stating that "*Assisted dying is not the same as suicide*" (s2.11, p11). This is simply to deny reality. Suicide is defined as 'the act of taking one's life.'[90] Assisted dying simply means receiving assistance to take one's own life. It is disingenuous to imply that there is a substantive difference between the terms suicide and assisted dying. It's disappointing that the Government of Jersey have adopted the misleading language used by lobby groups seeking a change in the law.

To most people, the term 'assisted dying' suggests 'providing hospice-type care to people who are dying' or 'giving people who are dying the right to stop futile life-prolonging treatment.' It is not generally understood to mean the giving of a lethal dose. Only 42% of those questioned in a July 2021 UK survey realised that it refers to giving lethal drugs to a patient to end their life intentionally.[91]

The Government of Jersey is proposing that both assisted suicide and euthanasia be legalised. If the proposals become law, it is very likely that, as in Canada, the overwhelming majority (99%) of assisted deaths will be acts of euthanasia, where lethal drugs are administered by a doctor or nurse.[92]

Section 3 Eligibility

We very much appreciate the efforts made by the Assembly to craft eligibility criteria that separate physical medical conditions from mental conditions. However, we have some remaining concerns:

- **Route 1 – terminal illness reasonably expected to cause death within six months (or twelve months in the case of neurodegenerative conditions) and to cause unbearable suffering.**

It can be fiendishly difficult accurately to predict how long a patient with a terminal illness might 'reasonably be expected' to survive. It is even more difficult to predict whether terminal illness will produce unbearable suffering. Individual tolerance levels vary considerably. Even experienced clinicians can arrive at prognoses that prove well wide of the mark (and there is no stipulation of minimal experience levels in the consultation document). We have concerns that, as worded, the eligibility criteria could open the door of assisted dying to those whose illnesses prove much less terminal than expected and/or whose suffering could be controlled through good quality palliative care.

- **Route 2 – Unbearable suffering, that cannot be alleviated in a manner the person deems tolerable.**

This definition captures a whole range of illnesses, progressive and otherwise, some of which might eventually prove fatal but perhaps not for five or ten years, or even longer. It represents, in effect, **euthanasia on demand**. One has simply to say 'I find this condition/treatment intolerable' to be eligible for assisted dying. It is one of the most liberal expressions of euthanasia/assisted suicide anywhere on the planet. Conditions such as muscular dystrophy, multiple sclerosis, progressive pulmonary fibrosis, cystic fibrosis, chronic obstructive pulmonary disease, chronic heart failure etc, are all captured. In many cases, when well-managed, these are compatible with life over many years. High quality palliative care can control symptoms in almost all cases. The 'intolerable' can become tolerable.

On p. 14 the report states that *'conditions such as dementia, which are conditions of the brain as opposed to mental or psychiatric illness, would fall within the physical conditions criteria*' and thus be eligible criteria for those who have capacity. This would, of course, capture a large cohort of people, as dementia is now so

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[90] 'Definition of Suicide.' 1985. Edwin Shneidman. John Wiley and Sons Inc.

[91] https://www.dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf

[92] 'Worries grow about medically assisted dying in Canada.' World Report by Paul Webster. *The Lancet*, September 2022

commonly diagnosed and increasingly so in the early years of its expression when capacity is retained. The fearful prospect of losing independence, control and capacity, and associated concerns about 'loss of dignity,' or 'becoming a burden' to loved ones and to healthcare services, can be experienced as 'intolerable.' We are concerned lest many people, depressed following a diagnosis of dementia in its early stages, feel coerced by their fears for the future into applying for assistance to die. Commenting of the 2013 figures for assisted dying in Oregon,[93] Baroness Sheila Hollins, former president of the UK Royal College of Psychiatrists, stated: *'Researchers have found that some patients who have ended their lives under the terms of Oregon's assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity; it is common in elderly people, and it is treatable. But in some cases in Oregon, it has not been diagnosed by the doctor who assessed the patient's capacity and prescribed lethal drugs. Oregon's law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened*.'

It is inevitable that many people suffering a terminal illness will also experience depression, anxiety and perhaps other psychological conditions. What will not be immediately clear is the degree to which those mental health conditions may account for the settled intention to end their own lives. It can be fiendishly difficult, even for well-acquainted family doctors, to assess the contribution that loneliness, depression or the desire 'not to be a burden' may be making to their patient's request for assisted dying. Even apparently settled wishes can change unaccountably, and apparently irreversible conditions can remit.

Successfully treating depression may change a person's outlook significantly, even if it doesn't change their prognosis. But it would appear from the experience in Oregon, for example, that routine psychiatric assessment is being overlooked. It is almost as if the declared wish to end one's life trumps all therapeutic considerations. But existential angst is not a terminal illness. Value and dignity are conferred by compassionate care, love and kindness. Depression and anxiety are amenable to medical treatment. We believe there is a better way to deal with the problem than by eradicating the patient.

To be able to make a fully informed decision, the sufferer must have access to quality palliative care services, be assessed for capacity by a qualified and experienced mental health professional and have been adequately treated over a sufficient time period for any co-existing mental health conditions. **Without qualified assessment of capacity, it is inevitable that some patients who could have been successfully treated will instead be helped to die.**

We appreciate the desire of the Assembly to provide assisted dying to those who are not terminally ill but who do face suffering that they consider intolerable. However, the example cited in the consultation guide of a person with life-changing injuries following a car crash is, we believe, inappropriate. Many people, who suffer such injuries through accidents or armed conflict, initially feel they cannot face life and want to die. With time, support from loved ones, and skilled rehabilitation, most of them recover the will to live and go on to find a measure of fulfilment despite their altered reality. Access to people who have made that journey, and whose stories may be inspiring, should be built into rehab services.

Palliative care

The UK has been a world leader in the hospice movement, building on the foundations laid by pioneers like Cicely Saunders who famously said: '*You matter because you are you, and you matter to the end of your life. We will do all we can not only to help you die peacefully, but also to live until you die.*' Those values still undergird the practice of good palliative medicine, providing high quality end-of-life care, controlling pain effectively and enabling people to 'live until they die.' **We submit that the solution to 'prolonged and painful death' is not to do away with the patient, but to provide access to, and experience of, high quality palliative and hospice care.** People often have fears or misunderstandings about what can be offered; giving palliative care services a reasonable chance to alleviate the situation should be a pre-requisite.

By legalising assisted dying, the incentive to invest in palliative care will be reduced rather than increased. '*Evidence shows that palliative care and 'assisted dying' do not, and cannot, co-exist harmoniously. They do not*

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[93] Levene I, Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. JME 2011;37:205

rise and fall together because they are not complementary but are diametrically opposed both in theory and practice. One can truly flourish only at the exclusion of the other.

Before permitting assisted suicide in 1997, Oregon, for instance, was comparatively advanced in palliative care provision, ranked highly in the US for hospice utilisation, hospital ICU utilisation, pain policy and advance care planning policy. After 2000, palliative care funding and provision stagnated as assisted suicide, encouraged by health insurers, took hold.

A similar pattern of diminution in palliative care has been observed since 2012 in the Netherlands, where investment is a third less than in the majority of European countries which prohibit assisted death. The same has occurred in Belgium since 2008 where promised increases in palliative care failed to materialise while the workload in doctor-assisted deaths climbed incrementally, sparking mass departures of palliative care specialists angry that their units were being turned into 'houses of euthanasia' and their functions reduced to preparing patients and their families for lethal injections.'[94]

We urge the Jersey government to commit the necessary resources to training a new generation of palliative care specialists and multiplying palliative care units and symptom control teams across the island, until excellent end of life care is available to every citizen.

Ethical concerns

There is, of course, a significant financial cost to the provision of high quality, widely accessible palliative care. But we would humbly suggest that the cost to society of legalising assisted suicide is much greater.

It would inevitably strengthen the perception that people with certain types of disease or disability have lives 'not worth living', that they would be 'better off dead', and that the costs of their care would be better directed towards healthcare provision for the more socially or economically 'productive' members of society.

The quotient of compassion in the caring professions and respect for human life in society in general would inevitably ebb.[95] Little wonder that organisations representing disabled people are among the most vociferous opponents of these proposals. It is our conviction that the calibre of a civilised society can be measured by the investment it is willing to make in the care of its most vulnerable members.

We are concerned, too, about the effect that the introduction of assisted dying might have on the doctor-patient relationship. Trust is crucial to this relationship. The patient's confidence that the doctor will always act in such a way as to 'do no harm' is foundational to the relationship. Giving doctors the power deliberately to end the lives of their patients will inevitably redefine the nature of the relationship and risks undermining that essential trust and confidence.

The long-term effect on doctors and nurses themselves could be equally damaging. They could become hardened to causing death, and even begin to see their most vulnerable patients as 'disposable.'[96] Such patients might then decide not to ask for medical help, for fear that they be encouraged to consider assisted dying by doctors whom they feel they can no longer fully trust.

Lord McColl of Dulwich described this change in medical conscience as 'chilling'. In a speech in the House of Lords in 2003, reporting on a visit to the Netherlands, where euthanasia had been legalised, he said: *'Noble Lords will be aware that the Select Committee visited Holland. When we inquired of a doctor what it was like doing the first case of euthanasia, he said, "'We agonised all day. It was terrible.'" But he said that the second*

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[94] Caldwell S. Palliative care and assisted dying – never the twain shall meet. Published in Conservative Woman, 19 November 2021. https://www.conservativewoman.co.uk/palliative-care-and-assisted-dying-never-the-twain-shall-meet/

[95] Wyatt J. Matters of Life and Death. Nottingham, England: IVP,2009 (2nd Edn):207

[96] Keizer B in Ross W. Dying Dutch: Euthanasia spreads across Europe. Newsweek, 12 February 2015

case was much easier and the third case – I quote – "'was a piece of cake." We found that very chilling indeed.'[97]

As a group made up largely of doctors, many of whom are involved in palliative care, CMF is aware of the hard cases, those whose symptoms are indeed very difficult to control. But we are also aware that, where there is access to the best palliative care, the proportion of terminally ill patients for whom this is true is tiny. We consider that the risks to vulnerable patients, the credibility it would give to the notion of 'a life not worth living,' and the undermining of confidence in the doctor- patient relationship, were assisted dying to be legalised, far outweigh any benefit to that tiny proportion of terminally ill patients.

Section 4: assisted dying service

- **A 'voluntary, settled and informed wish'**

How is the attending clinician to be satisfied that his or her patient's wish is a settled one? The consultation document answers this question by stating: *'The assisted dying process has built in controls to ensure the person's wish is settled. The person must articulate their wishes throughout the process, and each step of the process can only be initiated by the person expressing a wish to proceed to the next step.'* It appears that the 'built in controls' rely on the person's repeated articulation of their wishes at different stages of the process. There is no stated requirement that the Co-ordinating Doctor or Independent Assessment Doctor have any expertise in mental health assessment. They simply must have undergone 'assisted dying training.' It is quite possible that neither of the deployed medical personnel will ever have met the applicant and thus will have no first-hand knowledge of the person's vulnerabilities. There is not even a requirement that one or both of the doctors involved have any minimum length of clinical experience.

From the applicant's perspective, at the very time they would benefit most from a familiar medical face, in whom they have a history of trust and confidence, they will be faced with professionals, deployed by The Jersey Assisted Dying Service, who are quite possibly unknown to them. The whole process described in the Proposal document has about it the feel of a cold, standardised and impersonal production line, geared to death. The 14-day 'reflection period' for Route 1 applicants (which is not so much a period of reflection as an 8-stage process of assessment and preparation) is, in our opinion, unduly rushed. It is hard to see where an applicant, having first triggered the process, could find opportunity to discuss any doubts, let alone to change their mind. **We urge the Assembly to address this concern**.

- **Family involvement**

We note the role of the non-clinical Care Navigators. The proposals do not require the attending doctor to talk with the family. We suggest this is a significant omission that should be corrected in preparing the Bill, for the following reasons:

- As part of safeguarding against the risk of coercive influence by family members who may have a pecuniary interest in the patient's estate, or whose own struggles to cope emotionally with the distress and/or care needs of the patient, put pressure on the patient to 'do the right thing'. The attending doctor should explore these dynamics in liaison with the applicant's family practitioner.
- Family members are potential 'casualties.' Assisted dying, like any other act of suicide, leaves scars on friends and family that may never heal. The pain of loss, and possible feelings of guilt (did we do enough?) may be mixed in with relief that their loved-one is no longer suffering. A caring doctor, offering the opportunity to talk through these matters, can be a great help to friends and family as they process their feelings and can also consider prescribing appropriate medication or onward referral for talking therapies. These are not within the scope of a Care Navigator.

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[97] McColl I. Lords Hansard, 6 June 2003: Column 1681

We propose that the requirement to engage with family members be added, as a mandated duty upon the coordinating doctor, in liaison with the relevant general practitioner.

- **Conscientious objection**

The summary of proposals makes two, conflicting statements regarding conscience rights:

i) *The assisted dying law will state that no-one can be compelled to* ***directly*** *participate in the assessment, approval or delivery of an assisted death*

ii) *However, there may be certain elements of a person's job that may relate* ***indirectly*** *to assisted dying. A right not to participate in these indirect tasks would not be covered by a conscientious objection clause*

We appreciate, and record our thanks, that a consideration of conscience has been included in this proposal. For doctors, GMC guidance does not include the requirement to refer to another doctor who would not share the first doctor's conscientious objection, provided the patient has access to the information they need to access the help they seek.

The GMC recognises that onward referral brings with it moral complicity. To coerce a doctor (or any person) to act against their conscience is unethical, causing moral injury and harm. The World Medical Association has recently voted to protect conscientious objection for medical personnel concerning assisted suicide and euthanasia by excluding a provision that would mandate 'effective referral' in its International Code of Medical Ethics.[98]

This is not true simply where involvement is direct. The same complicity and moral harm results from indirect involvement of all kinds, whether for medical, nursing or supporting staff. **The issue should not turn on the threshold of involvement but on the threshold of objection**. For example, one person's conscience would be troubled by providing administrative support for appointments with doctors assessing eligibility for assisted dying. For another, whose conscience is calibrated differently, only direct involvement in the delivery of the dying substance might trigger objection. People vary in the thresholds at which they experience moral complicity and thus moral injury. It is simply not possible to draw up tidy categories – these activities represent 'direct' involvement and thus qualify for conscience rights to be respected, whereas those activities represent 'indirect' involvement and do not qualify – and we suggest that no survey will be able to draw lines that are workable in practice. **It is our view that nobody should be required to participate in any related activity that offends their conscientiously held beliefs, religious or otherwise**. To coerce such involvement would contravene human rights legislation[99] and is unacceptable.

If assisted dying is legalised, **we strongly urge that**:

1. a **statutory** right of conscientious objection be included, that will apply equally to all healthcare professionals, and cover both direct and indirect involvement, rather than relying on the guidance published by professional regulatory bodies

2. an **institutional** right of conscientious objection, so that individual hospices etc can decide not to provide assisted dying, without risking their funding. If this is not present in draft legislation, it would place an intolerable strain on the ethos of many existing services

Step 8: End of Life: Safety, Review and Audit procedures

Reflections on the dying process as outlined:

- The proposals, as they stand, envisage a scenario where one Administering Practitioner (AP) visits the chosen location of the person seeking assistance to die. It is quite likely that family members, and possibly even friends, will be gathered there, in a state of high emotion. We suggest that a minimum of two APs should be in attendance
- The barbiturate cocktail is unpleasant to take orally, and may be regurgitated, or simply not fully effective. The common misconception is that the patient will fall asleep quickly and die within

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[98] https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/

[99] https://www.equalityhumanrights.com/en/what-european-convention-human-rights

minutes. The reality is often different. It may take much longer before the patient dies, and sometimes they do not die following the prescribed dose. These are very distressing scenarios, for the patient if still aware, and especially for the family. It is not clear from the Proposals document how the AP should respond in these very difficult situations. Under para 296 the AP is told to stay with or nearby the patient until they die but no direction is given if they do not die. We are simply asked to accept that '*Detailed protocols will be developed should an unexpected medical event occur.'* Whatever those protocols look like, we suggest that no AP should be expected to cope alone in such circumstances. Again, **we recommend that a minimum of two APs be in attendance as a matter of course.**

- CMF welcomes the proposal that the Death Certificate would reference the administration of the assisted dying substance as the cause of death, both in the interests of transparency and to enable accurate audit and review processes
- We also welcome the proposal that the Jersey Care Commission (JCC) provide independent regulatory oversight of the Jersey Assisted Dying Service and any internal review and audit procedures. However, we are not aware that the JCC has any experience of regulating community services in Jersey, so we are sceptical of their capacity to delivery on this aspiration.
- We note that, as yet there is no HCS Service Delivery and Assurance Board, no Assisted Dying Service, no training programmes, clinical protocols or clinical governance or complaints procedures, let alone an Assisted Dying Review Committee that will be charged with the responsibility of reviewing every assisted death. Should 'assisted dying' legislation is passed in Jersey, **we strongly appeal that is should not come into force until after all the boards, commissions and committees involved in audit and review are up and running**.
- There is clearly a danger that an administrative review process amount to little more than a box-ticking exercise. Alongside the administrative review procedures, we ask that urgent consideration be given to the development of clinical review processes, where independent physicians (not involved clinically with assisted deaths) are given the mandate to monitor and audit the clinical pathway in every case. We suggest this is necessary for the development of public confidence in the service and should include the right of family members to register their concerns directly with clinicians, before and/or after the death.

RJT January 2023

9. Compassion & Choices

Strategic Policy, Planning and Performance Department

compassion
& choices
Care and Choice at the End of Life

11 January 2023

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Assisted Dying In Jersey
Submitted to AssistedDying@gov.je

Dear Committee:

Compassion & Choices is the oldest, largest and most active nonprofit working in the United States to improve care options and empower everyone to chart their own end-of-life journey. For more than 40 years, Compassion & Choices has worked across the United States to raise the voices of those people nearing the end of life, to change attitudes, practices and policies so that everyone can access the information about the full range of care options to ensure they have greater autonomy and comfort at the end of life. We submit this evidence to demonstrate what can be learned from medical aid in dying as authorized in the United States. We are submitting this evidence to the UK Parliament and the Isle of Man, as well.

Nearly 30 years ago, in November 1994, Oregon passed the nation's first law allowing mentally capable, terminally ill adults to have the end-of-life care option of medical aid in dying to peacefully end unbearable suffering.[100] Medical aid in dying is the preferred term for this end-of-life care option. Since that time, 6,378 terminally ill people have used this compassionate option to peacefully end their suffering.[101] There has not

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[100] Frequently Asked Questions: Oregon's Death With Dignity Act (DWDA). Available from: https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/faqs.aspx 2 Medical Aid-in-Dying Data Across Authorized States,2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12 -13-2022.pdf?sfvrsn=697faeca_2 3 Letter from Disability Rights Oregon (DRO), Available from: https://www.compassionandchoices.org/letter-from-disability-rights-oregon-dro 4 Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups, Journal of Medical Ethics. Available from: https://jme.bmj.com/content/33/10/591 [5] Medical Aid in Dying, Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

[101] Medical Aid-in-Dying Data Across Authorized States, 2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf?sfvrsn=697faeca_2

been a single documented incident of coercion or abuse.[131] Ten states and Washington, D.C., have authorized the compassionate option of medical aid in dying.[102]

With nearly 25 years of data since the first implementation of Oregon's medical aid-in-dying law in 1997, we no longer have to hypothesize about what will happen if this medical practice is authorized. The evidence is clear: medical aid in dying protects patients, affords dying people autonomy and compassion during the most difficult time, improves end-of-life care, and costs jurisdictions almost nothing to implement.

Eligibility Criteria, Core Safeguards and Established Process

Each law authorizing medical aid in dying in the U.S. establishes strict eligibility criteria, practice requirements, and core safeguards to ensure the highest standard of care, as described in the clinical criteria and guidelines published in the prestigious, peer reviewed Journal of Palliative Medicine,[103] To be eligible for aid-in-dying medication,[104] an individual must be:

>An adult (aged 18 or older);

>Terminally ill with a prognosis of six months or less to live;

>Mentally capable of making their own healthcare decisions; and

> Able to self-administer the medication through an affirmative, conscious, voluntary act to ingest the prescribed medication to enable the terminally ill person to die peacefully.
  - Self-administration does not include administration by injection or infusion via a vein or any other parenteral route (i.e., situated or occurring outside the intestine) by any person, including the doctor, family member or patient themselves.

Advanced age, disability, and chronic health conditions are not qualifying factors for medical aid in dying.

In addition to the strict eligibility criteria these laws establish the following core safeguards[105]:

> The attending healthcare provider must inform the terminally ill adult requesting medical aid in dying about all other end-of-life care options. These other options include comfort care, hospice care, pain control and palliative care;

> The attending healthcare provider must inform the terminally ill adult requesting medical aid in dying that they can change their mind at any time. This patient right to change their mind includes deciding not to take the medication once they have obtained it.

Additional Legislated Requirements

U.S. jurisdictions that have authorized medical aid in dying through legislation modeled their bills after Oregon's Death With Dignity Act. Jurisdictions' regulatory and procedural requirements are slightly different, but each requires that:

> The terminally ill adult must make at least one request to their attending healthcare provider.

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[102] Medical Aid in Dying, Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

[103] Clinical Criteria for Physician Aid in Dying.Journal of Palliative Medicine; D. Orentlicher, T.M. Pope, B.A. Rich, (2015).
Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4779271/

[104] Medical Aid in Dying…Who is eligible for medical aid in dying? Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

[105] Medical Aid in Dying…What safeguards are in place? Compassion & Choices. Available from: https://www.compassionandchoices.org/our-issues/medical-aid-in-dying

> The written request must be witnessed by at least one person, who cannot be a relative or someone who stands to benefit from the person's estate upon their death.

Further, at least one healthcare provider must confirm the terminal diagnosis, prognosis of six months or less to live, and the person's ability to make an informed healthcare decision prior to the attending healthcare provider writing a prescription. If an attending healthcare provider suspects the individual has any condition that may be impairing their ability to make a rational informed healthcare decision, then the individual is required to undergo an additional mental capacity evaluation with a mental health professional (such as a psychiatrist, psychologist, licensed clinical social worker, psychiatric nurse practitioner, or licensed clinical professional counselor). The request for aid-in-dying medication does not proceed unless the mental healthcare professional affirms that the individual is capable of making a rational and informed healthcare decision.

Voluntary Participation

Each law also ensures that individual healthcare providers' values and beliefs are respected; they specifically state participation is voluntary and that no provider is obligated to prescribe or dispense aid-in-dying medication. In other words, if a provider is unable or unwilling to honor a patient's request, they can opt-out and do not have to support the patient in this option.

The laws provide explicit authorization for qualified healthcare providers to participate in the practice of medical aid in dying. The laws protect both those qualified healthcare providers who choose to and those who choose not to participate in medical aid in dying from criminal liability, civil liability and professional discipline, as long as they comply with the requirements set forth in the law and act in good faith while meeting the standards of medical (end-of-life) care.

Criminal Conduct

While those who comply with all aspects of the law and meet the standard of care are provided immunity from certain criminal prosecution (for example, homicide, assisting suicide or elder abuse) or civil lawsuits (such as malpractice), the jurisdictions retain the ability to hold those who fail to adhere to these strict requirements criminally and civilly liable. Moreover, the existing laws establish that any attempt to pressure or coerce an individual to request or use medical aid in dying is a felony.

Evidence

The growing support for medical aid in dying is attributable, in part, to the fact that it is a proven and time-tested end-of-life care option. Researchers and legal scholars have confirmed that the experience across the 11 authorized jurisdictions "puts to rest most of the arguments that opponents of authorization have made — or at least those that can be settled by empirical data. The most relevant data — namely, those relating to the traditional and more contemporary concerns that opponents of legalization have expressed — do not support and, in fact, dispel the concerns of opponents."[106,107] Additionally, a 2022 sample of Colorado physicians showed that many physicians are both willing and prepared to discuss medical aid in dying with patients and to provide referrals.[108]

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[106] A History of the Law of Assisted Dying in the UnitedStates.SMU Law Review, A. Meisel, (2019). Available from: https://scholar.smu.edu/cgi/viewcontent.cgi?article=4837&context=smulr

[107] Rutgers Study Examines Who Uses Medical Aid in Dying.Rutgers University, Smith, A. (2022) Available from: https://www.rutgers.edu/news/medical-aid-dying-maid-mostly-used-well-educated-white-patients-cancer 11 Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey. Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. (2022) Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472/

[108] Physicians' Attitudes and Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey. Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. (2022) Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC8751472/

The evidence is clear: medical aid-in-dying laws protect terminally ill individuals, while giving them a compassionate option to die peacefully and providing appropriate legal protection for the providers who practice this patient-driven option.

Medical Aid in Dying Protects Patients

There have been no documented or substantiated incidents of abuse or coercion across the authorized jurisdictions. The Journal of the American Academy of Psychiatry and Law noted “there appears to be no evidence to support the fear that assisted suicide [medical aid in dying] disproportionately affects vulnerable populations.” Vulnerable populations include the elderly, women, the uninsured, people with low educational status, the poor, the physically disabled or chronically ill, minors, people with psychiatric illnesses, or racial or ethnic minorities, compared with background populations.[109]

Relatively Few Will Use Medical Aid in Dying, But Many Benefit From These Laws

The use of medical aid in dying by eligible terminally ill people accounts for less than 1% of annual deaths in every one of the 11 jurisdictions where this end-of-life care option is authorized. That said, these laws benefit more than the small number of people who decide to use them. Awareness of the law has a palliative effect, relieving worry about end-of-life suffering. In the jurisdictions that have already authorized medical aid in dying, for example, people report significant relief from worry about future physical and emotional pain just from knowing the option is there should they need it, regardless of whether or not they decide to pursue it. Quite simply, medical aid in dying is a prescription for comfort and peace of mind.

Medical Aid in Dying Improves End-of-Life Care

Oregon has long been on the forefront of end-of-life care, leading the nation in terms of the development of patient-directed practices, adherence to advance directives and hospice utilization. Oregon boasts among the highest number of people who die in their own homes, rather than in hospitals.[110] The experience and data demonstrate that the implementation and availability of medical aid in dying further promote these practices and improve other aspects of end-of-life care.[111]

> A 2001 survey of physicians about their efforts to improve end-of-life care following authorization of the Oregon Death With Dignity Act showed 30% of responding physicians had increased the number of referrals they provided for hospice care, and
76% made efforts to improve their knowledge of pain management.[112]

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[109] Physician-Assisted Suicide: Considering the Evidence,Existential Distress, and an Emerging Role for Psychiatry. Journal of the American Academy of Psychiatry and the Law. Gopal, AA. 2015. Vol 43(2): 183-190. Available from http://jaapl.org/content/43/2/183. 13 Lessons from Oregon in Embracing Complexity in End-of-LifeCare. New England Journal of Medicine, S.W. Tolle, MD, J.M. Teno, MD, (2017). Available from: https://www.nejm.org/doi/10.1056/NEJMsb1612511 14 Oregon’s Assisted Suicide Vote: The Silver Lining. Annals of Internal Medicine, M.A. Lee, S.W. Tolle, (1996). Available from: https://www.acpjournals.org/doi/10.7326/0003-4819-124-2-199601150-00014?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.or g&rfr_dat=cr_pub%20%200pubmed 15 Oregon Physicians' Attitudes About and ExperiencesWith End-of-Life Care Since Passage of the Oregon Death with Dignity Act.JAMA. L. Ganzini, H.D. Nelson, M.A. Lee, D.F. Kraemer, T.A. Schmidt, M.A. Delorit, (2001). Available from: https://pubmed.ncbi.nlm.nih.gov/11343484/ 16 Geographic Variation of Hospice Use Patterns at theEnd of Life.Journal of Palliative Medicine, S.Y. Wang, M.D, Aldridge, C.P. Gross, et al. (2015). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/

[110] Lessons from Oregon in Embracing Complexity in End-of-Life Care. New England Journal of Medicine, S.W. Tolle, MD, J.M. Teno, MD, (2017). Available from: https://www.nejm.org/doi/10.1056/NEJMsb1612511

[111] Oregon’s Assisted Suicide Vote: The Silver Lining. Annals of Internal Medicine, M.A. Lee, S.W. Tolle, (1996). Available from: https://www.acpjournals.org/doi/10.7326/0003-4819-124-2-199601150-00014?url_ver=Z39.88-2003&rfr_id=ori:rid:crossref.org&rfr_dat=cr_pub%20%200pubmed

[112] Oregon Physicians' Attitudes About and Experiences With End-of-Life Care Since Passage of the Oregon Death with Dignity Act. JAMA. L. Ganzini, H.D. Nelson, M.A. Lee, D.F. Kraemer, T.A. Schmidt, M.A. Delorit, (2001). Available from: https://pubmed.ncbi.nlm.nih.gov/11343484/

> A 2015 Journal of Palliative Medicine study found that Oregon was the only state both in the highest quartile of overall hospice use and the lowest quartile for potentially concerning patterns of hospice use."[113] Concerning patterns of hospice use" is defined as very short enrollment, very long enrollment or disenrollment. This same study suggested the Oregon medical aid-in-dying law may have contributed to more open conversations between doctors and patients about end-of-life care options, which led to the more appropriate hospice use.

> Hospice programs across Oregon, in fact, reported an increase in referrals following passage of the Oregon Death With Dignity Act.[114] More than 20 years later, more than 90% of individuals who used medical aid in dying were receiving hospice services at the time of their death.[115]

In California, the availability of medical aid in dying has had a profound effect on end-of-life care. On January 24, 2018, slightly more than a year-and-a half after the California law went into effect, the Assembly Select Committee on End of Life Health Care (California Select Committee) held a hearing on the implementation status. The testimony from patients, doctors and health system representatives supported the concept that although the regulatory process was more complicated and burdensome than anticipated, the law has been compassionately implemented, promoted better end-of-life care and provides peace of mind to countless Californians nearing their final days. This message was echoed during the California Select Committee's second hearing on February 25, 2020.[116]

For Some, Comfort Care and Pain Management Are Not Enough to Relieve Suffering

The evidence from scientific studies confirms that despite the wide availability of hospice and palliative medicine, many patients experience pain at the end of life. One study found that the prevalence of pain increases significantly at the end of life, jumping from 26% in the last 24 months of life to 46% in the last four months of life.[117]

Additionally, breakthrough pain — severe pain that erupts even when a patient is already medicated — remains a nightmare experience for many patients. In the National Breakthrough Pain Study, among respondents who had cancer (at all stages), 83.3% reported breakthrough pain. For those cancer patients who experienced breakthrough pain, only 24.1% reported that using some form of pain management worked every time.[118]

For some people the side effects of pain medication (sedation, nausea, obstructed bowels) are just as bad as the pain from the disease. Some agonies simply cannot be controlled or relieved unless a person is willing to be sedated to complete and deep unconsciousness. Even then, patients sometimes moan and grimace,

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[113] Geographic Variation of Hospice Use Patterns at the End of Life. Journal of Palliative Medicine, S.Y. Wang, M.D, Aldridge, C.P. Gross, et al. (2015). Available from: https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4696438/

[114] LD

[115] Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Docu ments/year24.pdf

[116] California Assembly Select Committee on End of Life Health Care, Wednesday, January 24, 2018 and Tuesday, February 25th, 2020. Available from: https://www.assembly.ca.gov/media/select-committee-end-life-health-care-20180124/video and https://www.assembly.ca.gov/media/assembly-select-committee-end-life-health-care-20200225/video

[117] The Epidemiology of Pain During the Last 2 Years of Life. The Annals of Internal Medicine, A.K. Smith, I.S. Cenzer, S.J. Knight, K.A. Puntillo, E. Widera, B.A. Williams, W.J. Boscardin, K.E. Covinsky, (2010.) Available from: http://annals.org/aim/article/746344/epidemiology-pain-during-last-2-years-life

[118] Impact of breakthrough pain on community-dwelling cancer patients: results from the National Breakthrough Pain Study. Katz, N.P, Gajria, K.L, Shillington, A.C., et. al. (2016). Postgraduate Medicine, 129(1), 32-39. Available from: https://pubmed.ncbi.nlm.nih.gov/27846789/

suggesting pain may still be present. Many value their consciousness so highly that they bear extraordinary pain in order to be somewhat alert during their final days.

People Choose Medical Aid in Dying as well as Hospice and Palliative Care

The majority of individuals who request and obtain aid-in-dying medication are enrolled in hospice services at the time of their death.[119]

Good hospice services and palliative care do not eliminate the need for medical aid in dying as an end-of-life care option. Terminally ill people should have a full range of end-of-life care options, whether for disease-specific treatment, palliative care, refusal of life-sustaining treatment or the right to request medication the patient can decide to take to shorten a prolonged and difficult dying process. Only the dying person can know whether their pain and suffering is too great to withstand. The option of medical aid in dying puts the decision-making power where it belongs: with the dying person.

Patients Involve Their Loved Ones in the Decision

The majority of eligible patients involve their family in their decision-making process and most have someone (family, and sometimes a trusted healthcare provider) present at some point during their planned death, according to the Oregon data.[120]

Medical Aid in Dying Utilization Report

Currently, public health departments in nine authorized jurisdictions have issued reports regarding the utilization of medical aid-in-dying laws: Oregon[121], Washington[122], Vermont[123],California[124],Colorado[125],Hawaii[126], the District of Columbia[127], Maine[128], and New Jersey[129].

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[119] Medical Aid-in-Dying Data Across Authorized States, 2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf?sfvrsn=697faeca_2

[120] Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[121] Oregon Death with Dignity Act. Annual Report, (2021). Available from: https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

[122] Washington Death with Dignity Act Annual Report (2020). Available from: https://doh.wa.gov/sites/default/files/2022-02/422-109-DeathWithDignityAct2020.pdf?uid=63463231758e3

[123] Vermont Patient Choice at the End of Life Data Report (2020). Available from: https://legislature.vermont.gov/assets/Legislative-Reports/2020-Patient-Choice-Legislative-Report-2.0.pdf

[124] California End of Life Option Act Annual Report (2021). Available from: https://www.cdph.ca.gov/Programs/CHSI/CDPH%20Document%20Library/CDPH_End_of_Life%20_Option_Act_Report_2021_FINAL.pdf

[125] Colorado End of Life Options Act Annual Report (2020). Available from: https://cdphe.colorado.gov/center-for-health-and-environmental-data/registries-and-vital-statistics/medical-aid-in-dying https://drive.google.com/file/d/1FmoyCcL2gHopDO9rCJ2lGFEMUye8FQei/view

[126] Hawaii Our Care, Our Choice Act Annual Report (2020). Available from: https://health.hawaii.gov/opppd/files/2020/01/OPPPD-Our-Care-Our-Choice-Act-Annual-Report -2019-1.pdf

[127] District of Columbia Death with Dignity Act Annual Report. (2019). Available from: https://dchealth.dc.gov/sites/default/files/dc/sites/doh/page_content/attachments/DWD%20Report%202018%20Final%20%20%208-2-2019.pdf

[128] Maine Death with Dignity Act Annual Report (2021). Available from: https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/Patient-Directed%20Care%20%28Death%20with%20Dignity%29%20Annual%20Report%20--%204-2021.pdf

[129] New Jersey Medical Aid in Dying for the Terminally Ill Act 2020 Data Summary Report (2021). Available from: https://nj.gov/health/advancedirective/documents/maid/2021.pdf

Compassion & Choices has compiled annual report data from the authorized jurisdictions that collect data[130]. Key highlights include:

- For the past 24 years, starting with Oregon and across all jurisdictions, just 6,378 people have ingested a prescription to end their suffering.
- Over one-third (37%) of people who go through the entire process and obtain the prescription never take it; however, they derived peace of mind from simply knowing that if their suffering became too great, they would have the option.
- The vast majority of terminally ill people who use medical aid in dying — more than 87% — received hospice services at the time of their deaths, according to annual reports for which hospice data is available.

>There is nearly equal utilization of medical aid in dying among men and women.

- Terminal cancer accounts for the vast majority of qualifying diagnoses with neurodegenerative diseases, such as ALS or Huntington's disease, following as the second leading diagnosis.
- Just over 90% of people who use medical aid in dying are able to die at home, which is where most Americans would prefer to die.[131]

The evidence confirms that medical aid-in-dying laws protect patients while offering a much-needed compassionate option.

Medical Ethical Considerations

Among U.S. physicians, support for medical aid in dying is also strong. A 2020 Medscape poll of 5,130 U.S. physicians from 30 specialties demonstrated a significant increase in support for medical aid in dying from 2010. [132] A 2021 Gynecologic Oncology survey showed 69% of respondents believed that medical aid in dying should be legalized, and in a 2020 Oncology Ethics report, 55% of oncologists surveyed said that medical aid in dying should be legalized.[133] A 2022 study of Colorado physicians noted "those who have participated in [medical aid in dying] largely report the experience to be emotionally fulfilling and professionally rewarding," despite barriers to offering the end-of-life care option.[134] Today, 55% of physicians surveyed endorse the idea of medical aid in dying, agreeing that "Physician assisted death should be allowed for terminally ill patients."[135]

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[130] Medical Aid-in-Dying Data Across Authorized States, 2023. Compassion & Choices. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_in_dying_utilization_report_12-13-2022.pdf

[131] Views and Experiences with End-of-Life Medical Care in the U.S. (2017). Hamel, Wu, and Brodie. Kaiser Family Foundation. Available from: https://www.kff.org/report-section/views-and-experiences-with-end-of-life-medical-care-in-the-us-findings

[132] Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-death-and-pain.pdf

[133] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

[134] Campbell EG, Kini V, Ressalam J, Mosley BS, Bolcic-Jankovic D, Lum HD, Kessler ER, DeCamp M. Physicians' Attitudesand Experiences with Medical Aid in Dying in Colorado: a "Hidden Population" Survey.J Gen Intern Med. 2022 Oct;37(13):3310-3317. doi: 10.1007/s11606-021-07300-8. Epub 2022 Jan 11. PMID: 35018562; PMCID: PMC8751472.

[135] Medscape Ethics Report 2020: Life, Death, and Pain, (2020). Available from: https://compassionandchoices.org/docs/default-source/fact-sheets/medscape-ethics-report-2020-life-

Additionally, a 2022 survey of nurses demonstrated that most nurses would care for a patient contemplating medical aid in dying (86%) and that 57% would support the concept of medical aid in dying professionally as a nurse.[136]

During the past six years, dozens of national and state medical and professional associations have endorsed or dropped their opposition to medical aid in dying in response to growing support for this palliative care option among qualified clinicians and the public.

Six national health organizations have taken positions supporting medical aid in dying:

>American College of Legal Medicine[137]

>American Medical Student Association[138]

>American Medical Women's Association[139]

>American Public Health Association[140]

>GLMA: Healthcare Professionals Advancing LGBT Equality[141]

>National Student Nurses' Association[142]

Because provider participation is critical to access medical aid in dying, lawmakers look to healthcare associations for input. Neutral positions, including engaged neutrality, recognize differences of opinion among providers and establish that those who participate in medical aid in dying are adhering to their professional, ethical obligations, as are those who decline to participate. Six national healthcare organizations have adopted neutral positions:

>American Academy of Family Physicians[143]

>American Academy of Neurology[144]

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death-and-pain.pdf [39] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

[136] Polling on Medical Aid in Dying (2022). Available from: https://compassionandchoices.org/resource/polling-medical-aid-dying

[137] American College of Legal Medicine, Position on Medical Aid in Dying, (2008). Available from: https://compassionandchoices.org/docs/default-source/policy/american-college-of-legal-medicine-position-statement.pdf

[138] American Medical Student Association, Excerpted from: Preambles, Purposes, Principles: Principles Regarding Physician Aid in Dying. (2008). Available from: http://www.amsa.org/wp-content/uploads/2015/03/PPP-2015.pdf

[139] American Medical Women's Association, Excerpted from: Position Paper on Aid in Dying (2013/2018). Available from https://www.amwa-doc.org/wp-content/uploads/2018/09/Medical-Aid-in-Dying-Position-Paper.pdf

[140] American Public Health Association, Excerpted from: Patient's Rights to Self-Determination at the End. Policy # 20086. (2008). Available from: https://www.apha.org/policies-and-advocacy/public-health-policy-statements/policy-database/2014/07/29/13/28/patients-rights-to-self-determination-at-the-end-of-life

[141] GLMA Letter of Support on AB X2-15, (2015). Available from: https://compassionandchoices.org/docs/default-source/california/20151002-glma-letter-in-support-of-ca-eoloa.pdf

[142] National Student Nurses' Association,NSNA Resolutions (2018). Available from: https://www.dropbox.com/s/8xwq5f827leqriq/NSNA%20Resolutions%202018.pdf?dl=0

[143] American Academy of Family Physicians COD Addresses Medical Aid in Dying, Institutional Racism. (2018). Available from: https://www.aafp.org/news/2018-congress-fmx/20181010cod-hops.html

[144] American Academy of Neurology position statement on Lawful Physician-Hastened Death. (2018). Available from: http://n.neurology.org/content/90/9/420

>American Academy of Hospice and Palliative Medicine[145]

>American Nurses Association[146]

>American Pharmacists Association[147]

>American Society for Health System Pharmacists[148]

>National Association of Social Workers[149]

Medical associations in many of the authorized jurisdictions currently have neutral positions on medical aid in dying, including Oregon[150], California[151],Colorado[152],Vermont[153],Hawaii[154], Maine [155], New Mexico[156], and the District of Columbia[60]. Seven other state medical societies and a medical resident society in non-authorized

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[145] American Academy of Hospice & Palliative Medicine. Excerpted from: Statement on Physician-Assisted Death (2007). Available from: http://aahpm.org/positions/pad

[146] American Nurses Association, The Nurse's Role When a Patient Requests Medical Aid in Dying (2019). Revised Position Statement. Available from: https://www.nursingworld.org/~49e869/globalassets/practiceandpolicy/nursing-excellence/ana-position-statements/social-ca uses-and-health-care/the-nurses-role-when-a-patient-requests-medical-aid-in-dying-web-format.pdf

[147] American Pharmacists Association, Actions of the 2015 APhA House of Delegates, Available from: https://docksci.com/report-of-the-2015-apha-house-of-delegates_5a35bf67d64ab2ddfc6de3a7.html

[148] American Society of Health-System Pharmacists, Board Report on the Joint Council Task Force on Pharmacist Participation in Medical Aid in Dying, (2016). Available from: https://www.ashp.org/-/media/assets/house-delegates/docs/hod-board-report-on-task-force.ashx

[149] National Association of Social Workers, NASW Standards for Palliative and End of Life Care, Available from: https://www.socialworkers.org/LinkClick.aspx?fileticket=xBMd58VwEhk%3D&portalid=0.

[150] Oregon Medical Association, Excerpted from: October 27 Board of Trustees Report. Available from: http://bit.ly/2CYT6Dx

[151] California Medical Association Position on Medical Aid in Dying. Available from: https://www.cmadocs.org/newsroom/news/view/ArticleId/27210/California-Medical-Association-removes-opposition-to-physician-aid-in-dying-bill

[152] Colorado Medical Society, Position on Medical Aid in Dying. Available from: https://www.cms.org/articles/prop-106-may-june

[153] Vermont Medical Society, Position on Medical Aid in Dying, (2017). Available from: http://www.vtmd.org/sites/default/files/2017End-of-Life-Care.pdf

[154] Hawaiʻi Society of Clinical Oncology, Hawaii Our Care, Our Choice Act Resources (2018). Available from: https://www.accc-cancer.org/state-societies/Hawaii/resources/medical-aid-in-dying

[155] Maine Medical Association (MMA) Position on Medical Aid in Dying, (2017). Available from: http://newsmanager.commpartners.com/mainemed/issues/2017-05-01/index.html

[156] New Mexico Medical Society Position on Medical Aid in Dying (2019). Available from: https://d2zhgehghqjuwb.cloudfront.net/accounts/14766/original/2019_1_5_Council_Minutes_-_PENDING_APPROVAL.pdf?1547577653

jurisdictions (New York, Connecticut, Maryland, Massachusetts, Minnesota, Delaware, and Virginia) have also recently dropped their opposition.[157][158][159][160][161][162][163]

Additionally, the American Medical Association (AMA) and the National Hospice and Palliative Care Organization (NHPCO), have amended their policies to state that it is ethical for a provider to provide medical aid in dying to qualified patients seeking it.[164] NHPCO went so far as to replace the outdated and pejorative expression, "assisted suicide," with the correct terminology, "medical aid in dying."[165] While the AMA and NHPCO do not yet have a fully

supportive policy, these changes are a significant step forward and demonstrate that acceptance within the medical field is gaining momentum.

There is growing recognition within the medical profession and healthcare organizations that patients want, need and deserve this compassionate option at the end of life. This recognition is burgeoning into collaboration. As more jurisdictions authorize medical aid in dying, the healthcare community is coming together and providers are sharing their experiences and fine-tuning their collaborative efforts to better serve dying patients.

Public Support for Medical Aid in Dying as an End-of-Life Care Option

Numerous public opinion polling from a variety of sources, both nationally and at the state level, demonstrates that the American public consistently supports medical aid in dying, with majority support among nearly every demographic group. A 2021 nationwide poll by Susquehanna Polling and Research reported that 68% of voters support medical aid in dying as an end-of-life care option. Additionally, when respondents are asked if they want the option of medical aid in dying personally for themselves, 67% said yes.[166] Gallup's 2020 Values and

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[157] Another State Medical Society Stops Fighting Assisted Death (2017). Lowes, Robert. Medscape. Available from: https://www.medscape.com/viewarticle/889450?reg=1&icd=login_success_gg_match_norm

[158] Connecticut State Medical Society Position on Medical Aid in Dying. (2019). Available from: https://www.cga.ct.gov/2019/PHdata/Tmy/2019HB-05898-R000318-Connecticut%20State%20Medical%20Society-TMY.PDF

[159] MEDCHI, The Maryland State Medical Society House of Delegates Position on Medical Aid in Dying. (2016) Available from http://www.medchi.org/Portals/18/files/Events/Resolution%2016-16.pdf?ver=2016-08-26-140448-047

[160] Massachusetts Medical Society Position on Medical Aid in Dying (2017). Available from: https://www.massmed.org/About/2017-Annual-Report/

[161] Minnesota Medical Association Position on Medical Aid in Dying (2017) Available from: http://www.mnmed.org/news-and-publications/News/MMA-Revises-Its-Policy-on-Physician-Aid-In-Dying

[162] MSD Support of Engaged Neutrality for Medical Aid in Dying (2022). Available from: https://files.constantcontact.com/01c210be101/c65122d3-bb72-4b9c-a2f6-8563b3304710.pdf?rdr=true

[163] 2022-2023 Policy Compendium, (2022). The Medical Society of Virginia. Available from: https://www.msv.org/wp-content/uploads/2022/11/2022-2023-Policy-Compendium.pdf

[164] Report 2 of the Council on Ethical and Judicial Affairs (2-A-19), Physician Assisted Suicide (Resolution 15-A-16 and Resolution 14-A-17) (2019). American Medical Association. Available from: https://www.ama-assn.org/system/files/2019-05/a19-ceja2.pdf

[165] Statement on Medical Aid in Dying (2021). National Hospice and Palliative Care Organization. Available from: https://compassionandchoices.org/docs/default-source/default-document-library/medical_aid_dying_position_st atement_nhpco.pdf

[166] Nationwide Poll Shows Strong Support for Advance Care-Dementia Planning, Medical Aid in Dying, Susquehanna Polling and Research, Omnibus Survey (2021). Available from: https://compassionandchoices.org/docs/default-source/default-document-library/usa-omnibus-cross-tabulation-report-final-n ovember-2021-2.pdf?sfvrsn=74705b4b_1 71 Prevalence of Living Wills in U.S. Up Slightly. Jones, Jeffrey (2020) Gallup. Available from: https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx

Beliefs poll shows that a majority of respondents have consistently favored [medical aid in dying] since Gallup first asked about it in 1996.[167]

Thank you for the opportunity to submit evidence for this inquiry. Please feel free to contact me with any questions at bnunley@compassionandchoices.org.

Most sincerely,
Bernadette Nunley
National Director of Policy

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[167] Prevalence of Living Wills in U.S. Up Slightly. Jones, Jeffrey (2020) Gallup. Available from: https://news.gallup.com/poll/312209/prevalence-living-wills-slightly.aspx

10. DIGNITAS

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Forch, 11 January 2023

Assisted Dying in Jersey Consultation

Responses to the questions in the consultation report of October 2022
Submission by DIGNITAS – To live with dignity – To die with dignity
Forch, Switzerland

for and on behalf of the 4 Island of Jersey and 1,433 UK members of DIGNITAS – To live with dignity – To die with dignity
submitted in electronic format to assisteddying@gov.je

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1) Introduction

This submission answers the 33 questions of and comments on the consultation report “Assisted Dying in Jersey”[168]. In this, it also provides information for the discussion on introducing assisted dying legislation in Jersey. It does not claim to, and it cannot cover the issue in all details.

The Swiss non-profit membership association “DIGNITAS – To live with dignity – To die with dignity” (hereafter abbreviated “DIGNITAS” for easier reading and writing) provides this submission based on its work of 24 years which includes know-how and experience from conducting over 3,400 cases of assisted dying (assisted / accompanied suicides, PSAS)[169] in line with Swiss law. The reason for providing this submission is obvious from the aims and further information available on the website of DIGNITAS[170]: DIGNITAS has, besides other work, focussed on implementing and safeguarding the human right of individuals to decide on time and manner of their own end in life and to have access to professional help to put this into practice in a legal and safe way at their home. DIGNITAS does this so that these individuals (and their loved ones) do not have to carry the burden of going abroad with all the negative consequences thereof. Alongside this, DIGNITAS and the country of Switzerland would not then have to take care of an issue which should be resolved by the states that these individuals travel from. The aim of DIGNITAS is that the “medical tourism of assisted dying” stops and DIGNITAS becomes obsolete for these people[171]. DIGNITAS will serve as an information provider and “emergency exit” only as long as many countries’ governments and legal systems disrespect their citizens’ basic human right to self-determination and choice in life and life’s end, ban the topic with a taboo, and force them either to turn to lonely risky do-it-yourself suicide attempts or to travel abroad instead.

DIGNITAS finds that the proposed assisted dying service in Jersey is an important step forward to resolve several problems of the present legal situation in Jersey which, in regard of assisted dying, is now inadequate and incoherent, as it (still) is all over the UK[172], despite recent developments which give rise to hope for a change. Therefore, DIGNITAS is fully supportive of the proposed assisted dying service in Jersey despite raising criticism in some points as explained hereafter.

DIGNITAS is happy to give further evidence, personal, oral and written, if anyone involved in the consultation would wish so, as DIGNITAS already did in other consultation processes. They are also welcome to visit DIGNITAS.

2) Assisted Dying: a human right, freedom and choice

All European states – with the exception of the Vatican, Belarus and Kosovo – have adhered to the European Convention on Human Rights (ECHR)[173]. In specific cases, set legal situations may be questioned whether they would be in line with the basic human rights and liberties

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[168] https://www.gov.je/SiteCollectionDocuments/Health%20and%20wellbeing/Assisted%20Dying%20Consultation%20Report.pdf

[169] See subheading 4) “terms and abbreviations used in this submission”.

[170] E.g. “The basic information at a glance and a ‘click” on http://www.dignitas.ch/index.php?lang=en

[171] See “The goal of DIGNITAS”, page 19 herein: http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dansketnomedicalsociety-31082022.pdf

[172] See the report by The Commission on Assisted Dying https://www.demos.co.uk/files/476_CoAD_FinalReport_158x240_I_web_single-NEW_.pdf?1328113363

[173] The Convention: http://www.echr.coe.int/Documents/Convention_ENG.pdf ; Member States: http://www.coe.int/en/web/conventions/full-list/-/conventions/treaty/005/signatures

enshrined in the ECHR. The European Court of Human Rights (ECtHR)[174] has developed an important jurisdiction on basic human rights, including the issue of the right to choose a voluntary death. According to its preamble, this international treaty is not only a fixed instrument, “securing the universal and effective recognition and observance of the rights therein declared” but also aiming at “the achievement of greater unity between its members and that one of the methods by which that aim is to be pursued is the maintenance and further realisation of human rights and fundamental freedoms”[175]. The ECHR text and case law are relevant in discussing an assisted dying law for Jersey[176], which is why DIGNITAS herewith outlines aspects of a selection of the ECtHR judgments, and further court judgments in relation to a self-determined and self-enacted end of suffering and life.

In the judgment of the ECtHR in the case of DIANE PRETTY v. the United Kingdom dated 29 April 2002[177], at the end of paragraph 61, the Court expressed:

> “Although no previous case has established as such any right to self-determination as being contained in Article 8 of the Convention, the Court considers that the notion of personal autonomy is an important principle underlying the interpretation of its guarantees.”

Furthermore, in paragraph 65 of this judgment, the Court expressed:

> “The very essence of the Convention is respect for human dignity and human freedom. Without in any way negating the principle of sanctity of life protected under the Convention, the Court considers that it is under Article 8 that notions of the quality of life take on significance. In an era of growing medical sophistication combined with longer life expectancies, many people are concerned that they should not be forced to linger on in old age or in states of advanced physical or mental decrepitude which conflict with strongly held ideas of self and personal identity.”

On 3 November 2006, the Swiss Federal Supreme Court recognized that someone’s decision to determine the way of ending his/her life is part of the right to self-determination protected by article 8 § 1 of the ECHR, stating:

> “The right to self-determination within the meaning of Article 8 § 1 [of the Convention] includes the right of an individual to decide at what point and in what manner he or she will die, at least where he or she is capable of freely reaching a decision in that respect and of acting accordingly.”[11]

In that decision, the Swiss Federal Supreme Court had to deal with the case of a man suffering not from a physical but a psychiatric/mental ailment. It further recognized:

> “It must not be forgotten that a serious, incurable and chronic mental illness may, in the same way as a somatic illness, cause suffering such that, over time, the patient concludes that his or her life is no longer worth living. The most recent ethical, legal and medical opinions indicate that in such cases also the prescription of sodium pentobarbital is not necessarily precluded or to be excluded on the ground that it would represent a breach of the doctor’s duty of care. […] Where the wish to die is based on an autonomous and all-embracing decision, it is not prohibited to prescribe sodium pentobarbital to a person suffering from a psychiatric illness and, consequently, to assist him or her in suicide. […] The question of whether the conditions have been met in a given case cannot be examined without recourse to specialised medical – and particularly psychiatric – knowledge and is difficult in practice; the respective assessment requires an in-depth psychiatric appraisal…”

Based on this judgment, the applicant made efforts to obtain an appropriate assessment, writing to 170 psychiatrists – yet he failed to succeed. Seeing that the Swiss Federal Supreme Court had obviously set up a condition which in practice could not be fulfilled, he took the issue to the ECtHR.

On 20 January 2011, the ECtHR rendered the judgement HAAS v. Switzerland[178] and stated in paragraph 51:

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[174] https://www.echr.coe.int

[175] http://www.echr.coe.int/Documents/Convention_ENG.pdf page 5.

[176] The ECHR came into force in the UK on 3 September 1953.

[177] Application no. 2346/02; Judgment of a Chamber of the Fourth Section http://hudoc.echr.coe.int/eng?i=001-60448 [11] BGE 133 I 58, page 67, consideration 6.1 (translated) http://bit.ly/BGE133I58

[178] Application no. 31322/07; Judgment of a Chamber of the First Section: http://hudoc.echr.coe.int/eng?i=001-102940

> "In the light of this case-law, the Court considers that an individual's right to decide by what means and at what point his or her life will end, provided he or she is capable of freely reaching a decision on this question and acting in consequence, is one of the aspects of the right to respect for private life within the meaning of Article 8 of the Convention."

In this, the ECtHR adhered to the Swiss Federal Supreme Court and acknowledged that the freedom to choose the time and manner of one's own end in life is a basic human right protected by the ECHR.

In a further case, ULRICH KOCH against Germany, the applicant's wife, suffering from total quadriplegia after an accident, demanded that she should have been granted authorisation to obtain 15 grams of pentobarbital of sodium, a lethal dose of medication that would have enabled her to end her ordeal by choosing suicide at her home. In its decision of 19 July 2012, the ECtHR declared the applicant's complaint about a violation of his wife's Convention rights inadmissible, however, the Court held that there had been a violation of Article 8 of the Convention in that the [German] domestic courts had refused to examine the merits of the applicant's own rights he claimed[179]. The case had to be dealt with by the German domestic courts again. Finally, the German Federal Administrative Court corrected the lower courts judgments: The general right to personality article 2,1 (right to life) in connection with article 1,1 (protection of human dignity) of the Basic (Constitutional) Law of Germany comprises the right of a severely and incurably ill patient to decide how and at what time his or her life shall end, provided that he or she is in a position to make up his or her own mind in that respect and act accordingly. The Court found, even though it was generally not possible to allow the purchase of a narcotic substance for the purpose of suicide, there had to be exceptions[180].

In the case of GROSS v. Switzerland, the ECtHR further developed its jurisdiction. The case concerned a Swiss woman born in 1931, who, for many years, had expressed the wish to end her life, as she felt that she was becoming increasingly frail, and she was unwilling to continue suffering the decline of her physical and mental faculties. After a failed suicide attempt followed by inpatient treatment for six months in a psychiatric hospital which did not alter her wish to die, she tried to obtain a prescription for sodium pentobarbital by Swiss medical practitioners. However, they all rejected her wish; one felt prevented by the Swiss code of professional medical conduct as the woman was not suffering from any life-threatening illness, another was afraid of being drawn into lengthy judicial proceedings. Attempts by the applicant to obtain the medication to end her life from the Health Board were also to no avail.

In its judgment of 14 May 2013[181], the ECtHR held in paragraph 66:

> "The Court considers that the uncertainty as to the outcome of her request in a situation concerning a particularly important aspect of her life must have caused the applicant a considerable degree of anguish. The Court concludes that the applicant must have found herself in a state of anguish and uncertainty regarding the extent of her right to end her life which would not have occurred if there had been clear, State-approved guidelines defining the circumstances under which medical practitioners are authorised to issue the requested prescription in cases where an individual has come to a serious decision, in the exercise of his or her free will, to end his or her life, but where death is not imminent as a result of a specific medical condition. The Court acknowledges that there may be difficulties in finding the necessary political consensus on such controversial questions with a profound ethical and moral impact. However, these difficulties are inherent in any democratic process and cannot absolve the authorities from fulfilling their task therein."

In conclusion, the Court held that Swiss law, while providing the possibility of obtaining a lethal dose of sodium pentobarbital on medical prescription, did not provide sufficient guidelines ensuring clarity as to the extent of this right and that there had been a violation of article 8 of the Convention. However, the case was referred to the Grand Chamber of the ECtHR by the Swiss government as, prior to a public hearing on the case, it became known that the applicant had passed away in the meantime. This led to the case not being pursued.

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[179] Application no. 479/09, Judgment of the Former Fifth Section: http://hudoc.echr.coe.int/eng?i=001-105112

[180] See the respective press release by DIGNITAS http://www.dignitas.ch/images/stories/pdf/medienmitteilung08032017.pdf (in English); link to the judgment by the Federal Administrative Court of Germany: http://www.bverwg.de/entscheidungen/entscheidung.php?ent=020317U3C19.15.0 (in German).

[181] Application no. 67810/10; Judgment of a Chamber of the Second Section: http://hudoc.echr.coe.int/eng?i=001119703

Another important judgment was rendered on 26 February 2020 by the Federal Constitutional Court of Germany[182]: The court declared unconstitutional and void § 217 of the German Criminal Code ("geschäftsmässige Förderung der Selbsttötung"), a statuary provision that had criminalised repeated – and thus professional – advisory work and assistance for a self-determined ending of one's own life[183]. The Court held:

> "As an expression of personal autonomy, the general right of personality (Art. 2(1) in conjunction with Art. 1(1) of the Basic Law) encompasses a right to a self-determined death. The right to a self-determined death includes the freedom to take one's own life. Where an individual decides to end their own life, having reached this decision based on how they personally define quality of life and a meaningful existence, their decision must, in principle, be respected by state and society as an act of personal autonomy and self-determination. The freedom to take one's own life also encompasses the freedom to seek and, if offered, make use of assistance provided by third parties for this purpose. […] The right to a self-determined death, as an expression of personal freedom, is not limited to situations defined by external causes. The right to determine one's own life, which forms part of the innermost domain of an individual's self-determination, is in particular not limited to serious or incurable illness, nor does it apply only in certain stages of life or illness. […] The right to a self-determined death is rooted in the guarantee of human dignity enshrined in Art. 1(1) GG; this implies that the decision to end one's own life, taken on the basis of personal responsibility, does not require any explanation or justification. […] What is decisive is the will of the holder of fundamental rights, which eludes any appraisal on the basis of general values, religious precepts, societal norms for dealing with life and death, or considerations of objective rationality […]."

On 11 December 2020, the Austrian Constitutional Court[184] rendered its judgment on a constitutional complaint against the prohibition of assistance in suicide and voluntary euthanasia. § 78 "participation in self-murder" (sic!) of the Austrian criminal code, which was set up in the Austro-fascist 1930s, said: "Any person who incites another to commit suicide [literally: 'kill himself'], or provides help in this, is liable to a custodial sentence of six months to five years." The Court found the second fact of § 78 ("or provides help in this") unconstitutional, with effect from 1 January 2022. In essence the Court held:

> "A right to free self-determination is to be derived from several constitutional guarantees, in particular the right to private life, the right to life, as well as the principle of equality. This right also extends to the freedom to end one's own life. Where a person decides to end his or her own life, this decision must be respected by the State provided that it is based on the free will of the individual concerned. The right to end one's own life also includes the freedom to seek and, where offered, make use of assistance provided by third parties for that purpose. […] From a fundamental rights perspective there is no difference between a patient that refuses life-prolonging or life-maintaining medical measures within his or her sovereignty over treatment or by exercising his or her right to self-determination within his or her living will, and a person willing to commit assisted suicide as part of his or her right to self-determination in order to die in dignity. In both cases, the decisive aspect is that the decision is taken on the basis of free self-determination."

In this context the so-called ARTICO-jurisdiction based on the ECtHR judgment of 13 May 1980, series A no. 37, no. 6694/74, paragraph 33[185] needs to be remembered:

> "The Court recalls that the Convention is intended to guarantee not rights that are theoretical or illusory but rights that are practical and effective; …"

Dignity and freedom of humans mainly consists of acknowledging the right and freedom of someone who does not lack capacity to decide even on existential questions for him- or herself, without outside interference. Everything else would be paternalism compromising dignity and freedom of choice. In the judgment PRETTY v. the United Kingdom mentioned before, the Court correctly recognized that this issue will present itself

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[182] https://www.bundesverfassungsgericht.de/SharedDocs/Entscheidungen/EN/2020/02/rs20200226_2bvr234715en.html

[183] See: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-26022020-e.pdf

[184] Abstract in English provided by the Court: https://www.vfgh.gv.at/downloads/Bulletin_2020_3_AUT-2020-3004_G_139_2019.pdf ; respective press release by DIGNITAS: http://www.dignitas.ch/images/stories/pdf/medienmitteilung-11122020-e.pdf

[185] http://hudoc.echr.coe.int/eng?i=001-57424

increasingly – not only within the Convention's jurisdiction, but internationally – due to demographic developments and progress of medical science.

It also presents itself increasingly because a growing part of the public wishes to have the freedom and right to choose the course of their own life *and* their end in life[186]. Yet sometimes it can be observed that politics and linked administrative authorities take another stand and block or delay assisted dying legislation, despite a majority of the public being in favour of such choice being legalised. The public opinion is relevant from an ECHR perspective: in the judgment OLIARI AND OTHERS v. Italy dated 21 July 2015, the ECtHR observed a reflection of the sentiments of a majority of the (in this case Italian) population as shown through official surveys[187].

3) Answers to the questions in the consultation document

Q. 1 Do you give permission for your comments to be quoted?

A. Yes, attributed.

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted? A. Yes.

Q. 3 If yes, do you think assisted dying …

A. … should be permitted? Yes.

Q. 4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less? A. Yes.

In fact, the eligibility criteria should be changed in doing away with the criterion of any life expectancy limit. No one, not even the most expert medical professional, is able to predict the future and to *know* whether a patient is still alive in 6 or 12 months or any other number of months or days. Quite rightly, the consultation report acknowledges that "any assessment of 'time remaining' cannot be exact…" (para 197). There may be life expectancy *estimates* based on experience, depending on the diagnosis; however, there is also the experience of exceptions. In result, the criterion of a certain limited life expectancy is a hypothetical, and it leads to arbitrariness and inequality: one medical professional may hold the opinion that the patient is going to die in 6 months, but another may estimate this to be 6 months plus one day. Depending on the opinions of the coordinating doctor, independent assessment doctor or second opinion doctor patients meets in the process, they may be judged differently. What is the purpose of a limited life expectancy criterion in relation to assisted dying law-making anyway? Some claim it to be a "safeguard". The opposite is the case. Patients who do not meet this eligibility criterion, in their despair might try an unguided do-it-yourself (DIY) suicide, or they will turn to DIGNITAS. Both outcomes are undesirable. The limited life expectancy criterion is a copy-paste from the now 20-year-old and outdated Death with Dignity Act of the state of Oregon USA. Most European assisted dying laws, i.e. Belgium, the Netherlands, Luxembourg, Switzerland (with the longest-standing professionally-medically assisted dying practice (PSAS) of over 35 years) and Germany, do not have such restrictive criterion.

Furthermore, to only allow access to assisted dying for individuals who face a terminal and/or neurodegenerative illness is to discriminate against individuals who suffer from health conditions that are, by medical opinion, not progressive and/or reasonably expected to cause death. For example, individuals such as the late PAUL LAMB, who was paralysed from the neck downwards after an accident, and who fought in the UK courts to obtain access to assisted dying[188].

In fact, prohibiting access to assisted dying on the grounds of the individual being part of a certain group, especially a minority group, constitutes a discrimination against such an individual and group. This applies to

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[186] As to Jersey, see e.g.: http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight.pdf and http://www.dignitas.ch/images/stories/pdf/umfrage-eolcjersey-4insight-2.pdf

[187] https://hudoc.echr.coe.int/eng?i=001-156265 paragraph 181 / 144

[188] The case of Paul Lamb (and Tony Nicklinson) was finally referred to the ECtHR, yet the ECtHR declared LAMB's complaint inadmissible because the rule of exhaustion of domestic remedies had not been observed. https://hudoc.echr.coe.int/eng?i=001-156476

individuals having a disability[189]. Those denied access to and help in assisted dying are left to illegal and/or risky approaches and methods, for example, unguided DIY-suicide of which the majority fail with dire consequences for the individual, their loved ones and society in general[190]. Not permitting access can violate the human right to (the protection of) life and/or constitute an inhumane or degrading treatment, besides the right to respect for private and family life. All are aspects of the ECHR.

Furthermore, individuals with severe psychiatric ailments are discriminated against – whilst in fact the very claimant before the ECtHR, Mr. HAAS, who brought about the judgment acknowledging the human right/freedom to decide on the time and manner of one's own end in life, was suffering from a psychiatric ailment but not a physical and/or terminal disease[191]. A psychiatric illness may impact a person's capacity to make decisions, but it need not. Sometimes it can be observed, especially amongst opponents of assisted dying working in the fields of psychiatry and psychology, that it is insinuated that individuals requesting assisted dying would up-front not have capacity. This approach not only tries to turn upside down the legal basis that a person is presumed to have decision-making capacity (in relation to assisted dying) unless the person is shown not to have that capacity, as stated in the consultation report para 21. But it labels and stigmatises people who contemplate end-of-life choices – with the negative effects of entrenching the taboo on suicide, on (assisted) dying and on death, and risking these people potentially not talking to doctors, therapists and their loved ones but "taking matters in their own hands"[192].

Making use of any form of assisted dying – whether by PSAS or voluntary euthanasia or discontinuing treatment ("passive euthanasia"; e.g. based on a legally effective advance directive) – is a personal choice in the frame of every individual's right to self-determination; no matter whether (or not) such individual is in fact or assumed to be a member of a certain group defined by medical diagnosis or life expectancy.

DIGNITAS suggests that the Jersey Assisted Dying legislation adopts eligibility criteria that do not give precedence to what some doctors judge about suffering of their patient, but rather to focus on the personal experience / point of view of the individual/patient.

Besides, permitting access to assisted dying for only those with a limited life expectancy appears illogical in the light of the fact that life itself is a "diagnosis" that is expected to cause death, whether or not a medical practitioner finds a condition that is neurodegenerative, progressive, terminal and estimates a certain life expectancy.

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months? A. No.

All discrimination related to the place of residency should be avoided. Even more so as this eligibility criterion discriminates against Jersey-born individuals who have been living elsewhere and towards the end of their life return back home and suddenly may face a health situation that makes them wish to have access to assisted dying. The issue of "death tourism", as the consultation report calls it, should not be solved with setting up discriminating criteria, but with engaging in the decriminalisation of assisted dying in legislations around Jersey, so that such people would not need to consider at all turning to Jersey (and elsewhere). In this context it is also to be noted that the residency criterion of the US State of Oregon was challenged to be unconstitutional in the GIDEONSE v. BROWN, et al. court case, which on 18 March 2022 led to a settlement in which the Oregon Health Authority, Oregon Medical Board, and the Multnomah County District Attorney have all agreed to "not apply or otherwise enforce the residency requirement" in the Oregon Death with Dignity

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[189] Cf. the findings of Prof. Ben Colburn, University of Glasgow, and further references in the section "Disability" in the Overview of the Assisted Dying Consultation of the Isle of Man: https://consult.gov.im/private-members/assisted-dying

[190] See also page 13, subheading 7) "The protection of life and the general problem of suicide" in DIGNITAS' submission to the Joint Committee on End of Life Choices South Australia: http://www.dignitas.ch/images/stories/pdf/diginpublic/stellungnahme-submission-end-of-life-choices-south-australia-31072019.pdf

[191] Case of HAAS v. Switzerland, application no. 31322/07, https://hudoc.echr.coe.int/eng?i=001-102940 ; see also subheading 2) "Assisted Dying: a matter of human right, freedom and choice" in this submission.

[192] See the TEDx talk "Cracking the taboo on suicide is the best means to prevent suicide attempts and deaths by suicide" http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-tedxzurich-08072021.pdf

Act, and the Oregon Health Authority agreed “to submit a legislative concept that would repeal the residency requirement”[193].

Q. 6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

A. No.

This, even though it is to be expected that requests for assisted dying in Jersey will come forward mainly from Islanders aged over 18. To compare: in Switzerland, according to the Federal Office of Statistics analysing the years 2010-14, most assisted dying cases (PSAS) took place in the age group 75-84, and overall 94% of the persons concerned were over 55 years old[194]. Yet, there may be cases of younger than 18-year-old individuals with an illness which impairs their quality of life grievously to the point of them possibly wishing to have the option of assisted dying. The assisted dying laws of Belgium and Netherlands adhere to this and allow for under-18 to access assisted dying under specific circumstances[195]. Jersey should take this as an example. A 17-year-old young Jersey Islander may well have capacity to understand the consequences of a diagnosis of a severe illness, may it be terminal cancer or neurodegenerative ailment or any other, and what assisted dying implies. Furthermore, if a 17-year-old is permitted to set up and/or have respected an advance directive to refuse treatment, which will hasten death if applied (passive euthanasia), it does not make sense to bar such young person from assisted dying which leads to the same result[196].

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria? A. Yes, it should be free.

This ensures that nobody is barred from access to assisted dying and such discriminated against due to their personal financial situation. Costs will occur of course, and if the service is for free this will be carried by the community. It could be considered to apply two approaches of DIGNITAS: a) fixed fees for the assessment and for carrying out PSAS which are reduced or waived on reasoned request for people who live under modest financial circumstances[31] and b) setting up a fund which anyone can donate to, from where monies are used to cover costs related to the service of assisted dying.

Q. 8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person’s eligibility for an assisted death?

A. Yes, they should have the right to refuse.

Assisted dying is about the right and freedom to choose; this concept of free choice should apply for the individual who wishes to make use of assisted dying just as much as for those directly co-decisive: medical professionals.

Q. 9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person’s place of residence or care)

A. No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises.

Assisted dying should always be possible at one’s home, one’s place of living. A care home may well be the new home, the new place of residency of a person, because due to health reasons they cannot live in their flat or house anymore. It would be undignified and a possible health risk to impose on such person to leave their

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[193] https://compassionandchoices.org/docs/default-source/legal/rec-doc-20-1-exhibit-wm.pdf?sfvrsn=6041423c_1 and https://compassionandchoices.org/legal-advocacy/recent-cases/gideonse-v-brown-et-al

[194] https://www.bfs.admin.ch/bfs/en/home/statistics/catalogues-databases/publications.assetdetail.3902308.html

[195] https://www.government.nl/topics/euthanasia/euthanasia-assisted-suicide-and-non-resuscitation-on-request

[196] Cf. judgment by the Austrian Constitutional Court of 11 December 2020 mentioned in subheading 2). [31] Cf. article 9, para 6 of the statutes / articles of association of DIGNITAS.

(new) home, their (new) place residency in the care home just because they wish to make use of assisted dying. Q. 10 Do you agree that the assisted dying register should be public?

A. Yes.

Q. 11 Do you agree that the nine proposed steps are all necessary?

A. No.

Whilst DIGNITAS acknowledges that involving two separate doctors and a tribunal in the process of assessing and possibly supporting an individual's request for assisted dying may be seen as a safeguard, it adds an unnecessary hurdle that consumes time which a rapidly declining individual may have little left of, and it prolongs the suffering.

Furthermore, the criterion of (incurable medical condition that is giving rise to) "unbearable suffering that cannot be alleviated" should be done away with. An incurable medical condition is itself sufficient grounds to permit access to assisted dying. This approach resolves the issue of complexity around objectivity and subjectivity as discussed in the consultation report (para 197 ff) and makes establishing a separate route and a tribunal unnecessary.

In the Swiss legal system of PSAS, one doctor is seen as sufficient[197]. This doctor may choose to reach out to one or several colleagues if, for example, the individual's situation and request for assisted dying appears complex and the doctor wishes for support and second opinion(s). Furthermore, there is no eligibility criteria of a limited life expectancy. This has proved to work well for over 35 years, and DIGNITAS suggests this approach.

In para 195, the consultation report states "Whilst the primary purpose of an assisted death is to end life…" By its experience, DIGNITAS finds this a wrong understanding of assisted dying and inappropriate, even stigmatising. People making use of assisted dying do not primarily wish to end their life. No one wishes to die. But, people wish to not continue suffering. If their suffering could be alleviated, if their medical condition could be resolved, they would continue living. In fact, assisted dying is about alleviating suffering and for this to provide a legal and safe framework which an individual can choose to make use of. Furthermore, assisted dying is about improving quality of life, protecting life and safeguarding public health, as it can make unnecessary that people travel abroad to DIGNITAS or take to risky unguided DIY suicide attempts.

In the analysis and discussion following the consultation, the question should be discussed whether *at all* doctors should be involved as "gatekeepers" for assisted dying. In the light of the human rights and constitutional court judgments mentioned in subheading 2 of this submission, it can be noted that the prerequisite of a medical condition, even more so one that is diagnosed as being progressive and causing death as foreseen in the proposed Bill, violates the very human right to decide on the time and manner of one's own end in life (and for this to reach out to voluntary help from others). A different assessment procedure should be discussed, in which doctors do not (need to) pass judgement on whether or not someone has a certain medical diagnosis, whether or not it is progressive and whether or not this is expected to cause death. Rather, they should put centre stage what the individual considers to be quality of life. The role of doctors would then be to focus on establishing that the individual requesting assisted dying:

- understands the information relevant to the decision relating to access to assisted dying and the effect of the decision; and
- has reached a voluntary decision without coercion or duress; and
- is informed as to palliative, hospice and other care options – this should include information as to the potential negative effects of unguided DIY-suicide attempts; and
- is able to communicate the decision and their views and needs as to the decision in some way, including by speech, gestures or other means, and also able to administer the life-ending medication themselves; and
- has discussed the matter with their loved ones with the aim of avoiding a negative

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[197] Cf. http://www.dignitas.ch/images/stories/pdf/diginpublic/referat-dansketnomedicalsociety-31082022.pdf pages 11, 13 and 31.

"surprise effect" and impact for these loved ones.

This approach would also alleviate any pressure that doctors may feel about making predictions about "reasonably expected to die within six months" (and twelve months with neurodegenerative conditions), and about whether or not a condition is "expected to result in unbearable suffering".

Q. 12 Do you think there are any further steps / actions that should be included?

A. No.

Q. 13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days? A. No.

Assisted dying in Jersey should adhere to the approach of Canada, Belgium, the Netherlands, New Zealand, Switzerland and Germany (the latter two were forgotten to be listed on page 33 of the consultation report), which have no such minimum timeframe in law. For the very reason stated in the consultation report, which matches DIGNITAS' 24 years' experience of having conducted over 3,400 PSAS[198]: by the time a person makes a formal first request, they have already carefully considered their decision

Any imposed minimum timeframe for a "period of reflection" – 14 days, 90 days, etc – appears arbitrary and paternalistic, and leads to possibly prolonging the suffering. The assessment procedure as outlined in the consultation report already takes time. In the Swiss legal system of PSAS, as mentioned, there is no such mandatory waiting period and it does not appear to have posed a problem in over 35 years of this being practice.

Q. 14 Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days? A. No.

See Q. / A. 13

Q. 15 Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

A. Yes – agree.

This is in line with the concept of the right and freedom of choice. See also Q. / A. 8.

Q. 16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service? A. Yes – agree.

See Q. / A. 15 and 8. However, all health care professionals should be obliged to answer questions about assisted dying at least on the minimum level of referring those patients asking about it to information sources, including other health care professionals.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

A. No.

This is an unnecessary criterion which limits access to assisted dying for people who suffer from slowly progressing illnesses and may not be seen as eligibly in the now limited to two rounds of assessments but possibly be found eligible in a third round in due course. Q. 18 Should the law allow for confirmation of consent to proceed?

A. Yes.

This is an element of safety ensuring that the person who wishes to have assisted dying reaches their goal.

Q. 19 Should the law allow for the option of a waiver of final consent?

A. Yes– the law should allow for a waiver of final consent.

This provides an important element of emotional relief for a severely suffering person, especially those with a diagnosis that is likely to rob them of their capacity of judgment e.g. a brain tumour or dementia.

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[198] http://www.dignitas.ch/images/stories/pdf/statistik-ftb-jahr-wohnsitz-1998-2021.pdf

Q. 20 Do you agree with the two different approval routes as proposed?

A. No.

See Q. / A. 11

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

A. See Q. / A. 11

Q. 22 Do you agree that the Law should provide for appeals to the Royal Court?

A. No.

As the consultation report points out in para 235, most jurisdictions do not provide for an appeal process within their assisted dying legislation, so it is not a necessity. The argument of making such provision in Jersey law "to help support public confidence" appears hypothetical in the light of the fact that a polls show a robust majority of the Jersey public in favour of assisted dying. Regarding para 250 "The decision of the Royal Court will be final. There will be no further right of appeal" overlooks that such provision may be in conflict with the ECHR.

Q. 23 Do you agree with proposed grounds for appeal?

A. See Q. / A. 22.

Q. 24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

A. No – do not agree, there should be no minimum time period for appeals.

Any time period, may it be 48 hours or longer or shorter, results in prolonging the suffering of the individual wishing to make use of assisted dying.

Q. 25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

A. See Q. / A. 22.

Q. 26 Do you agree that there should be no expiry date for the approval of an assisted death?

A. Yes – agree, there should be no expiry date.

This, for the reason stated in the consultation report. It matches the over 35 years legal practice of assisted dying / PSAS in Switzerland from which it is known that an "emergency exit door" (or "provisional green light" as it is called in the procedure at DIGNITAS) provides important emotional relief for suffering individuals[199].

Q. 27 Do you agree that there should be an Administering Practitioner with the person or nearby? A. Yes.

Q. 28 Do you agree that a loved one should be able to support the person to self-administer the substance? A. Yes.

This is an element of additional support and care. But it should be observed that this loved one is instructed by professionals about what to do, how, and to which extent.

Q. 29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying? A. Yes.

Q. 30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service? A. Don't know.

The people of Jersey will know best which authority, if any, makes sense to install.

Q. 31 Do you agree that post-death administrative review of each assisted death is required?

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[199] Cf. "Aims – Philosophy – Activities of DIGNITAS", pages 3 and 24, http://www.dignitas.ch/images/stories/pdf/broschuere-verein-e.pdf

A. Yes.

To compare with Swiss legislation: assisted dying is considered an “unusual death” which entails investigation to ensure compliance with the law of the procedures leading to the death. This review may also be understood as a duty of the state to protect life, in the sense of ensuring that no one will lose their life due to illegal actions by others. Clearance of the assisted dying case by the administrative review will also emotionally relieve everyone involved, e.g. medical professionals and loved ones, as they such will be assured of having acted correctly.

Q. 32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service? A. Don’t know.

See Q. / A. 30

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down) A. Yes – agree, it should not be considered an essential service.

The law should be changed as it is outlined in para 331 of the consultation report.

Additional comments on the consultation report

Re page 12 “A number of studies have been undertaken to try to understand whether assisted dying results in increased rates of suicide…”

The consultation report does not mention the suicide rate of Switzerland, a country with over 35 years standing practice of assisted dying / PSAS and arguably one of the most liberal of such schemes: the number of DIY-suicides has declined for many years (and levelled off from the year 2007 onwards)[200].

Re para 319 “The Jersey Assisted Dying service: […] must be safe, and protect and safeguard people who may be vulnerable to coercion and control”

It should be noted that the argument of protecting vulnerable people can have a stigmatising pretext side to it. Not every individual who may be seen by third parties as vulnerable would personally share this view. One needs to bear in mind that there is a fine line where well-meant protection turns into undesired paternalism. Such paternalism very much applies to psychiatry, which has a long-standing view that a desire to die is a manifestation of mental illness, whilst in fact patients who secure and utilise a lethal prescription are generally exercising an autonomous choice unencumbered by clinical depression or other forms of incapacitating mental illness[201].

Whilst in principle DIGNITAS agrees with the notion of protection of any individual (not only “vulnerable”) who does not wish to get involved with assisted dying, and there is a duty to protect life as enshrined in article 2 ECHR, one needs to aim for an assisted dying law which is, as pointed out earlier in this submission, practical and effective and not merely theoretical or even illusionary[202]. Only wide eligibility criteria will resolve the undesirable negative consequence that people travel to DIGNITAS or choose unguided risky DIY suicides.

Re Appendix 2 jurisdictions where assisted dying is permitted (page 102 of the consultation report): the list lacks three countries (though, two of them, Switzerland and Germany, are mentioned in the consultation report):

Country	Date legislation came into effect	For those with terminal illness only?

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[200] See: http://www.dignitas.ch/images/stories/pdf/statistik-suizid-ftb-bevoelkerung-lebenserwartung-ch-e.pdf

[201] Cambridge Quarterly of Healthcare Ethics 2014, http://journals.cambridge.org/action/displayAbstract?fromPage=online&aid=9333247&fileId=S0963180114000085

[202] In the sense of the ARTICO-jurisdiction of the ECtHR (case of ARTICO v. Italy, judgment of 13th May 1980, paragraph 33, https://hudoc.echr.coe.int/eng?i=001-57424).

Switzerland	1942 (though, suicide and assistance were decriminalised already earlier)	No
Germany	2020 (and earlier up until 2015)	No
Italy[203]	2019 (court judgment)	specific situation

4) Terms and abbreviations used in this submission

Assisted dying: an umbrella term including PSAS and/or voluntary euthanasia with the support of and/or carried out by doctors/physicians. In this submission, depending on the context, it is used as defined in the consultation report.

Assisted/accompanied suicide and physician-supported accompanied suicide (abbreviation: **PSAS**): this is what is made possible for members of DIGNITAS in the frame of Swiss law. A person wishing to put an end to their suffering and their life chooses a well-considered, carefully prepared self-administration of a lethal substance provided by a (Swiss) physician usually at their home. The physician has assessed the person's request and medical file, the person is accompanied by professionals all through the process until the end, and next-of-kin and friends are involved.

Voluntary euthanasia: a person wishing to end his/her suffering and life requests and permits a third person to put an end to his/her life, for example by injection of a lethal medication. This is prohibited in Switzerland, yet legal under certain circumstances in some countries such as Belgium, Luxembourg and the Netherlands.

Passive euthanasia: (termination of treatment, "to let die"): ending or not starting life-maintaining and life-prolonging therapies, renouncing treatments, waiving food and drink.

Palliative care: an approach that improves the quality of life of patients and their families facing the problems associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual (as defined by the World Health Organisation WHO).

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This response to the consultation report is submitted by e-mail. DIGNITAS confirms to have read and understood the Privacy Notice set out in the consultation document.

Yours sincerely,
DIGNITAS

To live with dignity - To die with dignity

Silvan Luley

Ludwig A. Minelli Silvan Luley

paraplegic, blind and on life-support after a car accident in 2014 – found article 580 of the Italian Criminal Code (prohibiting to help or convince someone to commit suicide) unconstitutional insofar as it did not make an exception for assisting in the suicide of a person fully capable of making free and conscious decisions with a

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[203] By judgment 242/2019 of 25 September 2019, the Constitutional Court of Italy – dealing with the case of criminal prosecution against MARCO CAPPATO for assisting in the suicide (at DIGNITAS) of Fabiano Antoniani, a man

condition such as Mr. Antoniani, that is, an irreversible pathology causing physical or psychological suffering which the person considers intolerable.
https://www.cortecostituzionale.it/actionSchedaPronuncia.do?anno=2019&numero=242

Response to online survey

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
DIGNITAS – To live with dignity – To die with dignity" (abbreviated for easier writing / reading as "DIGNITAS"), a non-profit membership organization founded 17 May 1998, located in Forch, Switzerland.
Survey completed for and on behalf of the 4 Island of Jersey and 1,433 UK members of DIGNITAS.

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

Yes

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note 'Jersey resident' on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid 'death tourism". It is proposed that a person will only be considered 'resident' if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

No

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note 'Age limit' on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

No

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Yes, it should be free

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes - they should have the right to refuse

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they 'opt-in' to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Yes

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

No

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

No

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

No - I do not agree

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

No - I do not agree

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes - I agree

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

No - I do not agree

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

Yes - I agree

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

Yes - the law should allow for a waiver of final consent

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Other (please specify):

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

No

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

Yes

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

Yes

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

No – I do not agree, there should be no minimum time period for appeals

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Yes

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

Yes - I agree, there should be no expiry date

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

Yes

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Q31. Do you agree that post-death administrative review of each assisted death is required?
Yes

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?
No

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)
Yes - I agree, it should not be considered an essential service

11. Dignity in Dying

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
Dignity in Dying.

Dignity in Dying is a campaign and membership organisation. We believe that everybody has the right to a good death, which includes terminally ill, mentally competent adults having the option of an assisted death. We welcome this consultation, including the compassionate, person-centred and evidence-based principles set out in Section 2. It is especially important that these proposals have recognised that assisted dying is not suicide, as this reflects the views of dying people who want this choice, bereaved relatives and the growing evidence-base on this subject.

We will answer all key questions that follow but also want to comment on paragraph 12(c) of the consultation document, specifically the proposal that ‘the report and proposition which be presented to the Assembly in early 2023 will ask Members to agree, in principle, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that all Islanders can access good palliative and end-of-life services.’

Dignity in Dying believes dying people should have the option of assisted dying subject to robust safeguards, and that all dying people should have access to appropriate care at the end of their lives. These two things are not mutually exclusive and evidence from around the world shows that they can be developed concurrently. Not only have palliative care services received additional funding in places where assisted dying legislation has been passed, research also shows that legislation has led to improvements in end-of-life practice. Therefore we strongly recommend further reflection on the design and intention of this proposal. We also suggest the report and proposition acknowledges that, for many people, having the option of assisted dying is itself an indicator of good end-of-life care provision.

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

Don't know

Please tell us the reason for your response
Dignity in Dying campaigns across the British Isles to allow terminally ill, mentally competent adults the option of an assisted death.

The consultation document acknowledges Australian laws that include a 12 month prognosis for those with a neurodegenerative disease, though it is also true that there are nuances in these laws. For example, if a person making a request under Victoria's law has a prognosis of 6-12 months then further specialist assessment is required. Tasmania's legislation allows the Voluntary Assisted Dying Commission to exempt people from a prognosis requirement in certain circumstances.

While it is prudent for the final assisted dying proposals in Jersey to incorporate best practice from the Australian models for legislation, it is also worth noting that assisted dying laws in the USA all have a 6 month prognosis requirement regardless of whether the person's terminal condition is neurodegenerative or not. 11.2% of people who have accessed assisted dying in Oregon have had a neurological disease. The majority of those deaths (69%) have involved been people with amyotrophic lateral sclerosis (also known as motor neurone disease) as their underlying illness.

In Scotland, Liam McArthur MSP's proposals for an assisted dying law defines terminal illness in line with the Social Security (Scotland) Act 2018, which relies on clinical judgement and does not include an estimate of prognosis. Dignity in Dying understands that there is no existing definition of terminal illness in Jersey law.

The consultation document also outlines that the justification for extending the prognosis requirement to 12 months in the case of a neurodegenerative conditions is the likelihood that people with these conditions will 'see a significant deterioration in quality of life and associated potential for unbearable suffering significantly before they reach the point of having six month's life expectancy.' While these generalisations might be accurate, they may not apply in individual circumstances. It is also unclear how this provision would work with someone who had a longstanding neurodegenerative condition and a diagnosis of a different physical medical condition that was the predominant cause of their suffering.

Dignity in Dying agrees with the intention to craft safeguarded legislation that is inclusive and accessible to dying people who are mentally competent. While we would not oppose a provision that would allow for an exceptional 12 month prognosis requirement for those with a neurodegenerative disease, we do not believe it is necessary, as the experience in several US States shows. We believe there are benefits to having clear and consistent eligibility criteria for all people who might access the law and we

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

recommend further consideration of this proposal and the rationale behind it, including exploration of the full range of options utilised by other jurisdictions as detailed above.

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism". It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes

Please tell us the reasons for your response
We agree with the residency requirement for the reasons outlined in the consultation document.

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes

Please tell us the reasons for your response
We agree that assisted dying should only be permitted for people aged 18 or over for the reasons outlined in the consultation document.

However, we note the suggestion that the law should allow for the Assembly, by Regulation, to lower

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

the age limit if, at some point in the future, they determine it was the correct course of action. Without limiting the Assembly to make decisions through its full democratic processes, we do not believe that any of the eligibility criteria should be highlighted for future review. It is our view that changes to the law on assisted dying must only be taken after careful consideration and consultation, and should be undertaken by primary legislation so that there can be proper scrutiny of such changes.

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Yes, it should be free

Please tell us the reasons for your response
Paragraph 30 states ‘the Jersey Assisted Dying Service will be available free of charge to any person who meets all the criteria in law.’ For the avoidance of doubt, we believe the Assisted Dying Service should be free to all people who seek to access an assisted death, regardless of whether they are later determined to have met the eligibility criteria in the law or not. In other words, a person should not be charged because they use the Assisted Dying Service but were found not to be eligible to have an assisted death.

We also believe any specific support services provided to bereaved relatives that are developed, as indicated in paragraph 318 of the consultation document, should also be free to those who use them.

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes - they should have the right to refuse

Please tell us the reasons for your response
Conscientious objection is key part of the assisted dying proposals and we believe this should extend to health professionals who may be asked to provide supporting assessments. This not only protects clinicians who do have a conscientious objection, but also people who are going through the assisted dying process, as an assessment by someone who is being compelled to be involved against their will has the potential to lack impartiality.

Arrangements for all professionals that refuse to undertake an assessment should be covered in the guidance proposed in paragraph 52 of the consultation document and include the requirement for the conscientious objector to inform the person of their conscientious objection and to document this conversation. We suggest this guidance also explores mechanisms to ensure the person is referred to the Assisted Dying Service and that conscientious objections are included in the monitoring and reporting of the service.

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

Please tell us the reasons for your response
This would create practical barriers for some people who wish to have an assisted death. It might be physically and emotionally distressing for some people to change location at the very end of their lives. For many people their place of residence is their home, regardless of who owns the premises. Forcing

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

people to have an assisted death in a location that is not their choice may result in them feeling torn between whether to have an assisted death or whether to die in a place of their choosing. This is inconsistent with the principles set out in Section 2. Such a provision may also compromise the decision-making process, for example if the assisted death needs to happen in another location that location may only be available at a certain date and time, meaning the individual may feel pressure to agree to that in case they lose the opportunity to have an assisted death at a later date.

Giving premise owners this power also imparts judgement on people who want the option of an assisted death, who may infer the choice that they want to make is viewed as wrong. This may have a coercive effect on that individual and any others who reside at the premises.

Given the proposals outline a considered and robust approach to conscientious objection, it is unclear why there is a need for or benefit to additional provisions such as this.

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Don't know

Please tell us the reasons for your response
While we recognise the need for transparency in this area the relatively small numbers of assisted deaths anticipated in Jersey, particularly in the initial years following implementation, means that it may not be possible to dissociate individual clinicians named in a public register and individual cases of assisted dying. This would inevitably compromise the privacy of those individuals and has the potential to cause harm. This risk may deter clinicians from opting-in to the service.

However, we understand that there are specific considerations in Jersey that impact on this decision, for example the fact that people pay a fee to see General Practitioners and therefore may expect a right to know what services they provide. Also the precedent that registers must be made public in order for services to be registered with the Jersey Care Commission.

We recommend further consideration is given as to what options are available for this and that further

Q10. Public or private register (consultation report paragraphs 56-59)

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The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

direct consultation is carried out with clinicians who have indicated a willingness to be involved in the service.

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

Yes

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

Yes

If yes, please detail the further steps or actions you think should be included.
We note that in adopting P95/2021 the Assembly agreed in principle that assisted dying should be introduced to enable people who meet the eligibility criteria to be able to receive assistance to 'end their own life.' However, the Steps outline that people have the option for the substance administered

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

by the Administering Practitioner. We recognise that a change in the law in this area that permits clinicians to administer substances is, for some clinicians, considered more contentious than one which does not. For example, the British Medical Association's 2020 membership survey found 50% of respondents supported a change in the law that permitted doctors to prescribe life-ending medication to eligible patients, compared to 39% who opposed and 11% who were undecided. When asked for their views on a change in the law that would permit doctors to administer life-ending medication, 37% of respondents supported this, compared to 46% who opposed and 17% who were undecided.

Allowing two different routes of administration may impact clinicians' willingness to be involved in the assisted dying process. We recommend further clarity is given on if clinicians would be able to opt-in to the service but limit their involvement to cases where the person opts for self-administration. We also encourage continued clarification that self-administration is not limited to oral ingestion and that a person would be able to choose self-administered intravenous delivery.

We also recommend this element of the proposals forms a key part of ongoing discussions with UK professional registration bodies to determine what impact permitting practitioner administration would have on their future guidance and regulation.

Step 8 refers to the administering practitioner arriving 'at the agreed location, on the agreed date and time'. However, it is unclear in the current proposals at what stage the date and time should be agreed. We recommend this is included as part of the assisted death plan conversations in Step 6.

We also recommend Step 6 includes a requirement for the administering practitioner to be satisfied the person still has decision-making capacity. This is needed given it is proposed there is no expiry date on the approval of requests, therefore it is possible a significant amount of time may have passed between Steps 5 and 6.

We also recommend Step 6 includes discussion of what the person themselves needs to do or not do on the day of the assisted death prior to the Administering Practitioner arriving. For example, if it is anticipated absorption of the assisted dying substance might be impacted by the presence of alcohol, certain foods or the person's existing medications then this should be fully explored and form part of the assisted death plan. Additionally, Step 6 should include discussion of what the person wishes the Administering Practitioner to do during the assisted death, i.e. whether to remain in the room or nearby in another room. We would expect guidance to be produced which sets out in detail what discussions should be had at Step 6.

Paragraph 305 of the consultation explains how a qualified registered medical practitioner (RMP) who will certify the person's death will have needed to have met with the person 14 days prior to their death, in order to prevent the automatic involvement of the Viscount. Paragraph 306 suggests it is the Administering Practitioner's responsibility to ensure this happens before or during Step 6. However, it is not clear whether or not the RMP can also be the Administering Practitioner, Coordinating Doctor or any other doctor involved in the process. If this is not the case more clarity is needed on how the need for the person to meet with an RMP will affect the 14 day minimum timeframe. We also believe that the requirement of the RMP to meet with the person is accompanied by explicit reassurance that the person is still able to change their mind at any point. We also believe more clarity is needed in Step 8 to outline that the Administering Practitioner must inform the person they are still able to change their mind, as well as detail as to what the next steps are if the person does change their mind at this point.

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes - I agree

Please tell us the reasons for your response
We agree the need to ensure there are no unnecessary delays in allowing someone to have an assisted death must be balanced with the need for clinicians to be assured that the person has a settled and informed wish to have an assisted death. We believe a minimum 14 day timeframe strikes the right balance. However, we recommend that further consideration be given to shortening this timeframe should a person's death or loss of decision-making capacity be expected to occur within 14 days so that what is intended to be a period of reflection period does not act as a barrier to access.

This question highlights the importance of allowing clinicians to initiate discussions about assisted dying, which we comment on in more detail in Q.15. This means people can be fully informed of their options and have sufficient time to be able to explore or pursue any and all end-of-life options available to them, including assisted dying.

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Don't know

Please tell us the reasons for your response
Dignity in Dying campaigns across the British Isles to allow terminally ill, mentally competent adults the option of an assisted death. We agree with the consultation document that the proposed Route 2 deaths are 'fundamentally different' from those in Route 1 and that assisting people to die who are not dying 'is not as readily comparable with existing medical practice and decision-making processes.'

We recognise the very clear need for additional safeguards should proposals be developed for Route 2, but given this proposal is outside of the scope of Dignity in Dying's campaign it is not for us to comment on what these safeguards should be.

We would also highlight, as in our answer to question Q.12 in regards to practitioner administered deaths, that given the fundamental difference between them we anticipate some clinicians may want to opt-in to involvement in Route 1 assisted deaths, but would not be prepared to participate in Route 2 deaths. We recommend that should it be decided that proposals for Route 2 be developed, further consideration must be given to the practical implications of this on the service around issues such as conscientious objection.

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes - I agree

Please tell us the reasons for your response
Facilitating honest and open conversations about end-of-life issues is a fundamental aspect of good care. This is captured in NHS England's Ambitions for Palliative and End of Life Care: A national framework for local action 2021-2026. The first ambition states:

"Each person is seen as an individual
I, and the people important to me, have opportunities to have honest, informed and timely conversations and to know that I might die soon. I am asked what matters most to me. Those who care for me know that and work with me to do what's possible."

Ensuring people are informed of their options also prevents the emergence of inequalities and unnecessary barriers to access to services. Clinicians in Jersey would be ethically compromised if they were only able to discuss assisted dying with people who had the language and health literacy skills to raise the subject and the knowledge that assisted dying was a legal option.

Research has found that restricting conversations about end-of-life options may lead to less optimal patient outcomes (https://spcare.bmj.com/content/10/1/105.abstract).

While it has become apparent during assisted dying debates in other jurisdictions that those who oppose law change may seek to prohibit clinicians from raising the subject of assisted dying through so called 'gag clauses', no evidence has been presented to suggest how these would act as a safeguard or why it would be logical for clinicians to be permitted to initiate discussions about some end-of-life options but not others.

While we strongly oppose the idea that clinicians should be prohibited from raising the subject of assisted dying, we do recommend guidance be developed on what prompts from a person might be appropriate prompts for clinicians to discuss the various end-of-life options that might be available to the person.

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Please tell us the reasons for your response
While we do not believe there should be an explicit requirement on relevant professionals to tell people

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

about the assisted dying service, for the reasons set out in the consultation document, we do recognise that there is overlap here between what constitutes sensitive and appropriate communication and what might be the result of a conscientious objection to assisted dying.

For the latter cases, guidance should make clear that clinicians must take appropriate action immediately should they believe a person might wish to pursue the option of assisted dying and that is something they conscientiously object to. For example telling the person they have a conscientious objection, documenting that conversation and referring the person to another professional who is prepared to discuss assisted dying or making a referral to the Assisted Dying Service. Simply not responding to cues that a person wishes to discuss assisted dying, even if they do not mention the words directly, or subtly and coercively shutting down conversations that might be about assisted dying, must be highlighted as unacceptable and unethical clinical practice.

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

No - I do not agree

Please tell us the reasons for your response
For clarity we believe that people should be entitled to a second opinion. However, the wording of this question suggests this proposal is intended to limit a person to one second opinion, rather than guarantee them one. We understand the logic of wanting to restrict the number of assessments a person is entitled to for practical reasons, however we recommend this is dealt with in the same way as current medical practices and no limit is placed in the legislation itself.

We recommend that the Assisted Dying Service takes on responsibility for ensuring those who do not meet the eligibility criteria for assisted dying receive all the support they need which, along with sensitive and honest communication, should reduce the possibility of someone who is deemed not to meet the eligibility criteria requesting repeat assessments when their circumstances have not changed.

We also do not agree that the co-ordinating doctor should be able to unilaterally decide that a person’s circumstances have not changed, as in effect this gives them the power to prevent the person from making a second request for assisted dying.

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

No - I do not agree

Please tell us the reasons for your response
In principle we believe assisted dying process should be conducted in line with the explicit wishes of a person who has decision-making capacity at the time. Consent to proceed undermines this principle by allowing the Administering Practitioner to administer life-ending medication to the person at a point when they lack decision-making capacity.

Practically, data from the USA shows complications with self-administered assisted deaths are extremely rare. These can be mitigated with mandatory training of preparation of medication and providing for different methods of self-administration which can be chosen in consultation with the Administering Practitioner.

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

No - the law should not allow for a waiver of final consent

Please tell us the reasons for your response
Dignity in Dying believes having decision-making capacity is a key requirement in any assisted dying legislation and that this applies throughout the approval process and at the time that the person dies. Therefore we do not support the waiver of final consent proposal.

The rationale for the waiver of final consent set out in the consultation document again highlights the importance of allowing clinicians to initiate discussions about assisted dying where appropriate. This ensures anyone who has an underlying terminal condition which could possibly lead to a loss of decision-making capacity, for example glioblastoma, can be fully informed of their options and have sufficient time to be able to explore or pursue those options before they lose capacity.

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Other (please specify):

Please tell us the reasons for your response
Dignity in Dying campaigns across the British Isles to allow terminally ill, mentally competent adults the option of an assisted death. We believe the approval process for Route 1 is appropriate.

We agree with the consultation document that proposed Route 2 deaths are 'fundamentally different' from those in Route 1 and that assisting people to die who are not dying 'is not as readily comparable with existing medical practice and decision-making processes.' We recognise the need for an alternative process should proposals be developed for Route 2, but given this is outside of the scope of Dignity in Dying's campaign it is not for us to comment on what this approval process should look like.

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Don't know

Please tell us the reasons for your response
See Q.20 for our position on the process for Route 2 requests. For the avoidance of doubt, we do not believe there is a need for a tribunal to be involved in the approval of Route 1 requests.

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

Yes

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

No

Please tell us the reasons for your response
We agree that individuals themselves should be able to appeal a decision on the grounds set out in paragraph 244 of the consultation document.

We do not agree that a third party should be able to appeal a decision to approve a request. The consultation rightly identifies that unconnected third parties such as a representative of a lobby group should not be permitted to appeal on the basis that they oppose assisted dying. However, there is still a risk that people who are deemed to have a special interest in the care of the person, for example family members or clinicians who might at some point have been involved in the person's care, may oppose assisted dying and could use this process in order to make a vexatious appeal to stop or delay an assisted death taking place. We cannot see any way in which the person can be protected from these types of appeals under the current proposal.

While we recognise the intention is to increase public confidence in the process we fear an appeals process on these grounds will actually have the opposite effect, as it suggests the approval process may in some cases be inadequate, something we wholly disagree with.

Having any period of time where the person must wait to see if somebody might come forward seeking to overturn the approval of their request risks inflicting extreme and unnecessary distress on individuals and there is no evidence to suggest this can be justified.

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Don't know

Please tell us the reasons for your response
We have selected don't know to avoid ambiguity in our answer. As outlined in our answer to Q.23, we have serious concerns about bad faith, vexatious appeals and we do not believe there should be any period of time in which any third party should be able to appeal a decision to approve an assisted dying request.

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Don't know

Please tell us the reasons for your response
We have selected don't know to avoid ambiguity in our answer. As outlined in our answer to Q.23, we acknowledge the proposals have sought to exclude third parties such as representatives of lobby groups from appealing a decision. However, we see no way of protecting individuals from vexatious appeals and we do not believe there are any gaps in the safeguards proposed in the rest of the process to justify such a mechanism. For example, paragraphs 124 to 134 of the consultation document set out the need for a separate complaints policy which will allow for safety concerns to be investigated and appropriate action taken.

We do not believe that there is a need for an additional mechanism by which a third party would be able to appeal a decision to approve an assisted dying request.

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

Other (please specify):

Please tell us the reasons for your response
While we do not believe the approval of assisted deaths should expire, we do recommend further consideration be given to what happens if a significant amount of time has passed between certain steps, particularly in relation to the person's decision-making capacity. See Q.12 for more detail.

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes

Please tell us the reasons for your response
This seems an essential part of the process given the Administering Practitioner's duties set out in Step 9 as well as their role of overseeing the return of any unused substance. See Q.12 for further recommendations on this issue.

In any case we believe it is appropriate for the Administering Practitioner to remain with the person or nearby to ensure appropriate preparation of the medication and reassurances to the individual and any loved ones present.

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

Yes

Please tell us the reasons for your response
In principle we agree that loved ones, following clear guidelines, should be able to support people to self-administer the substance and that this is consistent with practice in other jurisdictions. However, we recommend the Assisted Dying Service produces clear guidance on this issue so that individuals, their loved ones and the wider public understand exactly what this support encompasses and they are clear that it does not change the fact that it is the individual themselves taking the final act of self-administering the substance.

We note paragraph 265(b) of the consultation document suggests a person's assisted death plan should cover who will be present and what they will need to do. We recommend the assisted death plan makes reference to what, if any, specific support loved ones plan to provide.

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

No

Please tell us the reasons for your response
We recognise that practice in this area differs and the death certification process in Jersey does not necessarily map onto to those used in places where assisted dying is legal.

In the same way that assisted deaths are not suicides, because the intent of the person who is dying is markedly different, we believe what is causing someone to die is not the assisted death but the underlying condition that has meant they are eligible to utilise this option at the end of their lives. It is our understanding that at present if a dying person in Jersey refuses life-sustaining treatment, for example a person with motor neurone disease who requests their artificial ventilation to be withdrawn, then it would still be the underlying condition recorded on the medical certificate of the fact and cause of death (MCFCD). Therefore our preference would be for death certificates to record a person’s underlying condition as the cause of death. This would not impact on monitoring or oversight of the law given the proposals set out for other means of data collection and reporting.

While Dignity in Dying acknowledges and respects efforts to de-stigmatise assisted dying practice we believe this can be achieved by creating parity across all end-of-life choices available to people (for example those set out in paragraph 194 of the consultation document). We also believe the privacy of the individual has to be paramount. This is particularly relevant given it is anticipated there will be a relatively small number of assisted dying cases in Jersey compared to other jurisdictions.

However, we also recommend that further consultation be conducted with dying people who have indicated they would want the option of an assisted death and bereaved relatives who have been affected by the lack of a safeguarded assisted dying law. Given the personal and sensitive nature of this element of the proposals it is critical that their views and wishes are prioritised.

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Please tell us the reasons for your response
We are aware that during the course of the assisted dying debate in Jersey there have been passionate views expressed on both sides by a number of clinicians who practice in Jersey. While we understand the reasoning behind the suggestion that members of the committee may be specialists in end-of-life care, medical ethics or social care, we believe the most critical requirement is for committee members to be able to impartially consider whether the requirements of law have been followed, rather than focus on ethical debates on the principle of assisted dying, which risks undermining the integrity of the service.

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Yes

Please tell us the reasons for your response
While it is appropriate that the Jersey Care Commission (JCC) would independently regulate and inspect the Assisted Dying Service, it is less clear that the JCC should be responsible for publishing an annual data report on the service. We recommend consideration be given as to whether the assisted dying review committee might be better placed to publish such a report, which would more closely mirror the role of the Voluntary Assisted Dying Review Board in Victoria, Australia.

This would ensure the annual report will be as informative and insightful as possible, given the committee will have reviewed all assisted dying cases. In addition to the quantitative datasets listed in paragraph 327(g) of the consultation document, we also recommend the annual report includes qualitative data to shed light on the value of the service.

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

No - I disagree, it should be considered an essential service

Please tell us the reasons for your response
The Jersey Care Commission (JCC) should not be given the power to unilaterally withdraw the option of assisted dying, which would undo a thorough and informed democratic process.

We recommend the States proceed with caution and explore possible alternatives to giving the JCC this power, such as clarifying a mechanism for which the JCC can provide a recommendation for the Assembly to consider should the JCC believe there is a need to close down the Assisted Dying Service.

12. End of Life Choices Jersey

Consultation Statement

On behalf of *End of Life Choices Jersey*, I have completed the States consultation questionnaire. The Proposals contain many truly excellent features, and the authors should be thanked and congratulated on their good work. However, we would like to draw attention to the following issues:

Paragraph 12e—what counts as "good" palliative care? The law should not be drawn up in such a way as to allow opponents to obstruct the introduction of assisted dying indefinitely, while waiting for perfection in that area.

Paragraphs 17 & 21 insist that the condition suffered from be physical, not mental. This is not a distinction that modern medical science clearly supports: mental illness is recognised as being 'brain-based' and the understanding of this keeps evolving: let's not get left behind! We would say that **any** condition which is currently incurable, and is the cause of unbearable suffering, should qualify for relief, irrespective of whether it is being classed as physical or mental.

Paragraph 100a refers to the feeling of "being a burden." This should not be 'flagged up' in law to be drafted, lest that may persuade practitioners to disregard or belittle that feeling, which may for particular patients be deeply heartfelt and should be respected as much as any other.

Perhaps the least convincing section of the proposals is Paragraphs 197>201, under the heading Subjectivity/Objectivity. Which kinds of judgment can rightly be classed as objective and which subjective, and how this relates to their certainty, are philosophical questions which the writers do not seem qualified to determine, and in our view the conclusions they reach on this are precisely the wrong way around.

Para 198 says that, as to unbearable suffering, "the assessments made by doctors are more subjective". However, in our view, the process should never require a doctor to make any such assessment, because, as is rightly stated in Para 199, "It is only the person affected who can determine if they can bear the suffering." Thus, it will not matter that a doctor's opinion **as to unbearability** would be subjective if we don't make the mistake of asking the doctor that particular question. There is much else for the doctor to determine, but not that.

As regards having six months or twelve months to live, that area of medicine has never attained scientific certainty, and it is a mistake to treat such a prognosis as if it were objective fact. As the document repeatedly admits, one can speak only of 'reasonable expectation' and whatever is only reasonably objective must be somewhat subjective. Expert opinions may still differ, and therefore if one **must** have a tribunal, this is the kind of thing they might debate.

With suffering, it is otherwise. If a person is in severe pain, they know with absolute certainty that they are in pain, and no expert can tell them otherwise (as when your dentist asks 'does that hurt?' he doesn't contradict your answer). Of course, the patient may be in doubt as to whether they can manage to tolerate their suffering, but again, this is not a question as to which a doctor, or a tribunal, or anybody else can or should persuade them. Thus, there is simply nothing for a tribunal to say on the matter.

Of course, we need to know that the patient is benefitting from the best available palliative care, but that applies equally on both 'Routes' and is not thought to necessitate a tribunal.

Why do the States proposals get this the wrong way around? Well, one sees in several parts of the document what looks (I am afraid) like a bias in favour of limited life-expectancy and against suffering as determinants of entitlement to an assisted death. These include Paras 151 & 185 — why should 'waiver of final consent' be denied to those who 'only' suffer? Then there is Para 76b, with its phrase 'altering the trajectory of their life" — is this a belief in 'fate' or 'natural law'? How can it be said to apply to only one of the Routes? Next, Para 169 ominously refers to "multiple consultations" for those on Route 2, as if encouraging the doctor to be reluctant to accept what the patient is telling them. How can this be justified? Para 246, also, is curiously one-sided.

All this discrimination may perhaps arise from a wish to appease those people who oppose all assisted dying because of their belief in 'the sanctity of life'. Such appeasement is not achievable: one cannot satisfy everybody, and the broad principle of assisted dying (which inevitably shortens life) was clearly accepted by the States last November.

Anyone requesting an assisted death will have weighed curtailment of pain against curtailment of life, and made their choice. They simply do not agree that length of life is the top priority. Are we really going to say to them, 'The official priority remains life, therefore we will only really help you to shorten your painful life by a little, not by too much'— or to say, 'because you want to alter what we call the natural trajectory of your life, you are to be faced with extra months of suffering and extra legal hurdles.' This is irrational and cruel.

Finally, the proposals pick out their two groups of applicants rather oddly, so as to include those with a terminal illness who are likely to go on to suffer unbearably (note the future tense), and those with no terminal prognosis but nonetheless with unbearable suffering. No mention is made of a third category (quite possibly a majority of applicants) who have **both** a terminal illness **and** current suffering. Which Route are they on? Do they have the choice? If so, it would be madness for them to choose Route 2, with all its extra burdens. In practice, most applicants would be putting pressure on their perhaps reluctant doctors to give them a terminal prognosis, so as to get onto Route 1.

The answer to all these conundra is to have only one Route. It is to be regretted that the consultation questions do not include 'Do you agree that there should be more than one Route' nor 'Do you agree that there should be a tribunal.' As a result, we may never know what is generally felt on those matters. We would have answered both questions in the negative.

Michael Talibard

End of Life Choices Jersey

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
Michael Talibard
End of Life Choices Jersey

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No

Please tell us the reason for your response
In our view, neither 6 nor 12 months should be specified. If you must refer to terminal illness, use some such phrase as 'reasonably foreseeable.'

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism". It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes

Please tell us the reasons for your response
Seems reasonable.

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Yes, it should be free

Please tell us the reasons for your response
It should be seen as a basic right, not something to purchase.

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

No - they should not have the right to refuse

Please tell us the reasons for your response
If the assisted death co-ordinating doctor needs an assessment of any kind from (for example) the patient's general practitioner, then that GP should be obliged tom provide it, whatever their stance on AD.

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

Please tell us the reasons for your response
It would be cruel and sometimes dangerous to move the patient elsewhere in these circumstances.

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Yes

Please tell us the reasons for your response
The register should generally be public, but if individuals who are qualified for the register wish to remain anonymous, they should have the right for their names to be omitted from the publication.

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

Yes

Please tell us the reasons for your response
It all seems very well thought out (except for the two Routes—see below)

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

No

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes - I agree

Please tell us the reasons for your response
Really, I would like it to be shorter than this, but 14 days seems reasonable.

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

No - I do not agree

Please tell us the reasons for your response
No— this would be horribly cruel and discriminatory. Unbearable suffering is the most valid of all possible criteria: it should not be ranked below terminal illness.

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes - I agree

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Please tell us the reasons for your response
'Raising the subject' does not amount to persuasion. It should be seen as a duty to make the patient aware of all their options.

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

No - I do not agree

Please tell us the reasons for your response
Not sure—but maybe all relevant professionals share in that duty to make the patient aware of all their options.

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

Yes - I agree

Please tell us the reasons for your response
This seems reasonable: it is not really in the patient's best interests to let them prolong a painful process which is very unlikely to yield the result they want.

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

Yes - I agree

Please tell us the reasons for your response
An excellent provision.

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

Yes - the law should allow for a waiver of final consent

Please tell us the reasons for your response
Another excellent provision, the existence of which will give comfort to the sufferer.

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor (i.e. 2 doctor assessments only for all requests)

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Please tell us the reasons for your response
The division of the proposal into two 'Routes' is cruel, discriminatory and irrational. I will write separately on this issue, and submit by email.

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

No

Please tell us the reasons for your response
There should be no tribunal, but if we must have one, let it concern itself with factual matters on which expert opinions may differ—such as whether the patient's condition is incurable. The kind of question a tribunal is LEAST appropriate for is whether suffering is unbearable, since only the sufferer can determine that. Therefore it would be quite wrong to aim the tribunal selectively at 'Route 2.'

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

Yes

Please tell us the reasons for your response
It is unlikely, but possible, that a person's right to assisted dying be unfairly refused. In that case, they must be able to appeal.

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

Yes

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Yes

Please tell us the reasons for your response
In such situations, time is of the essence. Let this period for possible appeals be as short as possible.

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

No

Please tell us the reasons for your response
The notion of 'special interest' is fraught with danger. If a patient has satisfied the requirements and been granted an assisted death, it should not be possible for a family member to appeal, because even with inadequate grounds, they could employ lawyers to drag out the process.

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

Yes - I agree, there should be no expiry date

Please tell us the reasons for your response
The patient's wishes must always be paramount, and if they are not ready, they may delay the end.

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

No

Please tell us the reasons for your response
On grounds of safety, we would prefer to strike out, or else more carefully define that phrase 'or nearby.' The administering practitioner cannot adequately supervise the process from a next door room. He needs to be there, and to observe; he can surely be trained not to make his presence unduly intrusive.

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

Yes

Please tell us the reasons for your response
Yes—provided only that this is the patient's wish.

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Yes

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

No - I disagree, it should be considered an essential service

13. European Institute of Bioethics

Assisted dying proposals in Jersey public consultation

17 october 2022 to 14 january 2023

1. **Questions on sharing your responses:**

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted? *

○
- No

○
- Yes, anonymously

●
- Yes, attributed

Name or organisation to attribute comments to, if applicable:

European Institute of Bioethics (Brussels, Belgium)

Odile Maisonneuve –

Research Assistant Léopold Vanbellingen – Research

Officer

www.ieb-eib.org – secretariat@ieb-eib.org - +32 2 647 42 45

2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted? *

●
- Yes

○
- No

○
- Prefer not to say

3. If yes, do you think assisted dying: *

☐
- Should be permitted

☑
- Should not be permitted

4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less? *

- ○ Yes
- ● No
- ○ Don't know

Please tell us the reason for your response

The text provides that, to be eligible for assisted dying, the patient must be diagnosed with a terminal illness that will cause death within 6 months. This extension poses several problems:

- It treats neurodegenerative diseases in the same way as a terminal illness. However, there are people living with these diseases, sometimes for several years. Will they not feel obliged to turn to assisted dying in order not to be a burden or out of fear of suffering?
- This first broadening of the criteria for eligibility for assisted dying calls for others. In Belgium, euthanasia is possible for people with early-stage dementia. However, there are legislative proposals that would allow access to euthanasia for people who are no longer conscious but who have written an advance declaration for euthanasia. What about the criterion of consent? What if the patient withdraws the advance declaration in the phase of dementia?

5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism”. It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months? *

- ● Yes
- ○ No
- ○ Don't know

Please tell us the reasons for your response

It would seem prudent to reserve assisted dying for those who have been resident in Jersey for at least 12 months. Death tourism is a reality in Belgium, with requests for euthanasia from foreign patients arriving every year.

6. Eligibility – age (see consultation report paragraphs 25 & 26 and note 'Age limit' on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over? *

- ● Yes
- ○ No
- ○ Don't know

Please tell us the reasons for your response

In Belgium, euthanasia was extended to minors in 2014. The existence of physical suffering is mandatory in this case: psychological suffering alone cannot be the basis for a request for euthanasia in a minor.

The minor must have the capacity of discernment and formulate the request himself or herself. This latter notion is very vague and open to abuse. In the Netherlands, Dutch authorities are already proposing to authorize euthanasia on children between 1 and 12 years old without their request or consent. It is clear that the criterion of consent is weak and that the desire to relieve the parents finally takes precedence over the care given to the children.

The question arises as to whether there are really criteria that can verify the validity of the consent of children for euthanasia.

7. **Key questions on Section 4 - Assisted Dying Service**

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria? *

- ○ Yes, it should be free
- ● No, it should be paid for
- ○ Don't know

Please tell us the reasons for your response

Free assisted dying could lead to this choice being made by default, especially if, on the other hand, palliative care is not fully reimbursed. In Belgium, there is a palliative care package to relieve the costs of palliative care at home, but it is only valid for one month and renewable only once.

Does not the fact that assisted dying is free or inexpensive compared to palliative care encourage patients, especially those with limited means, to use it?

8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.
In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example:

- professional opinion provided by a specialist on the person's prognosis or life expectancy
- pulmonary function tests, carried out by a physiotherapist
- assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death? *

- ● Yes - they should have the right to refuse
- ○ No - they should not have the right to refuse
- ○ Don't know

Please tell us the reasons for your response

The right to freedom of thought, conscience and religion is protected by various treaties at European and international level, such as the European Convention on Human Rights and the Universal Declaration of Human Rights.

Health professionals who know that their diagnosis will be used to determine whether a person is eligible for assisted dying would in fact be participating against their will in the act of killing. This involvement, even indirectly, would be a violation of the freedom of conscience of those who disapprove of euthanasia.

Insofar as this assessment can be made by other doctors, insofar as this refusal corresponds to values already protected by law such as the prohibition of homicide and insofar as, in the case of euthanasia, the refusal to cooperate with it is a legitimate conscientious objection, these health professionals should be able to refuse to make this assessment.

9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care) *

- ● Yes - they should have the right to refuse
- ○

- No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises
- ○ Don't know

Please tell us the reasons for your response

In Belgium, in the parliamentary discussions leading to the law decriminalising euthanasia in 2002, there was a consensus that health institutions could prohibit euthanasia within their walls. However, in 2020, an amendment to the law restricted the freedom of association and freedom of conscience of doctors, nursing staff, volunteers and other residents of these institutions by forcing them to accept euthanasia within their walls.

Other approaches exist, such as palliative care. Can palliative care and euthanasia co-exist in the same health facility and be practiced by the same staff? It is up to the State that authorises it to put in place the means to access euthanasia, not to the care institutions. If the prospective resident is duly informed of the care project of the living community, which excludes euthanasia or assisted suicide, it is not unreasonable to require that he or she refrains from demanding that euthanasia or assisted suicide be carried out within the walls of the institution, at the risk of undermining the freedom of conscience and association of others (residents, healthcare workers, volunteers).

10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.
The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public? *

- ○ Yes
- ● No
- ○ Don't know

Please tell us the reasons for your response

Making public a register of doctors who agree to perform assisted dying may lead people who wish to be euthanised directly to these doctors. As we have seen in Belgium, there is a risk that the patient determined to die by euthanasia or assisted suicide, even if he or she does not meet all the conditions, will manage to find a doctor who will more easily agree to approve assisted suicide or to perform euthanasia. Even if the patient meets the substantive conditions, turning to a doctor who is known to be in favour of such a practice may put the importance of respecting the free and informed consent of the patient into perspective.

Furthermore, the medical profession should not be divided between those who accept and those who refuse to participate in assisted dying. Some doctors may be prepared to provide assisted dying, but with additional medical conditions to those provided for by the law. This could be the case, for example, by including a palliative filter, which would make access to the patient's request for death conditional on the prior implementation of palliative care.

11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:
Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary? *

●
- Yes

○
- No

○
- Don't know

Please tell us the reasons for your response

In countries such as Belgium that allow euthanasia, and even in countries that have not legalised it, requests for euthanasia vary greatly. Psychological care, pain relief and support for relatives lead patients to reconsider their initial request.

These nine steps must not be shortened, because it is only in the course of time and with appropriate care that it may become clear that the patient does not want to die, but to be spared suffering and to be better supported.

12. **Do you think there are any further steps / actions that should be included?**
(Please note, further Sections of this document include more detailed questions about specific steps) *

●
- Yes

○
- No

○
- Don't know

If yes, please detail the further steps or actions you think should be included.

Many actions need to be implemented before approving assisted dying:

o ensuring better management of patients' physical and psychological suffering o ensuring the deployment of volunteers to visit people at the end of life o increasing awareness of palliative care solutions o allocating more resources to palliative care

13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8):

- 14 days minimum for those eligible under 'Route 1 (terminal illness)
- 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days? *

- ○ Yes - I agree
- ○ No - I do not agree
- ● Don't know

Please tell us the reasons for your response

The reflection period is not a simple question of days but must truly allow the patient to choose the best option for him or her; therefore, the question is whether, in 14 days, it is possible to provide them with physical and psychological support so that their choice is not a default choice.

Does the time constraint allow real freedom in the decision?

14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days? *

- ○ Yes - I agree
- ○ No - I do not agree
- ● Don't know

Please tell us the reasons for your response

Same answer as for question 13:

The reflection period is not a simple question of days but must truly allow the patient to choose the best option for him or her; therefore, the question is whether, in 90 days, it is possible to provide them with physical and psychological support so that their choice is not a default choice.

Does the time constraint allow real freedom in the decision?

15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying? *

- ○ Yes - I agree
- ● No - I do not agree
- ○ Don't know

Please tell us the reasons for your response

Raising the possibility of assisted dying to a suffering patient may lead him or her to choose this option against his or her will.

- How can we be sure that the doctor will also offer palliative care? Is it consistent to offer both together?
- For a patient's request for assisted dying to be considered voluntary, free and thoughtful, should it not come solely from the patient?
- If the doctor raises this possibility, will the patient not feel pressured into this option?

It would therefore be preferable for doctors not to propose it.

16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service? *

- ● Yes - I agree
- ○ No - I do not agree
- ○ Don't know

Please tell us the reasons for your response

Health professionals should not discuss assisted dying with their patients for the reasons mentioned above, but also to:

- Uphold their right to freedom of conscience
- Preserve the meaning of palliative care, which can be confused if the same doctor offers palliative care and is required to mention assisted dying

17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion? *

- ○ Yes - I agree
- ○ No - I do not agree
- ● Don't know

Please tell us the reasons for your response

The question of opinions shows that it is not easy to make a decision as serious as death depend on criteria that will inevitably be assessed in a subjective and varied manner by different doctors.

This raises the question of the independence of the doctors whose opinion is sought, in particular regarding the doctor requesting it.

In Belgium, a form of proximity has been observed between pro-euthanasia doctors who are members of the same association and who ask each other for a favourable opinion concerning the euthanasia of their respective patients.

18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a 'confirmation of consent to proceed form', allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed? *

- ○ Yes - I agree
- ● No - I do not agree
- ○ Don't know

Please tell us the reasons for your response

This question highlights the complications inherent in inducing death.

Empowering a patient to die implies here that the process must eventually be carried out by another person, at the risk of leaving a patient in agony.

19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a 'waiver of final consent'.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent? *

- ○ Yes - the law should allow for a waiver of final consent
- ● No - the law should not allow for a waiver of final consent
- ○ Don't know

Please tell us the reasons for your response

This procedure would remove the final step and thus lead to death being administered to a person incapable of consenting. This would call into question the entire consent process and ultimately give the doctor the decision to end the patient's life. The eligibility criteria for assisted dying would be more important than the patient's consent. Writing a waiver of final consent in advance is contradictory to the entire procedure that precedes it and raises several critical questions:

- Who will make the decision? o How do we know if the patient has changed his or her mind? o Can consent be waived in advance?
- How can the loss of capacity to decide be assessed? What medical conditions will be considered? Should this loss be temporary or irreversible?
- Will the doctor be free to accept or not this waiver of final consent?

In Belgium, there is an advance declaration of euthanasia for cases where the patient is no longer able to request death (e.g. irreversible coma). Some people are already calling for this possibility for people with medium or advanced dementia. The criteria are subjective and changing, and they evolve according to the demands.

20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203) It is proposed that there are two different approval routes:

a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)

b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal

Do you agree with the two different approval routes as proposed? *

- Yes
- No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor (i.e. 2 doctor assessments only for all requests)

○

- ○ No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)
- ● Don't know
- ○ Other (please specify): ☐

Please tell us the reasons for your response

The proposal to seek court validation highlights the difficulty of knowing what decision to make on a criterion as subjective and personal as unbearable suffering. This possibility shows two things: o The criterion of suffering is too subjective to be valid

o The interpretation of this suffering as a criterion for administering death is not within the scope of medical knowledge

21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal:

- always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard)
- does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).

Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests? *

- ○ Yes
- ● No
- ○ Don't know

Please tell us the reasons for your response

The tribunal's review of the coordinating doctor's decision could be a guarantee that it is not arbitrary, but on the other hand, it casts doubt on that decision and taints the relationship of trust that should exist between the doctor and the patient. Nevertheless, it seems preferable that the court does not reverse the doctor's decision not to approve the request for assisted death, as the court is only confirming the doctor's decision who, in this case, is prudent.

22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court? *

- ○ Yes
- ○ No
- ● Don't know

Please tell us the reasons for your response

23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds:

- whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months
- a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed
- a failure, or perceived failure, to make determinations or act in accordance process set out in law

Do you agree with proposed grounds for appeal? *

- ○ Yes
- ○ No
- ● Don't know

Please tell us the reasons for your response

24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

- ○ Yes
- ○ No – I do not agree, there should be no minimum time period for appeals
- ● No– I do not agree, there should be a time period longer than 48-hours
- ○ Don't know

Please tell us the reasons for your response

Same answer as for questions 13 and 14.

25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest? *

●

- Yes

○

- No

○

- Don't know

Please tell us the reasons for your response

It seems preferable to restrict the right to appeal to the patient alone or to his or her agent. Because of their emotional closeness, family members or close friends may be driven by the pain of seeing the patient dependent, suffering or impaired. This may lead them to ask to end the patient's life to relieve, sometimes unconsciously, their own suffering.

On the other hand, allowing family members to appeal a decision to euthanise may lead the patient to reconsider their request, feeling supported by family or friends.

26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death? *

- ○ Yes - I agree, there should be no expiry date
- ○ No - I disagree, there should be an expiry date
- ○ Don't know
- ● Other (please specify):

Please tell us the reasons for your response

Approving a request for assisted dying without a time limit could lead to two opposite situations:

  - On the one hand, it would allow the patient to reconsider his decision if he or she so wishes and to consider other possibilities for relieving suffering, such as palliative care. He or she would then have time to mature his or her decision.
  - On the other hand, this indefinite period of time during which it would be possible to resort to assisted dying could cause some discomfort and, notably, prevent the patient from living serenely at the end of his or her life, or even from accepting his or her condition or even saying goodbye to his or her loved ones.

27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

- ○ Yes
- ○ No
- ● Don't know

Please tell us the reasons for your response

This issue raises the question of whether it is possible to help someone to commit suicide if he or she is unable to do so on their own?

The possibility of legalising suicide makes it necessary to make this act possible by a third person if the patient who requests it cannot do it alone.

The question remains whether it is the doctor's role to give a patient the means to end his or her life, and even, more fundamentally, to approve the patient's request to end his or her life.

28. It is proposed that a loved one (ie. friend or family member) may support the person to selfadminister the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? *

- ○ Yes
- ● No
- ○ Don't know

Please tell us the reasons for your response

No one wants to die alone. The question is whether the presence of a relative has the same impact on the patient as on the relative in the case of natural and induced death. If the relative helps the patient to die, what are the psychological consequences? Is the grieving process the same after a natural death as after an induced death in which the person has participated?

29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying? *

- ● Yes
- ○ No

- ○ Don't know

Please tell us the reasons for your response

It is important to have reliable data on assisted dying, but it has been observed, particularly in Belgium, that there is a discrepancy between the number of officially reported euthanasia and the number of euthanasia actually performed.

This suggests that there is no guarantee that the criteria for access to euthanasia are met and that abuses continue after legalisation.

In Belgium and Canada, death by euthanasia is artificially reported as "natural death", which can seriously mislead relatives and society about the nature of euthanasia or assisted suicide as a voluntarily administration of death to the patient.

30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include:

- an HCS Service Delivery and Assurance Board
- an assisted dying review committee to undertake a post-death administrative review of each individual assisted death
- independent regulatory oversight by the Jersey Care Commission.

Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service? *

- ○ Yes
- ○ No
- ● Don't know

Please tell us the reasons for your response

31. Do you agree that post-death administrative review of each assisted death is required? *

- ● Yes
- ○ No
- ○ Don't know

Please tell us the reasons for your response

32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service? *

- ● Yes
- ○ No

- ○ Don't know

Please tell us the reasons for your response

33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down) *

- ● Yes - I agree, it should not be considered an essential service
- ○ No - I disagree, it should be considered an essential service
- ○ Don't know

Please tell us the reasons for your response

14. General Medical Council

1. **Questions on sharing your responses:**

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted? *

○ No

○ Yes, anonymously

● Yes, attributed

Name or organisation to attribute comments to, if applicable:

General Medical Council

2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted? *

○ Yes

● No

○ Prefer not to say

The GMC does not take a position on whether the law on assisted dying should change; we consider this to be a matter for relevant governments or legislatures.

In terms of our responses to this consultation, some of the questions fall outside our regulatory remit or areas of expertise – or for which we would not take a view because of our position on assisted dying. We have therefore restricted our comments to a specific number of areas. Where we do not hold a position on a particular question, we have marked it as a 'Prefer not to say' or 'Don't know'.

3. **Key questions on Section 3 - eligibility criteria**

<u>Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)</u>

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.

It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less? *

○ Yes
○ No
● Don't know

Please tell us the reason for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change (see question 2). As such, we would not take a position on the eligibility criteria for an assisted death.

4. Resident definition (see consultation report paragraphs 25 & 26 and note 'Jersey resident' on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid 'death tourism". It is proposed that a person will only be considered 'resident' if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months? *

○ Yes
○ No
● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change (see question 2). As such, we would not take a position on the eligibility criteria for an assisted death.

5. Eligibility – age (see consultation report paragraphs 25 & 26 and note 'Age limit' on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over? *

○ Yes
○ No
● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change (see question 2). As such, we would not take a position on the eligibility criteria for an assisted death.

6. **Key questions on Section 4 - Assisted Dying Service**

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria? *

○ Yes, it should be free

○ No, it should be paid for

● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a position on questions of funding.

7. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example:

- professional opinion provided by a specialist on the person's prognosis or life expectancy
- pulmonary function tests, carried out by a physiotherapist
- assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death? *

○ Yes - they should have the right to refuse

○ No - they should not have the right to refuse

● Don't know

Please tell us the reasons for your response

It doesn't fall within our remit to advise on whether or not providing supporting assessments constitutes 'direct participation' in line with the legal principles set out in the Supreme court ruling on Greater Glasgow Health Board (Appellant) v Doogan and another (Respondents) (Scotland). Although we are supportive of the principle of introducing a statutory right, these questions of scope are legal ones that we do not have specific expertise on.

However, it might be helpful to provide some background on our conscientious objection guidance and the interface with a statutory right to conscientious objection.

The GMC supports the right for doctors to practice in line with their beliefs and supports the proposal to introduce a statutory right to conscientiously object to participate in an assisted death.

Our guidance on ‘Personal beliefs and medical practice’ sets out that doctors can opt out of providing a procedure which they have a conscientious objection to, as long as this doesn’t result in direct or indirect discrimination against individual patients or groups of patients and doesn’t obstruct patients from accessing services.

Paragraphs 8-16 also sets out the steps a doctor should take when exercising a conscientious objection.

Our guidance is not limited to activities for which there is a statutory right to conscientious objection. In the UK, this is limited to participating in abortion and activities falling under the Human Fertilisation and Embryology Act 1990. A statutory right to conscientious objection would ensure that healthcare providers are not under any duty from, for example, an employing or contracting body to participate in a procedure that they conscientiously object to (except, in emergencies). In the case of other activities (where there is no statutory right to conscientious objection), doctors’ freedom to work in accordance with their conscience could be restricted by contractual requirements from employing or contracting bodies.

Our guidance is in line with the UK law; however, it is important to stress that it does not amount to legal advice, nor are we able to provide legal advice. Further, although we set out detailed guidance on this issue, the types or range of activity that a doctor can conscientiously object to is not specified in our guidance.

8. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care) *

○ Yes - they should have the right to refuse

○ No - they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises

● Don't know

Please tell us the reasons for your response

The GMC does not take a position on this question as it falls outside our remit.

9. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public? *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

We have a neutral stance and neither agree nor disagree that the assisted dying register should be public. Our view is that any decision in terms of whether the assisted dying register should be public or private rests with the relevant authorities in Jersey.

The GMC's approach to publication and disclosure may be of interest to those considering this issue. Information about UK registered doctors is published on the List of Registered Medical Practitioners (LRMP). We publish this information to fulfil our legal obligations and help meet our objectives to:

- protect, promote, and maintain the health, safety, and well-being of the public
- promote and maintain public confidence in the medical profession
- promote and maintain proper professional standards and conduct for members of the profession.

Our Registration & Revalidation publication and disclosure policy sets out our general approach to the publication and disclosure of registration and revalidation information relating to registrants. Paragraphs 25-30 explain the limited circumstances, such as where publication of information presents a significant risk of serious harm to the physical or mental wellbeing of a registrant, where we'll consider requests to withhold registration and revalidation information from the LRMP'.

10. **Key questions on Section 5 - assisted dying process: request and approval**

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary? *

● Yes

○ No

○ Don't know

Please tell us the reasons for your response

We recognise the need for a robust set of steps to ensure that treatment is only offered and provided in cases where it is unequivocal that patients meet the eligibility criteria and have made a clear and settled decision to end their lives. This is vital with decisions of this nature and magnitude. The nine proposed steps include the requirement that two doctors independently assess and determine a patient's eligibility and asks patients to re-affirm their request for an assisted death, all of which should help to create necessary safeguards. We also note that the process is designed to ensure that patients have control throughout (in terms of whether to continue with the request and, if so, at what pace), which we fully endorse.

The service model would necessarily require the involvement of multiple professionals at various stages, including the assessment stages, which we understand could present a challenge to delivering a service in Jersey from a staffing point of view. As such, we note that the consultation states (at page 21) that '*should the HCS not be able to recruit or contract the staff needed to deliver the Jersey Assisted Dying service, it would be permitted in law but no service available. Hence, people would not have assisted deaths in Jersey*.'

11. **Do you think there are any further steps / actions that should be included?**

(Please note, further Sections of this document include more detailed questions about specific steps) *

● Yes

○ No

○ Don't know

If yes, please detail the further steps or actions you think should be included.

We have some comments about the sequencing of decision making and consent as it is set out in the consultation document, since it is not consistent with our guidance. We suggest addressing this by introducing an additional step to the proposed assisted dying process.

This additional step would be introduced after step 5 (i.e. after the assessments and after an assisted death has been approved), and would involve the patient formally recording their consent to an assisted death, and the scope of that consent. This would be different to the written declaration recording their decision to proceed with an assisted death – i.e. the second request (at step 4) as it would be a formal record of the option(s) agreed by *both* the relevant clinician(s) and the patient and would not be conditional on a future approval of a request for an assisted death.

Alternatively, we suggest that this stage of providing a written record of consent (and its scope) could be explicitly incorporated at the 'planning' step (step 6).

Rationale

Steps 1-4 concern establishing the patient's eligibility for an assisted death and, as such, whether an assisted death is an option for them. However, the consultation suggests that during the assessment stages (steps 2 and 3), the patient will be asked whether they wish to provide 'confirmation of consent to proceed' and/ or 'a 'waiver of final consent' (see paragraph 101c and paragraph 172b). The consultation also states that a 'confirmation of consent to proceed' and/ or 'a 'waiver of final consent' can be given at step 4, when the patient is making their second formal request (see paragraph 143 and paragraph 150). (It is not entirely clear if the intention is that consent could be provided at any or all of these steps (i.e. steps 2,3 or 4) or just at step 4, when the patient makes their second formal request. Either way, the consultation envisages that consent would be sought *before* a final determination that a patient is eligible for an assisted death.)

We suggest that seeking consent at this stage (i.e. steps 2,3 or 4) may be premature, given the possibility that the patient might not be eligible for an assisted death. Although it is entirely appropriate to discuss these issues with patients, it is our view that an actual consent should *only* be sought after eligibility is established and the option of an assisted death is confirmed.

At paragraph 14 of our guidance on 'Treatment and care towards the end of life', we set out a decision making model which makes clear that it is only *after* an assessment has been carried out and relevant options are identified and offered that the patient decides amongst those different options.

Indeed, seeking consent after (rather than during) the assessment and approval stages seems to best meet the description of the purpose of the assessment, at paragraph 100 of the consultation document. This states that:

'The purpose of the first assessment is:

> a) *For the person to fully explore, in dialogue with the doctor:*
> *• their request for an assisted death and the fears, anxieties and suffering that gives rise to that request*
> *• other care / treatment options and other ways to alleviate their fears and anxieties (for example, they may have financial concerns or concerns about being a burden on family carers)*
>
> *b) for the doctor to determine if the person meets the eligibility criteria in law and, if so, on the grounds of*
> *• Route 1 (terminal illness); i.e., they have a physical medical condition, which is expected to result in unbearable suffering that cannot be alleviated and are reasonably expected to die within six months or 12 months or*
> *• Route 2 (unbearable suffering); i.e., they have an incurable physical medical condition, that is giving rise to unbearable suffering that cannot be alleviated in a manner that the person deems tolerable*
>
> *c) to consider the decision-making capacity of the person.*

Finally, we suggest that the scope of the patient's consent could also be clearly established and documented at this new step, including whether they wish to provide 'confirmation of consent to proceed' and/ or 'a 'waiver of final consent'. These decisions should be reviewed regularly.

At paragraph 31 of our guidance on 'Decision making and consent', we set out the importance of being clear about the scope of decisions, so that patients understand exactly what they are consenting to. It goes on to explain that:

'Agreeing the scope of a patient's consent with them in advance is particularly important if:

> a. *treatment or care will be provided in stages with opportunities to review and adjust in between*
>
> b. *different healthcare professionals will provide different parts of the treatment or care*
>
> c. *there may be opportunity, once an intervention is underway and the patient's decision-making ability is compromised, to carry out another intervention*

Finally, Paragraphs 56-59 of 'Decision making and consent' set out the importance of regularly reviewing decisions.

12. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8):

- 14 days minimum for those eligible under 'Route 1 (terminal illness)
- 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days? *

○ Yes - I agree

● No - I do not agree

○ Don't know

Please tell us the reasons for your response

It is vital that patients have sufficient time and opportunity to reflect on their decision to end their own life, to ensure it is 'clear and settled'. This principle is reflected at paragraph 27g of our guidance on 'Decision making and consent' and is particularly important given the grave nature of the decision.

However, it is not clear that this requires a mandatory minimum timeframe (see paragraphs 74-76 of the consultation), set out in legislation. The risk is that introducing such a timeframe would not allow for the exercise of flexibility and judgement in cases where a patient is suffering acutely, and this is unduly prolonged (for example, because the patient had been reflecting on their decision for a significant period of time before approaching the service). An alternative may be to introduce minimum timeframes in guidance, whilst allowing for any exemptions in exceptional circumstances (with the onus on decision makers to justify any deviations from guidance). The other benefit of covering this type of issue in guidance instead of legislation is that guidance is more amenable to being reviewed and amended (if necessary), as evidence bases develop and good practice evolves.

13. **Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?** *

○ Yes - I agree

● No - I do not agree

○ Don't know

Please tell us the reasons for your response

Please see our response to question 12 above.

14. **Key questions on Section 5 - assisted dying process: request and approval**

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying? *

● Yes - I agree
○ No - I do not agree
○ Don't know

Please tell us the reasons for your response

We agree that the legislation should be silent on this issue, but that this is an area that could be covered in guidance instead.

A blanket prohibition would mean that doctors would be prevented from exercising judgement and there may be situations where a patient has not actually raised the subject of assisted dying - but where the discussion is such that the clinician judges they would benefit from them openly bringing it up.

Addressing this area in guidance (rather than legislation), would allow for greater flexibility and personalised decision making. As outlined at question 12, it is also quicker and easier to review and amend guidance (if necessary) than it is to change legislation, as evidence bases develop and good practice evolves.

15. **Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?** *

● Yes - I agree
○ No - I do not agree
○ Don't know

Please tell us the reasons for your response

For similar reasons as those outlined at question 14, we don’t believe that there should be an explicit requirement to inform people about the assisted dying service. Indeed, it may be inappropriate to do so with some patients. For example, where the clinician is aware that they have deeply-held convictions about the sanctity of life. Discussions with patients should be tailored to their individual circumstances.

In addition, it might be challenging to identify which groups/ categories of patients any such requirement would apply to, given that the assisted dying service is intended to be available for non-terminal patients who are experiencing ‘unbearable suffering’ (a predominantly subjective determination – see paragraph 198 and 199 of the consultation). For example, we would query the appropriateness of an explicit requirement to raise the issue with all accident victims with severe, life-limiting injuries – as it should clearly not be assumed that they are all experiencing what they would consider to be ‘unbearable suffering’.

We believe that these types of decisions should be matters of judgement, which will vary from case to case. In addition, as outlined above at question 12, covering this type of issue in guidance would allow for greater flexibility and personalised decision making. It is also quicker and easier to review and amend guidance (if necessary) than legislation, as evidence bases develop and good practice evolves.

16. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion? *

- ○ Yes - I agree
- ● No - I do not agree
- ○ Don't know

Please tell us the reasons for your response

It is not clear to us why legislation should limit a patient's right to a single second opinion only. This may be unnecessarily inflexible and it might not be in line with our guidance, which states, at paragraph 16e) of 'Good medical practice', that doctors should '*respect a patient's right to seek a second opinion*'.

In addition, it is not obviously true that just because a further second opinion is sought, this is evidence that the patient's case (for an assisted death) is not sufficiently clear and unequivocal. This is particularly the case if the co-ordinating doctor, who originally judged the patient not to meet the relevant criteria, is convinced by the second opinion doctor's judgement. In this situation, both doctors would be in agreement that the patient meets the eligibility criteria.

17. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a 'confirmation of consent to proceed form', allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed? *

○ Yes - I agree
○ No - I do not agree
● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a position on the circumstances when it should be possible to carry out an assisted death.

However, as long as there is no evidence that the patient may have changed their mind, this proposal would not be inconsistent with our guidance (in particular, see paragraph 31 of 'Decision making and consent', discussed above at question 11).

18. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent? *

- ○ Yes - the law should allow for a waiver of final consent
- ○ No - the law should not allow for a waiver of final consent
- ● Don't know

Please tell us the reasons for your response

As with question 17 above, this is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a position on the circumstances when it should be possible to carry out an assisted death.

However, as long as there is no evidence that the patient may have changed their mind, this proposal would not be inconsistent with our guidance (in particular, see paragraph 31of Decision making and consent, discussed above at question 11).

In addition, at paragraph 35 of Decision making and consent, we state that:

If a patient has a condition that is likely to impair their capacity as it progresses, [doctors] should sensitively encourage them to think about what they might want to happen if they become unable to make healthcare decisions.

That said, if the law were to allow this, practitioners would need to be alert to any signs or behaviour that could suggest the patient’s wishes had changed. We suggest that if this provision is included in legislation, this area will need to be covered in guidance.

Finally, from a conceptual point of view, the ‘waiver of final consent’ may be better described as a ‘waiver of final *confirmation* of consent’. To make clear that consent to an assisted death has already been provided and is reasonably believed to have endured up until the time that the patient lost capacity.

19. **Key questions on Section 5 – approval process**

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:

a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)

b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal

Do you agree with the two different approval routes as proposed? *

○ Yes

○ No - all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor (i.e. 2 doctor assessments only for all requests)

○ No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)

● Don't know

○ Other (please specify):

Please tell us the reasons for your response

The GMC does not have a position on this question.

20. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal:

- always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard)
- does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).

Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests? *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

The GMC does not have a position on this question.

21. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court? *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

The GMC does not thave a position on this question.

22. It is proposed that the law will provide for appeals to the Royal Court on the following grounds:

- whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months
- a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed
- a failure, or perceived failure, to make determinations or act in accordance process set out in law

Do you agree with proposed grounds for appeal? *

○ Yes

○ No

○ Don't know

Please tell us the reasons for your response

The GMC does not have a position on this question.

23. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

○ Yes

○ No – I do not agree, there should be no minimum time period for appeals

○ No– I do not agree, there should be a time period longer than 48-hours

● Don't know

Please tell us the reasons for your response

The GMC does not have a position on this question.

24. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest? *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

The GMC does not have a position on this question.

25. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death? *

○ Yes - I agree, there should be no expiry date

○ No - I disagree, there should be an expiry date

● Don't know

○ Other (please specify):

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a position on whether or not an approval should expire after a certain period of time has elapsed.

However, if the legislation were to exclude an expiry date, we suggest that a system of regular review would need to be in place, to ensure that there have been no relevant developments that could have a bearing on the original approval. This could include, for example, ensuring that the patient's wishes and circumstances haven't changed. It might also include establishing whether there have been any significant therapeutic developments since the approval was granted, that could materially affect whether the patient remained eligible under the statutory criteria.

Paragraph 58 of our guidance on 'Decision making and consent' states that:

Reviewing a decision is particularly important:

a. if you haven't personally had a discussion with the patient because they were initially seen by a colleague
b. if significant time has passed since the decision was made
c. if the patient's condition has changed
d. if you have reason to believe the patient might have changed their mind
e. if any aspect of the chosen treatment or care has changed
f. if new information has become available about the potential benefits or risks of harm of any of the options that might make the patient choose differently.

26. **Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death**

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

*

● Yes
○ No
○ Don't know

Please tell us the reasons for your response

We agree that this should be a necessary safeguard, in the event something goes wrong. Indeed, the patient may have provided a 'confirmation of consent' in case the self-administration does not go to plan and an administering doctor would need to be present for precisely this type of eventuality. In addition, if the proposal to allow a loved-one to support the person to self-administer (see question 27 below) is taken forward, the doctor may need to be available or present in order to provide supervision.

27. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance?

substance? *

○ Yes
○ No
● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change. As such, we would not take a view which different options for administering the medication should be legal, (other than that they should be safe and meet the patients' needs).

That said, it may be helpful to set out some GMC guidance relevant to this question.

We recognise that loved ones can play a vital role in supporting and helping to deliver care and treatment to their loved ones (see paragraphs 17-19 of our guidance 'Treatment and care towards the end of life').

However, it is important to be clear that the treating doctor retains overall responsibility for their patient's care when, under their direction, particular treatments are being administered by others (including the patient themselves, with or without the help of loved ones). It is part of the doctor's responsibility to make sure that arrangements are appropriate and safe and that the person providing care has been suitably trained and has support.

Therefore, if the legislation were to permit a loved one to support a person to self-administer, doctors should ensure that arrangements are appropriate and safe for both the patient and the loved one. This may mean that supervision is needed, both to ensure that administration is carried out correctly, as well as to ensure that there are no signs to suggest that the patient may, in the moment, have changed their mind about proceeding with an assisted death. (See our response to question 18).

28. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying? *

● Yes

○ No

○ Don't know

Please tell us the reasons for your response

We do not provide specific advice to doctors on how to fill in death certificates. However, our guidance (see paragraph 71 of 'Good medical practice') makes clear that when completing certificates and other documents, doctors are expected to be honest and that any forms they sign should not be misleading.

29. **Key questions on Section 7 – Regulation and oversight**

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include:

- an HCS Service Delivery and Assurance Board
- an assisted dying review committee to undertake a post-death administrative review of each individual assisted death

- independent regulatory oversight by the Jersey Care Commission.

Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service? *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

We agree that the service should be subject to oversight to ensure the safety and quality of the service, however it does not fall within our remit to comment on what form this should take.

30. **Do you agree that post-death administrative review of each assisted death is required?** *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

We agree that the service should be subject to oversight to ensure the safety and quality of the service, however it does not fall within our remit to comment on what form this should take.

31. **Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?** *

○ Yes

○ No

● Don't know

Please tell us the reasons for your response

We agree that the service should be subject to oversight and regulation, however it does not fall within our remit to comment on what form this should take.

32. **Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)** *

○ Yes - I agree, it should not be considered an essential service

○ No - I disagree, it should be considered an essential service

● Don't know

Please tell us the reasons for your response

This is not a question that the GMC would take a view on, given that we do not take a position on whether the law on assisted dying should change.

15. Go Gentle Australia

Assisted dying in Jersey consultation
Strategic Policy, Planning & Performance | Jersey States Assembly | January 2023

While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care. – Palliative Care Australia

Dad didn't choose death. Dad chose life over and over again. He chose it when he knew he would have his sides ripped out. He chose it when he knew he would have chemotherapy that would make him sick for another six months. He chose life, he chose life, he chose life. And when life was no longer a choice, he decided to die on his own terms. - Katie Harley, whose father Phil, 70, metastatic bowel cancer, elected to have an assisted death in Victoria in 2019.

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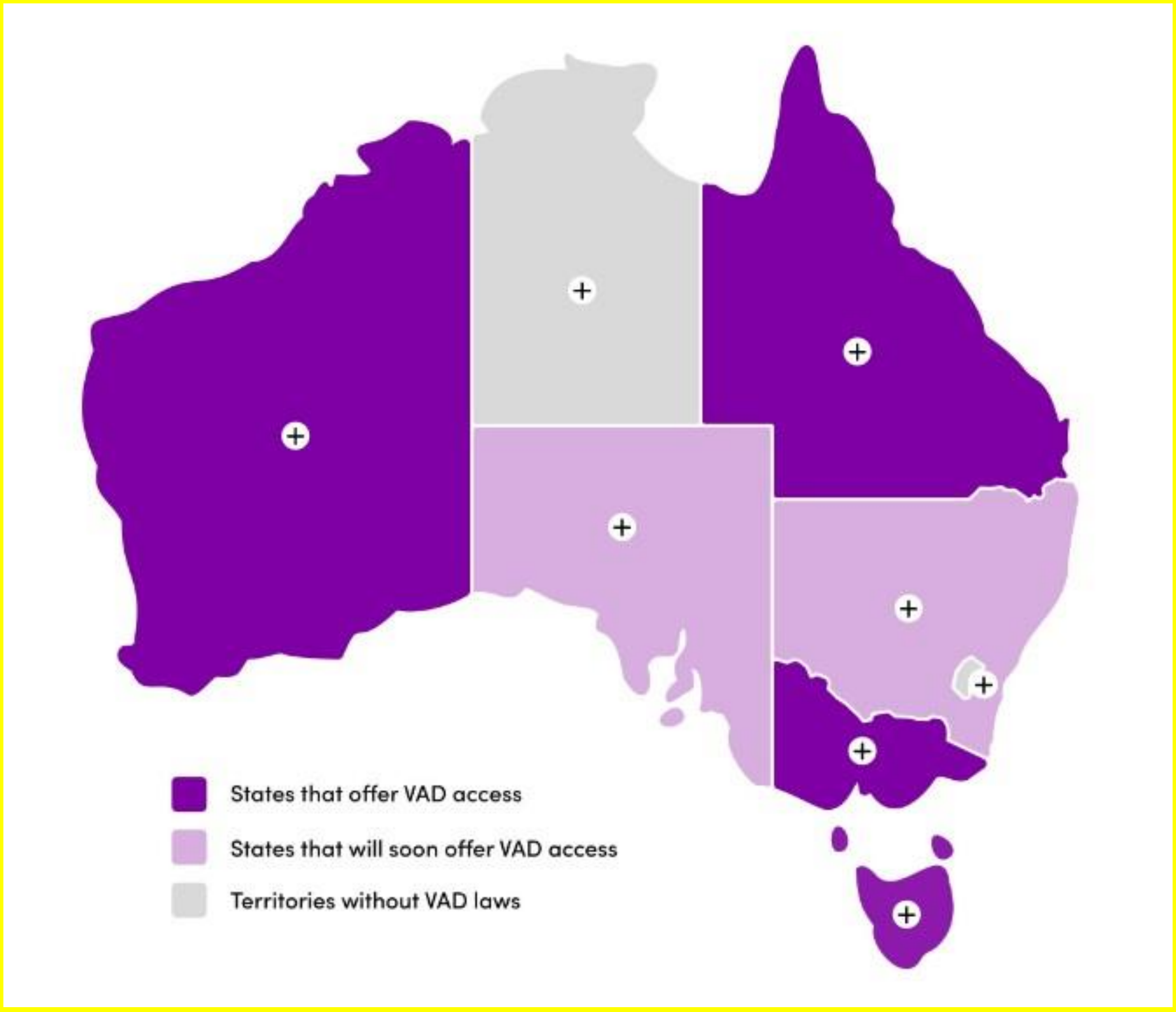
Introduction

Go Gentle Australia is a national charity established in 2016 to promote choice at the end of life. We empower people to choose the end-of-life care that is right for them, including the option of voluntary assisted dying (VAD). We have played a critical role in the introduction of VAD legislation in Australia, where all six states have now passed laws. We believe the voices of dying people should be heard and their decisions respected.

This submission will focus on: **What can be learnt from the evidence in countries where assisted dying is legal?**

Voluntary Assisted Dying in Australia



Australia’s embrace of VAD began in 2017 when Victoria became the first state to pass a law. It was described as “the most conservative law of its kind in the world.”[204]

Since then, all state parliaments have passed their own legislation; Western Australia in 2019, Tasmania, South Australia and Queensland in 2021 and New South Wales in 2022.

Each state’s law came about after significant levels of public consultation. Each built on the strengths (and addresses the weaknesses) of laws that came before. The result is similar, but not uniform, legislation across the country.

All the laws have had at least 18-month implementation periods before they take effect, to establish processes and train healthcare professionals. Victoria, Western Australia, Tasmania and Queensland’s laws are all currently effective.

By the end of 2023, all state laws will be operating (South Australia’s law commences operation on 31 January and the NSW law will begin on 23 November). This means all Australians, bar the 700,000 people in the Northern Territory and Australian Capital Territory (ACT), will be able to access VAD if they become terminally ill (and they meet strict eligibility criteria).

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[204] ‘Assisted dying law a credit to Victoria’s Parliament; now for federal change’ 29 Nov 2017, The Age https://www.theage.com.au/national/victoria/assisted-dying-law-a-credit-to-victorias-parliament-now-fo r-federal-change-20171129-gzvct2.html

The ACT government has begun public consultation with the aim of introducing legislation in mid 2023.[205]

The Australian model

Although each state's law differs slightly, all Australian VAD legislation follows a similar framework, which has become known as the 'Australian model' of VAD. This limits medical assistance to die to terminally ill adults of sound mind who are suffering intolerably. Broadly, to use VAD in Australia a person must be:

- **Diagnosed with an incurable disease, illness or medical condition** that
    - is advanced, progressive and will cause death within 6-12 months (depending on the nature of a person's disease)
    - is causing suffering that cannot be relieved in a manner the person finds tolerable
- **Capable of making decisions** about their medical treatment and communicate those decisions throughout the assessment process
- **Acting freely and without coercion**
- **Aged 18+**
- **An Australian citizen or permanent resident** who has lived in their chosen state for at least 12 months
- **Request VAD** at least three times
- **Be assessed and approved** by at least two doctors

Disability, mental illness and advanced age alone do not meet the above criteria; to access VAD in Australia, a person must also be terminally ill.

There is a rigorous request and assessment process and the process can be stopped at any time - by the individual, or by a VAD practitioner if any duress or coercion is suspected.

This diagram summarises the process[206]:

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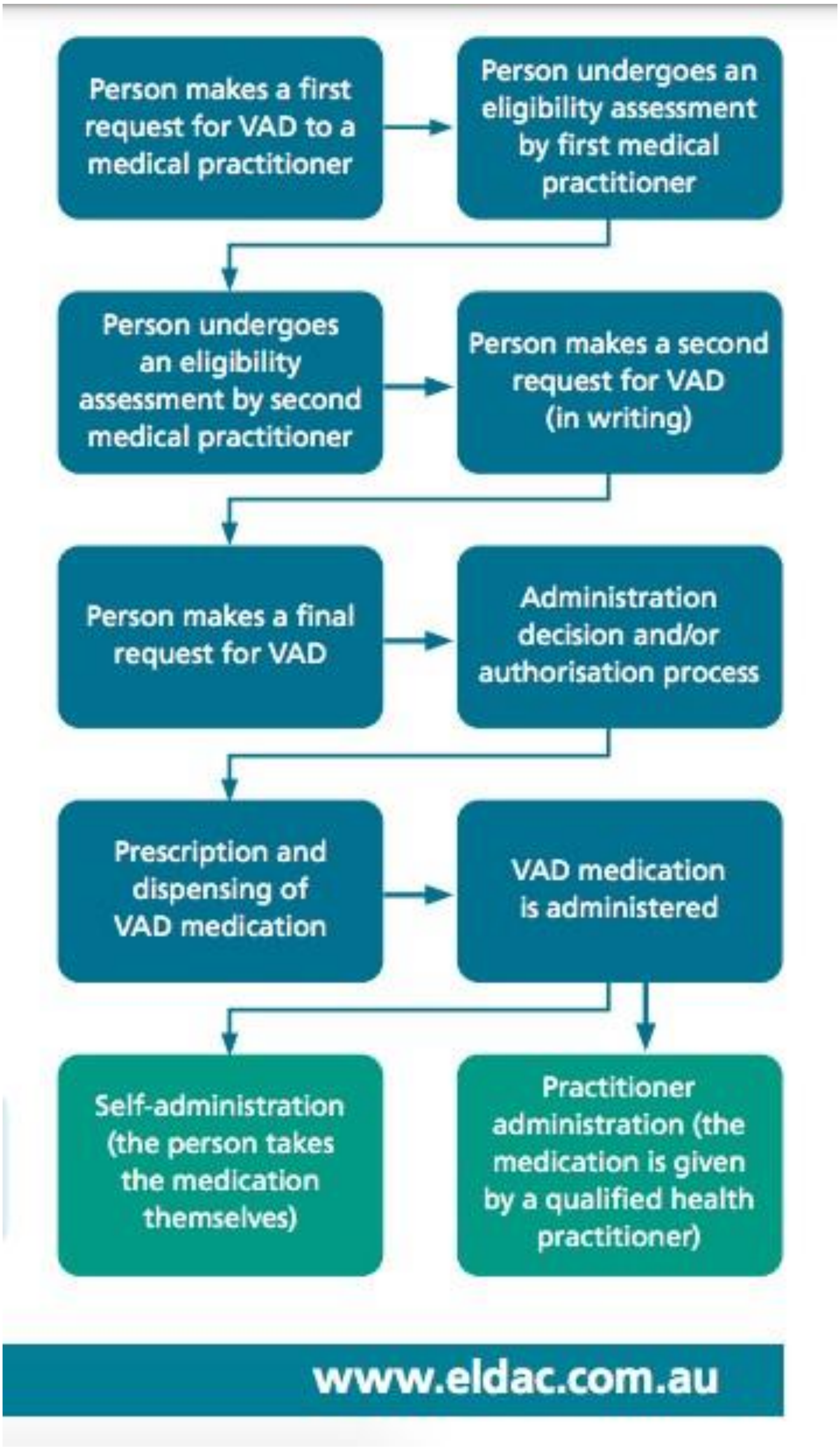
[205] 'Andrew Barr says ACT to introduce voluntary assisted dying laws in 2023' 1 Dec 2022, Canberra Times
https://www.canberratimes.com.au/story/8002335/barr-outlines-path-to-acts-voluntary-assisted-dying-l aws/

[206] End of Life Direction for Aged Care
https://www.eldac.com.au/Portals/12/Documents/Factsheet/Legal/Toolkit-Voluntary-assisted-dying_v1_1_2022.pdf



What we’ve learnt from Victoria and Western Australia

Victoria’s law has been in operation since June 2019, providing more than three years of robust evidence of how VAD works in an Australian context. Crucially, the Victorian experience makes it possible to examine the concerns raised about VAD (for example, vulnerable people would be killed, or that palliative care would be damaged) and determine whether they have turned out to be true.

Victoria's Voluntary Assisted Dying Review Board, the statutory body tasked with monitoring the law, have published biannual reports[207] containing data and feedback from those who have chosen to use the law, and those who were with them when they died, including family, friends, doctors and carers.

The reports show that the Victorian legislation is operating safely and as intended. Terminally ill people are being helped to die under the circumstances of their choosing with a deep level of compassion, integrity and care. **They also make clear that none of the dark predictions about VAD have come to pass**. The law is operating within the strict eligibility criteria and safeguards determined by parliament, with a compliance rate close to 100%.

Assisted deaths in Victoria account for a tiny proportion of total deaths each year – less than 0.5%. There have been no 'wrongful' deaths referred to police, no rogue doctors abusing the system and no evidence of coercion of the vulnerable.

Feedback from Western Australia[208], where a similar VAD scheme has been operating for 18 months, mirrors the positive Victorian experience. In its first annual report, the independent Review Board noted that the Voluntary Assisted Dying Act is working well and that "medical practitioners, care navigators and pharmacists have given beyond the normal call of duty to provide comprehensive end of life care to those Western Australians who have made [this] choice". The WA Board noted that demand for VAD had been greater than in Victoria, with VAD deaths representing 1.1% of all deaths in the time period. The Board's recommendations centred on ensuring equity of access for people in rural areas by increasing the number of trained VAD practitioners and ensuring doctors are properly remunerated for the hours - and often significant travel time - they put into VAD assessments.

Laws in Tasmania and Queensland have been effective for less than six months and as such there has been no release of official data. However, given the similarities of the laws, their performance is expected to mirror the positive experiences in other states.

Why legislate for VAD?

Key points

Palliative care works for most - but not all

While palliative care is excellent and accommodates the needs of the majority of dying people, even the best-resourced care cannot relieve the extreme suffering some people endure. Palliative Care Australia acknowledges this:

> *While pain and other symptoms can be helped, complete relief of suffering is not always possible, even with optimal care.*[209]

It's not about pain, it's about suffering

Pain isn't the only suffering experienced at the end of life. Depending on your condition, there can also be bone metastases, distention, open sores, weight loss, odour, disfigurement, incontinence, fatigue, disfigurement, a sense of suffocation, continuous bleeding and paralysis. It is hard to imagine why a modern health system would abandon patients to these horrors when there exists a means to relieve them.

Palliative care and assisted dying work together

It is not a choice between palliative care OR assisted dying. The two can, and do, coexist. Evidence from Victoria and WA shows around 80-85% of people who choose VAD are also receiving excellent palliative care. VAD is simply another option.

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[207] Victorian Assisted Dying Review Board reports available here:

https://www.safercare.vic.gov.au/publications?f%5B0%5D=agency%3A751&search=voluntary%20ass isted%20dying%20review%20board

[208] Western Australia Voluntary Assisted Dying Reports available here:

https://ww2.health.wa.gov.au/Articles/U_Z/Voluntary-Assisted-Dying-Board

[209] Palliative Care Australia, 'Policy Statement on voluntary euthanasia', Canberra , 2006, p.2

Quoted by Neil Francis, Dying For Choice, 'AMA Uncovered: How its own review exposed its assisted dying policy as indefensible' p. 20
https://www.dyingforchoice.com/docs/AMAuncoveredFullReport27Mar2017.pdf

Moreover, the existence of VAD laws does not result in a decline in palliative care. In fact the opposite is true. A 2018 report commissioned by Palliative Care Australia, looking at the impact of VAD on palliative care internationally, found:

> *"There is no evidence that assisted dying has substituted for palliative care due to erosion of safeguards… if anything, in jurisdictions where assisted dying is available, the palliative care sector has further advanced*.[210]

The Australian experience reinforces this. Since the first VAD law was passed in Victoria in 2017, more than $1 billion in extra funding has gone to palliative care across Australia, including a $743 million boost in NSW, the last state to pass a law.

Australians' experiences of VAD

Families of those who have used VAD laws in Victoria and Western Australia have described the peace of mind and relief that having choice and control gives to dying loved ones.

The words they most commonly use to describe these VAD deaths are "peaceful", "dignified" and "perfect."

The extent to which the laws are working safely and compassionately is revealed by the case studies of the first people to use VAD in each state.

The stories of Kerry Robertson & Mary Ellen Passmore

'She left this world with courage and grace'

Kerry Robertson was the first person to use Victoria's VAD law. The following account was written after an extensive interview with her daughters.[211] A version can also be read in *The Age*.[212]

> *Kerry Robertson, 61, died in a nursing home in Bendigo on 15 July (2019) of metastatic breast cancer.*
>
> *Her daughters said: "It was a beautiful, positive experience. It was the empowered death that she wanted".*
>
> *"We were there with her; her favourite music was playing in the background and she was surrounded by love," Jacqui said.*
>
> *"That was the greatest part, knowing that we did everything we could to make her happy in life and comfortable in death," Nicole said.*
>
> *Ms Robertson was diagnosed with breast cancer in 2010. Despite treatment, the cancer metastasized into her bones, lungs and brain. When the disease had also spread to her liver and the side effects from the chemo were no longer manageable, she made the decision to stop all treatment. Jacqui and Nicole said their mother had always known what she wanted.*

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[210] Aspex Consulting, 'Experience internationally of the legislation of assisted dying on the palliative care sector – Final Report, Palliative Care Australia, October 2018 https://palliativecare.org.au/wp-content/uploads/dlm_uploads/2018/12/Experience-internationally-of-th e-legalisation-of-assisted-dying-on-the-palliative-care-sector-APEX-FINAL.pdf

[211] Interview with Nicole Robertson and Jacqui Hicks, Go Gentle Australia, 29 July 2019 https://www.gogentleaustralia.org.au/the_first_to_use_voluntary_assisted_dying_law

[212] Melissa Cunningham 'She left with courage and grace': Daughters farewell Victoria's first person to access assisted dying' The Age Aug 4 2019 https://www.theage.com.au/national/victoria/she-left-with-courage-and-grace-daughters-farewell-victor ia-s-first-person-to-access-assisted-dying-20190802-p52d97.html

> *"Mum already had an appointment booked to see her specialist the day the legislation came into effect, she made her first request that same day," Nicole said.*
>
> *"Mum had always been brave, a real 'Feel the fear then do it anyway' mentality to life; it's the legacy she leaves with us."*
>
> *The sisters said the assisted dying application process went smoothly and took 26 days. Ms Robertson took the medication on the same day it was dispensed by the statewide pharmacy.*
>
> *"It was quick, she was ready to go. Her body was failing her and she was in incredible pain. She'd been in pain for a long time," Jacqui said. "Palliative care did its job as well as it could. But it had been a long battle. She was tired, the pain was intolerable and there was no quality of life left for her."*

'Eternally thankful'

In July 2021, a 63-year-old Indigenous woman from Perth became the first identified Western Australian to use the state's Voluntary Assisted Dying law. Her story was told to Go Gentle Australia by her family[213]. It was also published in *The West Australian*[214] and *SBS Online*[215].

> *Mary-Ellen Passmore, a Wongatha-Yamatji woman, died in Perth on 29 July from motor neurone disease (MND). Her family described her death as "beautiful".*
>
> *"All were singing along to 'Hallelujah', including her doctors," her sister said.*
>
> *The family said Mrs Passmore had confirmed her choice multiple times before accepting the medication. She thanked her doctors and VAD coordinator and "gave them her love".*
>
> *Mrs Passmore had applied to be assessed for VAD soon after the law came into effect on 1 July and said she was profoundly grateful.*
>
> *"I feel very honoured to choose when and where I can die," Mrs Passmore said. "I am excited because I won't have to suffer any more."*
>
> *Her family said: "We wish to express our gratitude that our proud Black mother, daughter, grandmother, sister, aunty, niece, cousin, godmother, friend, and mentor Mary-Ellen Passmore has been able to have her choice of a dignified death, voluntary assisted dying, finally fulfilled.*
>
> *"We wish to thank the campaigners, the medical professionals, the families, and the state politicians who fought for the right thing - for the law to catch up and allow for choice and dignity.*

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[213] Interview with Mary Ellen Passmore's family, Go Gentle Australia, 30 July 2021
https://www.gogentleaustralia.org.au/indigenous_woman_among_first_to_use_western_australia_volu ntary_assisted_dying

[214] Rangi Hirini, First known Aboriginal voluntary assisted dying (VAD) patient Mary-Ellen Passmore dies in Perth hospital, July 30 2021, The West Australian
https://thewest.com.au/news/health/first-known-aboriginal-voluntary-assisted-dying-vad-patient-maryellen-passmore-dies-in-perth-hospital-ng-b881946986z

[215] Aaron Fernandes. 'I'm at peace': Aboriginal grandmother among first to use WA's new voluntary assisted dying laws, July 30 2021, SBS.
https://www.sbs.com.au/nitv/article/2021/07/30/im-peace-aboriginal-grandmother-among-first-use-was -new-voluntary-assisted-dying

Mrs Passmore had lived with MND, a degenerative neurological condition, for up to 12 years and received a formal diagnosis in 2015. In the past few months her pain had become unbearable.

She had become totally bedridden, had difficulty speaking and swallowing and was fed through a tube.

"It is terrifying being trapped by your own body and it's a relief to know there will be an end to my suffering," she said.

Medical perspectives

Voluntary assisted dying is increasingly accepted by the Australian medical community. In 2017, only two medical bodies openly supported VAD and 15 were opposed. By 2021, the number in support had risen to six, with 15 declaring a neutral position.

Medical practitioners in Victoria and WA also describe the benefits of being involved in the assisted dying process.

Gentle and peaceful deaths

Dr Nick Carr, GP (VIC)

For the people who have gone through the process – and I have been there for a number of people who have taken the medication – it has been, it sounds odd really to describe dying as beautiful, but it has actually been a beautiful experience… It's been a positive experience for myself as a doctor.

Dr Simon Towler (WA)

I am amazed by how hard the VAD providers are working, driving and striving with little financial reward and putting significant pressure on their own families. In the end, the energy that drives the community of practice comes from the enormous privilege of looking after people who are showing all of us that facing your own death is an important part of living.

The patients have given so much more back and we have given to them. They are the heroes in the story and will continue to provide for them even if there are impediments. We respect, admire and applaud every VAD patient. It has been an absolute privilege to be part of the process.

Dr Clare Fellingham, Consultant Anaesthetist (WA)

Overwhelmingly, voluntary assisted dying deaths are peaceful, they're dignified, they’re calm, they’re gentle and compassionate, and they are truly, truly patient centred.

Personally, I found it an immense privilege to be involved so deeply and intimately in another person's life and experiences that I've gained and conversations that I've had with people. And what they've imparted in me has allowed me to cherish the time that I have, and appreciate my own life even more. I now choose to live more broadly, and actively look to seek out the joy in everything. And that is with an immense debt of gratitude to all the people who've shared all of their experiences with me.

Professionally rewarding

Dr Gareth Wahl, emergency physician (WA)

I had previously seen a very large number of unplanned deaths with things left unsaid and with both patient and family profoundly distressed and sometimes in pain. These [VAD] deaths are the complete opposite.

One patient chose to die with no one in the room except myself and my required witness. Mostly they've been surrounded by their closest family and on occasion, up to 30 of their closest friends. They've been surrounded by love. And most importantly, it's been how they've wanted. These people have died well. What I get back from this is really tremendously professionally satisfying. I walk away from this feeling that I've helped people. And that is something that my patients are giving me, that is worth much more than what I'm giving them. So yes, there is a cost, but there's a greater personal and professional gain.

Dr Peter Lange, geriatrician (VIC)

You’re required to ask people the nature of their suffering, and I was a bit ashamed to see that my practice had unconsciously been to direct people to the suffering that I could relieve. So, I might have talked about suffering but the next immediate follow up question might have been how is your pain, how is nausea and those kinds of things which are more amenable to treatment. So, after starting to assess patients I realised that the nature of their suffering was often not those immediate symptoms but might well be a loss of purpose and dignity. I think it has changed my practice outside VAD. **Powerful palliative effect**

Dr Philip Parente, oncologist (VIC)

Voluntary Assisted Dying is exceptionally patient-centred. We're allowing patients to take control when all the appropriate conditions are met in a very controlled way.

It's quite an amazing sight. They feel definitely more at ease, less anxiety, and they feel more in control. It doesn't necessarily mean they take it. Just having the option there gives them control and gives them hope.

Fiona Jane, Clinical Hospice Manager, Albany Community Hospice (WA)

In our experience of patients requesting VAD, we've seen improved patient-related symptom control of previously difficult to manage symptoms such as fatigue and anxiety. And this has happened almost as soon as the first assessment has been completed.

The process of VAD assessment acknowledges suffering caused by the burden of the disease process and the patient feels heard that their fear of increased disability, suffering and being a burden on their family is acknowledged.

Conclusion

VAD is working safely, as intended and with extraordinary integrity, care and compassion in Australia. It is increasingly recognised as a much-needed and powerful addition to end-of-life care. Given medical services and palliative care provision in Australia is comparable with Jersey, we see no reason why Jersey's patients cannot also benefit from this same end-of-life choice.

16. Humanists Against Assisted Suicide and Euthanasia (HAASE)

Humanists Against Assisted Suicide and Euthanasia (HAASE)

Response to Consultation on Jersey Assisted Dying proposals published Oct 2022

EXECUTIVE SUMMARY: Based on information only just emerging from Canada, we feel that any move to legalise assisted dying in any form will be detrimental and would cheapen life for many more people than the very few cases of severely ill people who are determined to die on their own terms.

Who are Humanists Against Assisted Suicide and Euthanasia?

HAASE was formed as a response to the characterization of the debate as one of outdated religious mores against those who are 'pro-choice' and progressive. Our patrons and members share only atheism or agnosticism and great concerns about the legalization of assisted dying – assisted suicide and euthanasia (ASE). Many of us regard ourselves as liberal on most issues; a majority of our members favour abortion rights for women.

Though we are non-believers, our reasons for opposing legislation are moral. We feel it is wrong for the state to take a life simply because it is wretched. Like **capital punishment**, we feel assisted dying would be wrong regardless of the numbers involved. We do not deny that there are some cases where a swift death would be best for a person but we believe strongly that the position of the community should not be to decide who should die and who should live but equal protection of all lives, sometimes from people themselves.

The lessons from Canada

We send this communication in the hope that Jersey rethinks its embrace of assisted suicide and euthanasia. One difficulty we feel is inherent to legalised assisted suicide and euthanasia is that it is **impossible to draw a line** between those who should be allowed ASE and those who should be prevented from using it. We have argued that the justification of ASE as medical treatment for unbearable suffering creates additional demand from those who feel they suffer unbearably but fall outside the criteria.

New evidence from Canada indicates the tendency to expand to those who suffer not from physical diseases or conditions but from depression borne of poverty, homelessness, or other social conditions. **In the context of increasing numbers of people defining themselves as suffering from various medical conditions, we think the numbers will climb in any area where ASE is legalized.**

What do we know

- We know that where assisted suicide and/or euthanasia has been legalised, the numbers receiving assisted deaths have consistently gone up and more categories have been made eligible.[216]
- We know that, once an assisted death becomes medical treatment for unbearable suffering, more and more people who feel they are suffering unbearably demand it.
- We know that proponents, in areas where assisted dying is legal, campaign to extend its purported benefits to more and more groups. For example, the Right to Die Society in the Netherlands (NVVE) campaigns to extend euthanasia to all those over the age of 74. In Canada, Dying with Dignity campaigns for mature minors to have access to euthanasia. In Belgium, the Association for the Right to Die with Dignity (ADMD) campaigned successfully for euthanasia to be extended to children.
- We know that pain is not an important reason why people opt for an assisted death. In Oregon reports – conducted since 1998 – pain has never entered the top 5 reasons why people opt for an assisted suicide.[217]

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[216] In Canada, where ASE was legalised in 2016, assistance in dying cases increased from 1018 cases in 2016 to 10,064 in 2021, accounting for 3.3% of all deaths in Canada. The number of Dutch people being euthanised began to rise sharply, from under 2,000 in 2007 to almost 6,600 in 2017. The numbers rose again to 7666, including 206 patients with earlier stage dementia helped to die and 115 people with severe psychiatric illness.

[217] The top reason in 2021 were: 1. losing autonomy 2. Less able to engage in activities making life enjoyable 3.

- We know that that legalising assisted suicide has minimal impact on suicide rates, belying both the claim by opponents that it encourages more suicides but also the claim by proponents that it will reduce suicides by providing a safer outlet for those forced to take their lives because of terminal illness. Switzerland and Oregon reported elevated rates of self-initiated death among older women. If we regard assisted deaths where it is legal as suicides, it evens the ratio between men and women.

Conclusion

Once we back away from the emotional stories used to justify ASE, there are complex issues and implications that arise. Rather than a case of archaic religious objections preventing a common-sense change in the law, legalising ASE is stepping off of a moral precipice. We hope that Jersey will reconsider its embrace of assisted dying.

Loss of dignity 4. Burden on family, friends/caregivers 5 Losing control of bodily functions 6. Inadequate pain control, or concern about it 7. Financial implications of treatment. See https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year24.pdf

17. Jersey Dying Well Group

Public Consultation – Jersey Dying Well Group Submission 14 January 2023

The Jersey Dying Well Group is an unincorporated group of individuals and representatives from several organisations in Jersey and elsewhere that includes local, national, and international expertise. The group has a desire to see the continued development of palliative and end-of-life care to be the best achievable in Jersey.

The group opposes the introduction of the proposed law on Assisted Suicide and Euthanasia, holding a similar position in line with 85% of specialists who are members of the Association of Palliative Care of Britain and Ireland, and who stated that they would not be involved in any way. The Jersey Dying Well Group is working alongside the All-Party Parliamentary Group on Dying Well that is based in Westminster.

Vulnerability:

There are no sufficient safeguards for euthanasia or assisted suicide. The proposed law will affect vulnerable people. In Oregon USA over 50% of cases of persons who had assisted suicide did so because they believed that they were a burden to others.[218] What has been put forward as a 'right to die' will, for a significant number of vulnerable people, result in them believing that they have a 'duty to die' due to being a burden on carers and relatives.

Vulnerable people due to age, disability or illness will be especially at risk of harm. A letter was written to the Guernsey Post in 2018 by Helen Arkwright, who was a care manager with vulnerable people for 20 years. The letter was entitled 'Legalising Euthanasia, would put sick & elderly at great risk.' Her letter to the Guernsey Post makes this very clear that this can be the only conclusion.[219]

Elder Abuse is hidden and very common, particularly financial abuse. The proposed so called 'safeguards' will not protect the elderly from coercion and manipulation by unscrupulous relatives who for selfish motives will manipulate the vulnerable person for financial gain and even their own convenience.

'Hourglass', a UK charity states: 'One in six older people are victims of abuse.' [220]

In Jersey in 2021 about a sixth (18%) were 65 years or older, which equates to about 18,000 people. Calculation of the UK equivalence of Elder Abuse would mean that there could be thousands who suffer, and

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[218] Oregon Death with Dignity Act: 2021 Data Summary. Oregon Health Authority (Public Health Division), 2022. https://www.oregon.gov/oha/ph/providerpartnerresources/evaluationresearch/deathwithdignityact/pages/ar-index.aspx

[219] https://guernseypress.com/news/voices/readers-letters/2018/01/19/legalising-euthanasia-would-put-sick-and-elderly-at-great-risk/

[220] *https://wearehourglass.org/who-we-are*

for a significant majority of these, it will be financial abuse. Even a small proportion of this number would be exposed to coercion and manipulation and therefore early death by Assisted Suicide. [221]

Route 1 (Terminal illness with 'unbearable suffering') and Route 2 (Chronic Illness with 'unbearable suffering') are being proposed in the Public Consultation document. The inclusion of Route 2 is alarming as it opens up both assisted suicide and euthanasia for many chronic health conditions.

Unbearable Suffering:

The Jersey proposals state that Assisted Suicide and Euthanasia would be implemented for 'unbearable suffering'. In 'Route 1 – terminal illness' and 'Route 2 – unbearable suffering'. This raises the question – can suffering be reliably estimated and understood? It is very subjective and there are no known methods or tools for measuring or estimating suffering by healthcare professionals.

Route 2 is for suffering an incurable physical condition, causing unbearable suffering. This opens the door very wide to many long-term medical conditions such as diabetes, depression, COPD, chronic pain, incontinence, and mobility problems.

Eventually legal challenge on equality of availability could result in the inclusion of conditions such as memory loss, personality disorders, treatment-resistant schizophrenia, PTSD (Post Traumatic Stress Disorder), and Anorexia Nervosa. Oregon's 2021 report includes Anorexia in the broad list of medical reasons for Assisted Suicide.

Although the present proposals exclude mental health disorders, this will not be the case in practice as these co-exist with physical illnesses. A person with severe Anorexia Nervosa will eventually have physical symptoms due to their condition and could request assisted dying on that basis.

Any person with anorexia over 18 years of age would qualify under the proposed 'safeguards' by being an adult, having capacity, being terminal if they failed to take enough nutrition, suffering unbearably and, since it is no longer seen as a solely psychological illness, would fit the requirement for it to be a physical illness. A person's estimate of their own suffering is strongly affected by a wide range of treatable issues including psychosocial support, loneliness, and depression. Physical illness and depression commonly co-exist.

In Belgium, 82.8% of causes for "unbearable suffering" are of a psychological nature, including loss of autonomy, loneliness, despair, feelings of unworthiness.

Route 1 (terminal illness):
The definition of what is a 'terminal illness' in terms of prognosis is very difficult and imprecise as predictions of life expectancy can be inaccurate. This could be days, weeks, months, or years.
Misdiagnosis commonly occurs. 88% of head & neck cancer prognoses are wrong, nearly half of predictions in heart failure are wrong, and 5% of terminal diagnoses are wrong.

Route 2 (unbearable suffering):
A person's estimate of their own suffering is strongly affected by a wide range of treatable issues including

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[221] https://www.gov.je/Government/JerseyInFigures/Population/Pages/PopulationStatistics.aspx

psychosocial support, loneliness, and depression. [222] [223] [224] [225] [226] [227] [228]

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Mental capacity:

The mental Capacity law was only introduced into Jersey in 2018 and there is no mandatory training in place. Mental capacity is not a one-off assessment and even trained psychiatrists find these assessments challenging. This would be even more so in a situation of life and death. The Irish Psychiatrist Position Paper in Sept 2021 clearly stated their opposition to Physician Assisted Suicide and Euthanasia, as outlined in their Executive Summary points.[229]

Drugs Used in Assisted dying:

There will be significant legal risks to the Jersey Government. Is the Jersey Government willing to authorise lethal 'substances' that have never been approved of by any regulatory authority anywhere in the world? And will the Jersey Government provide unlimited indemnity in the event of a problem with an assisted death?

In a small island, is independence possible?

Independence may be impossible in a small medical community which would mean even more expense of involving doctors from outside Jersey. In Oregon and Canada, only 2% of doctors prescribe assisted dying drugs. Time and investment would be far better used for resources towards improving palliative care support.

Developments in Canada:

There is increasing evidence of the harmful effects of the Medical Assistance in Dying (MAiD) in Canada. This evidence was not available at the time of the Citizens Jury when they met in 2021, which is nearly 2 years ago. Due to poverty, disability, and other social reasons there are people in Canada who have accessed MAiD. The press / media are becoming aware of these emerging facts, with increasing numbers reporting great concern about these developments. An example is the article in the Guardian by Sonia Sodha, who though in principle

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[222] Hoesseini A *et al*. Physicians' clinical prediction of survival in head and neck cancer patients in the palliative phase. *BMC Palliative Care*, 2020; **19**: 176-85. https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-020-00682-2

[223] Warriach HJ *et al*. Accuracy of physician prognosis in heart failure and lung cancer: comparison between physician estimates and model predicted survival. *Palliative Medicine*, 2016; **30**(7): 684-9. https://journals.sagepub.com/doi/abs/10.1177/0269216315626048

[224] House of Lords Report 86-II (Session 2004-05), p730. https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

[225] Neimeyer RA *et al*. Confronting suffering and death at the end of life: the impact and religiosity, psychosocial factors, and life regret among hospice patients. 2011; 35(9): 770-80. https://www.tandfonline.com/doi/abs/10.1080/07481187.2011.583200

[226] RA *et al*. Confronting suffering and death at the end of life: the impact and religiosity, psychosocial factors, and life regret among hospice patients. 2011; 35(9): 770-80. https://www.tandfonline.com/doi/abs/10.1080/07481187.2011.583200

[227] Lee SL *et al*. The association between loneliness and depressive symptoms among adults aged 50 years and older: a 12-year population-based cohort study. *Lancet Psychiatry*, 2021; 8: 48-57. https://www.thelancet.com/journals/lanpsy/article/PIIS2215-0366(20)30383-7/fulltext

[228] Hartog ID, Zomers ML, van Thiel GJ, Leget C *et al*. Prevalence and characteristics of older adults with a persistent death wish without severe illness: a large cross-sectional survey. *BMC Geriatrics*, 2020; **20**: 342-356. https://bmcgeriatr.biomedcentral.com/articles/10.1186/s12877-020-01735-0

[229] https://www.irishpsychiatry.ie/wp-content/uploads/2021/12/CPsychI-Position-Paper-Physician-Assisted-Suicide-and-Euthanasia-17-December-2021-.pdf

would be in favour of Assisted Dying, has indicated that she is not so, in view of the risks to vulnerable people.[230]

Conscience

The effect on a broad number of people who would not want to be involved in any way because of conscience issues is not addressed by a simple 'opt-in' or 'opt-out' decision. The issue of conscientious objection is a complex one, and although there would be some protection for medical staff such as doctors or nurses, this would not extend to others if they were required by their employers to be involved in some part of the process. Doctors would be required to make 'effective or effectual referral' which although not legally required in the Jersey proposal, could result in the doctor being reported to the GMC. It could be claimed that this is a cause of distress for the patient, if the doctor is unwilling to refer on grounds of conscience or what they believe to be in the patient's best interest. It has been suggested that they could hand on a printed leaflet, which some may do but others would not.

Conscience issues, alongside the desire to do no harm, are very strongly held by some people. There will be doctors or nurses who would consider leaving the Island rather than being forced into referral of patients for assisted dying. There will be those who will not wish to be involved, who would otherwise have returned to the Island as a medical professional and would choose not to do so. There is a shortage of medical professionals in Jersey, and this would adversely affect recruitment.

The Irish Psychiatrist Position Paper in Sept 2021 stated:[231]

"There is a moral equivalence in performing an action (be it for benefit or for harm) and having someone else perform it. Requiring doctors to refer patients to other practitioners for the purpose of assisted suicide would likely be felt by someone with strong views on the ethics of this process as collusion, as morally equivalent to performing the action themselves, and as ethically unacceptable." (Page 9)

Adverse effect on the collective conscience and culture of society:

There is a concern that the effect of a change of law will affect the general population's perception of the value of life. The prohibition of killing other people is a foundation of societal life, due to the highly regarded view of the worth of human life. Everyone has a right to life under Article 2 of The Human Rights Act 1998.

The UN Universal Declaration of Human Rights affirms, 'the inherent dignity and the equal and inalienable rights of all members of the human family.'

A State decision to sanction taking an individual's life is a significant action. The primary danger of assisted suicide and euthanasia is that individuals are devalued by society.

Harm to Medical Professionals:

There is a harmful effect on the medical staff themselves, who have been involved in administering 'assisted dying', which results in about 20% of them suffering from Post-Traumatic Stress Disorder.

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[230] https://www.theguardian.com/commentisfree/2023/jan/01/assisted-dying-seems-humane-but-can-we-protect-the-vulnerable-from-the-malign?CMP=Share_iOSApp_Other

[231] https://www.irishpsychiatry.ie/wp-content/uploads/2021/12/CPsychI-Position-Paper-Physician-Assisted-Suicide-and-Euthanasia-17-December-2021-.pdf

Canadian physicians' refusal to participate in assisted deaths was not based on religious or moral grounds, but because of the emotional burden and fear of psychological repercussions. [232] [233] [234]

Many medical organisations do not support change. [235] [236] [237] [238] [239] The Royal College of Physicians stated in 2020 "…the *RCP clarifies that it does not support a change in the law to permit assisted dying at the present time."* The British Geriatrics Society are not in support and the following have stated their opposition: the Royal College of General Practitioners, the World Medical Association, and the UK Association for Palliative Medicine.

Most countries have not legalised assisted dying. This covers 96% of the world population.

Palliative Care:

A quote in the Irish Times Newspaper 10 Nov 2020:

'Dr Twomey said that, while he couldn't speak for everyone, based on the experiences of the members of the Irish Palliative Medicine Consultants' Association (IPMCA) who have cared for thousands of highly complex palliative care patients with severe symptoms over many decades, it was "an extremely rare event" that extreme pain and distress could not be managed.' (End of quote)

Early identification and assessment of patients in palliative care intervention improves quality of life.

There needs to be an in-depth assessment of the provision of specialist Palliative Care in Jersey, with support provided through government, which would give Jersey an opportunity to become world class in the provision of Palliative Care, rather than opting for a law that results in the killing of patients.

In conclusion, the suggested safeguards in the consultation document are not safeguards but eligibility criteria. There are no sufficient safeguards, and the greatest safeguard is the existing law.

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[232] Kelly B *et al*. "An indelible mark" the response to participation in euthanasia and physician-assisted suicide among doctors: a review of research findings. *Palliative and Supportive Care*, 2019; **18**(1): 82-8. https://www.cambridge.org/core/journals/palliative-and-supportive-care/article/abs/an-indelible-mark-the-response-to-participation-in-euthanasia-and-physicianassisted-suicide-among-doctors-a-review-of-research-findings/38E83F6E75B2F3A671CF48205612498A

[233] Bouthillier M-E, Opatrny L. A qualitative study of physician's conscientious objections to medical aid in dying. *Palliative Medicine*, 2019; **33**(9): 1212-20. https://journals.sagepub.com/doi/abs/10.1177/0269216319861921

[234] Rutherford J *et al*. What would the doctor prescribe: physician experiences of providing voluntary assisted dying in Australia. *Omega- Journal of Death and Dying*, 2021; July 20. https://journals.sagepub.com/doi/10.1177/00302228211033109

[235] Royal College of Physicians of London. RCP clarifies its position on assisted dying. https://www.rcplondon.ac.uk/news/rcp-clarifies-its-position-assisteddying

[236] British Geriatrics Society. Physician Assisted Suicide, 2021. https://www.bgs.org.uk/resources/physician-assisted-suicide

[237] Royal College of General Practitioners. Assisted dying RCGPs 2020 decision. https://www.rcgp.org.uk/representing-you/policy-areas/assisted-dying

[238] World Medical Association. WMA statement on Physician-assisted suicide, 2019. https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/

[239] Association for Palliative Medicine Position Statement/ The Association for Palliative Medicine (apmonline.org)

The Jersey Dying Well Group desire to see the continued development of palliative and end-of-life care to become the best that is achievable in Jersey and opposes the introduction of the proposed law on Assisted Suicide and Euthanasia.[240]

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ii. https://guernseypress.com/news/voices/readers-letters/2018/01/19/legalising-euthanasia-would-put-sick-and-elderly-at-great-risk/

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vii. House of Lords Report 86-II (Session 2004-05), p730. https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

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xxii. Association for Palliative Medicine Position Statement/

18. Jersey Evangelical Alliance

JERSEY
EVANGELICAL
ALLIANCE

13 January 2022

Dear Sir or Madam,

It is important to acknowledge that the issue of physician assisted suicide will be a sensitive issue for many, particularly for those who have cared for a loved one at the end of their lives. Seeing a family member go through the end of life's journey is a process that can leave us with negative memories, and yet for caring professionals and for the family, who provide care and support, there is also a sense of privilege to have shared that journey with them. For this reason the Jersey Evangelical Alliance is in favour of the government expanding and funding palliative care, like hospice, but we oppose the proposal that would legalise physician assisted suicide (i.e. euthanasia, assisted dying).

We recognise that there is a vocal minority who are strongly advocating for legalising physician assisted suicide. However, the overwhelming majority; of ethicists, palliative care doctors and nurses, mental health professionals, disability campaigners, those within the hospice movement, and church leaders recognise that allowing doctors to participate in the killing of their patients is not the best practical and compassionate response that is available. This is because the argument for assisted suicide ignores the wonderful discoveries of modern palliative care that make it possible not only to control most physical pain, but also to address the psychological, relational, and spiritual challenges experienced by people at the end of their lives. Further, there is no evidence that participating in the killing of a patient will effectively bring about positive outcomes in any of these areas. In fact, evidence from other jurisdictions suggests that assisted suicide can have a detrimental impact on these measures of health and can also contribute to the marginalisation, abuse, and neglect of the most vulnerable in society.

We also specifically oppose the proposal being put before the States Assembly because it does not have any safeguards in place, as was required by the enabling legislation. Instead, the proposal has opted to only create qualifying criteria. Given the big risks associated with taking someone's life, introducing assisted suicide demands robust safeguards. Sadly there are no safeguards in the government's proposal. For instance, there are no safeguards to guarantee that those who do not wish to participate directly or indirectly in assisted suicide have the right of conscientious objection. There are no safeguards to make certain that doctors are able to make independent judgments. There are no safeguards to ensure that patients are given balanced information and access to real palliative care or alternative treatments. There are no safeguards to protect vulnerable people who are in danger of persuasion or coercion. There is no training in place for doctors to be able to identify if patients are being coerced. There are no standards in place to assure that training of practitioners is appropriate. There is no protocol for the types and proportions of lethal substances that will be used. There are no safeguards for assuring that patients who are not self-administering lethal substances are exercising their own autonomy. There are no safeguards in place to mitigate the impact this will have on the mental health of participating medical practitioners, family members, and other patients who are in hospital or care homes who will be in contact with someone who chooses to take their life through assisted suicide. There are no mechanisms in place to monitor the likely negative impact this law will have on: access to palliative care, suicide prevention on the Island, and access to alternative or more expensive end of life treatments. The proposal being put forth offers no safeguards. It only provides for eligibility requirements. Without robust safeguards in place physician assisted killing cannot go forward in Jersey.

Attached to this letter we also have a more detailed list of specific concerns we have about the proposal. Given that there is no evidence that physician assisted suicide will improve the welfare of islanders, and given the high level of risk associated with legalising the killing of people, and given that there are no safeguards in the proposal, we strongly oppose introducing assisted suicide in Jersey.

Thank you for your continued service to the Island and we pray for wisdom as you consider this issue.

Best Regards and God Bless,

Drew Waller

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19. Lives Worth Living

LIVES WORTH LIVING

A CAMPAIGN OF SPUC PRO-LIFE

3 Whitacre Mews, Stannary Street London, SE11 4AB

Re Submission to the Consultation on Assisted Dying in Jersey

LIVES WORTH LIVING is a campaign of the Society for the Protection of Unborn Children (SPUC), a human rights group established in 1966 and since then has been active in the field of public campaigning, debate and lobbying in relation to abortion and other issues, such as embryo experimentation and euthanasia. Its aims include, inter alia, the following:

- To affirm, defend and promote the existence and value of human life from the moment of conception until its natural end.
- To examine existing or proposed legislation, regulations or public policies relating to the protection of human life and the promotion of human dignity and to support or oppose such as appropriate.

In furtherance of the above aims, SPUC has been involved in major litigation surrounding abortion, freedom of conscience and the right to life of vulnerable individuals over several years.

SPUC espouses the ethical tradition that recognises the inviolability of human life and the prohibition on doctors taking the life of their patients set out by the Hippocratic Oath (*c* 400-350 BC) when it states:

> "I will neither give a deadly drug to anybody if asked for it nor will I make a suggestion to this effect. Similarly, I will not give to a woman an abortive remedy."[241]

This tradition was reaffirmed in 1948 by the Universal Declaration on Human Rights, the International Code of Medical Ethics adopted by the World Medical Assembly and the Declaration of Geneva which bound doctors to "maintain the utmost respect for human life from the time of conception, even under threat," and not to use their medical knowledge "contrary to the laws of humanity."[242]

The legalisation of assisted suicide creates additional pressure for the vulnerable. When the frail, the ill or the elderly are told that they can end their lives if they choose to do so, it conveys a perception that they might be better off dead. Even if this impression is unintentional, it generates pressure for them to choose death.

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[241] Ludwig Edelstein, *Ancient Medicine: Selected Papers of Ludwig Edelstein,* (eds, O Temkin and C Lilian Temkin, trans from German, C Lilian Temkin, John Hopkins Press, 1967) 6

[242] International Code of Medical Ethics, Duties of Doctors to the Sick: *A doctor must always bear in mind the importance of preserving human life from the time of conception until death*" 1948

Where assisted suicide has been legalised, a major reason cited by people who choose to end their lives prematurely is the feeling that they are a burden on others.

In one study researchers also identified a range of pressures on vulnerable people who desire assisted suicide, leading to a choice "strongly influenced by fears, sadness and loneliness". The same researchers were concerned about the development of a culture that would "increase social pressure on older people and reinforce negative ideas surrounding old age".[243]

Legalising assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The evidence shows that the difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death for the socially devalued group.[244]

In light of the evidence cited in this submission, Lives Worth Living, on behalf of SPUC's members resident in Jersey, urges the States Assembly to reconsider its decision to change the law and instead address the shortcomings in end of life care that propel some individuals to take the desperate step of seeking to end their own lives.

A Note on Terminology

This submission uses the term "assisted suicide" or "physician assisted suicide". The term "assisted dying" is sometimes used to refer to both assisted suicide and euthanasia in countries like Belgium and the Netherlands where both are permitted. In the UK, the term is used by its proponents as a gentler sounding alternative to assisted suicide and euthanasia, but it has no meaning in law. The definition provided by the Parliamentary POST briefing on the subject states:

> "'Assisted dying' refers here to the involvement of healthcare professionals in the provision of lethal drugs intended to end a patient's life at their voluntary request, subject to eligibility criteria and safeguards. It includes healthcare professionals prescribing lethal drugs for the patient to self-administer ('physician-assisted suicide') and healthcare professionals administering lethal drugs ('euthanasia')."[245]

The assertion made on page 2 of the *Summary of Proposals* that "Assisted dying is not the same as suicide" is not born out by the evidence. Attempts to dismiss or obfuscate the psychological factors which are often associated with terminal illness could represent an obstacle to a patient receiving appropriate care. As the New York State Task Force On Life and The Law states in *When Death Is Sought: Assisted Suicide and Euthanasia in The Medical Context:*

> "While evaluating the patient's physical pain or symptoms, health care professionals may identify symptoms of depression or other psychiatric disorders. Psychiatric consultation should be considered in these cases. As discussed above, major depression is relatively common among severely ill patients. While often difficult to diagnose, depression is distinct from normal feelings of sadness that generally accompany terminal illness. Depression in terminally ill patients generally can be treated successfully

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[243] E van Wijngaarden, *et al* Assisted dying for healthy older people: a step too far? (2017) *BMJ* 357:2298

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[245] Devyani Gajjar, Abbi Hobbs, UK Parliament POSTbrief 47, 26 September 2022. https://post.parliament.uk/research-briefings/post-pb-0047/

> using antidepressant medications and psychotherapeutic interventions. (See AJ Roth & J C Holland, "Treatment of Depression in Cancer Patients," *Primary Care in Cancer* 14 (1994): 24-29)”[246]

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[246] The New York State Task Force On Life and The Law, *When Death Is Sought: Assisted Suicide and Euthanasia in the Medical Context*, May 1994. 41 https://www.health.ny.gov/regulations/task_force/reports_publications/when_death_is_sought/chap3.htm

LIVES WORTH LIVING
A CAMPAIGN OF SPUC PRO-LIFE

Submission to the Consultation on Assisted Dying in Jersey

Q.1 Do you give permission for your comments to be quoted?

Yes.

Q.2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes.

Q.3 If yes, do you think assisted dying:

Should not be permitted.

The introduction of assisted suicide is not required and attempts to legitimise it are unethical and dangerous. Its legalisation creates additional pressure on the vulnerable. In Oregon in 2020, a majority of people killed by assisted suicide (53.1%) cited a fear of being a "burden on family, friends/caregivers" as a reason to end their lives.[247] In Washington State in 2018, 51% of people who were killed by assisted suicide said that being a burden on family, friends and caregivers was a reason to end their lives.[248]

Disabled people fear assisted suicide. Its legalisation risks reinforcing negative stereotypes of disability adding to the difficulties already faced by disabled people.

Assisted suicide cannot be controlled. In several countries assisted suicide has been used to introduce euthanasia. Vulnerable groups, including children, infants, dementia patients, psychiatric patients, those who are not dying, and those who have not requested death are then vulnerable to euthanasia.

The majority of doctors in the UK do not support assisted dying. This opposition is strongest amongst doctors who work most closely with dying patients.

Evidence suggests that in countries with assisted suicide, there is a rise in suicide more generally. A 2015 study

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[247] Oregon Death with Dignity Act 2020 Data Summary
[248] 2018 Death with Dignity Act Report (July 2019)

from the United States found that making it legal for doctors to assist someone to end their life resulted in a 6.3% increase in total suicides and a 14.5% increase for those over 65 years of age.[249] A 2022 study of nations in Europe showed that after countries introduced assisted suicide the number of people ending their lives either by themselves or on request rose significantly when compared to neighbouring states. There was no evidence of a reduction in non-assisted suicide when compared to their neighbours. In some cases, cases of non-assisted suicide also increased.[250]

No safeguard can be considered capable of preventing abuses since assisted suicide by nature is an abuse of medical ethics and human rights. It is not a medical procedure but acts contrary to the goals of medicine, namely to cure and care but not to harm or kill patients.

The proposals are not capable of overcoming the dangers and negative consequences inherent in assisted suicide.

For all these reasons, assisted suicide should not be authorised and measures that genuinely address the current shortcomings in end of life care should be promoted instead.

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No. People with end-stage neurodegenerative conditions have needs "similar to that of advanced cancer patients. Therefore, the principles and practice of palliative care should be applied to such patients."[251] Diagnosis with a neurodegenerative disease should not be presented as a "death sentence" but treated as a condition deserving the same level of respect and palliative care management as other life-limiting conditions. Palliative care training specific to the needs of neurodegenerative conditions (eg, for management of neuropathic pain) should be undertaken in nursing homes where such patients are often located.

Attempts to widen the scope of the original eligibility criteria at such an early stage confirm the arbitrary nature of the criteria. It also demonstrates the level of pressure which has inevitably led to safeguards being abandoned in other jurisdictions. Once legalised measures aimed at protecting the vulnerable are increasingly viewed as unfair barriers and are gradually removed. This has been the experience in Canada, the Netherlands, Belgium, Washington, Hawaii and Oregon.

Since arguments for assisted suicide are essentially the same as those for voluntary euthanasia, its legalisation in some countries has led to vulnerable groups such as disabled infants, dementia patients and the mentally ill — people who are not dying and have not requested death — being euthanised in the belief that they would ask to die if they could. Reports from Belgium and Holland up until 2010 show that between 7 and 9% of all infant deaths involved active euthanasia by lethal injection.[252] More recent reports almost certainly underestimate the rate as practitioners often fail to report cases, some of these are not considered to be euthanasia even though a lethal injection was used. In the Netherlands, the number of people with dementia

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[249] D A Jones, D Paton, "How Does Legalization of Physician-Assisted Suicide Affect Rates of Suicide?" (2015) *South Med J*, 108 (10) 599-604 doi: 10.14423/SMJ.0000000000000349. PMID: 26437189

[250] D A Jones, "Euthanasia, Assisted Suicide, and Suicide Rates in Europe", (2022) *J Ethics in Mental Health*, 11, (5)

[251] J A Low, et al, "A palliative care approach to end-stage neurodegenerative conditions" (2003) *Annals of the Academy of Medicine Singapore,* 32 (6), 778-84

[252] Gregory K Pike, *Euthanasia and Assisted Suicide – When Choice is an Illusion and Informed Consent Fails*, 2020 https://bioscentre.org/wp-content/uploads/2020/11/Euthanasia_and_Assisted_Suicide_GPike_WEB.pdf

killed by euthanasia has risen steadily from 12 cases in 2009 to 162 in 2019.[253]

Under guidance from the Royal Dutch Medical Association, issued in late 2021, doctors are to be deemed the best judge of whether a dementia patient is "suffering unbearably" – one of the legal requirements for euthanasia – and they do not have to ask the patient.[254] The government of Quebec has recently indicated its support for the adoption of a similar policy there.[255]

Q.5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Lives Worth Living rejects the premise of this question as it requires an acceptance of assisted suicide to a greater or lesser extent.

Opening access to assisted suicide to non-residents could lead to the kind of suicide tourism seen in Switzerland. If legalised there may well be pressure to seek whatever financial benefit could be gained from such a market. Other jurisdictions have seen residency criteria being successfully overturned, notably through a court challenge in Oregon, in 2022. A similar campaign is currently underway in Vermont.

Q.6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

Lives Worth Living rejects the premise of this question as it requires an acceptance of assisted suicide to a greater or lesser extent.

The eligibility criteria set out in the Report are entirely arbitrary. Experience indicates that whatever criteria are selected will be subject to expansion. The only viable guarantee that children will be excluded from assisted suicide is to reject its introduction completely. The current proposals for Jersey will allow their future extension to children by regulation rather than by a new law.

This has been the pattern in other jurisdictions. For example, in Canada, on March 17, 2021, Bill C-7 received Royal Assent. This legislation includes a review to consider the eligibility of under-18s ambiguously described as "mature minors" for Medical Assistance in Dying (MAiD). The lobby group Dying with Dignity Canada recommends that: "the informed consent of a competent parent or guardian be required for eligible minors seeking MAiD who are 12 to 15 years of age inclusive, and that MAiD assessors be required to consult a competent parent or guardian for eligible minors aged 16 and 17."

At a meeting of the Canadian House of Commons' Special Joint Committee of Medical Assistance in Dying on 7 October 2022, Dr Louis Roy, of the Quebec College of Physicians, recommended that babies up to one year old

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[253] Regional Euthanasia Review Committees RTE Annual Report 2019 https://english.euthanasiecommissie.nl/the-committees/documents/ publications/annual-reports/2002/annual-reports/annual-reports

[254] *Tijdig praten over het levenseinde Handreiking voor artsen om met patiënten in gesprek te gaan, (Timely talk about the end of life Guide for doctors to patients to talk to)* KNMG, 1 December 2021. https://tijdig-praten-over-het-levenseinde.maglr.com/knmg-tijdig-praten-over-het-levenseinde/tijdig-praten-over-het-levenseinde

[255] "Les collaboratrices et collaborateurs de la Commission spéciale sur l'évolution de la Loi concernant les soins de fin de vie," (Special Commission on the Evolution of the Law on End-of-Life Care) Assemblée Nationale du Québec (National Assembly of Quebec), Décembre 2021

be made eligible for MAiD if they have "severe deformations or very grave and severe syndromes."[256]

Q.7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?

No. Making assisted suicide available free of charge would act as an incentive for those in financial difficulties who would prefer to end their lives simply to avoid incurring medical expenses. This is especially dangerous for vulnerable individuals who fear becoming a burden to their families. Reports indicate that increasing numbers of Canadians with disabilities and chronic conditions are resorting to assisted suicide because of poverty and a lack of social care.[257]

There should be no consideration of legalising assisted suicide while palliative care is not freely available.

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes. The right to conscientiously object to playing a role in the intentional death of a human being is particularly important where the moral and psychological well-being of health professionals is concerned. This is true of ancillary staff, ambulance drivers, etc, as well as doctors and nurses and no one should be required to assist in ending the life of an innocent human being if it violates their conscience.

Paragraph 48 of the Consultation report refers to Greater Glasgow Health Board v Doogan and another (Scotland). It should be noted that this case focused specifically on the statutory rights provided by Section 4 of the Abortion Act 1967. The Supreme Court, while allowing the appeal of the Greater Glasgow Health Board, acknowledged that a state employer still has an obligation to respect the Article 9 rights of their employees stating at [23]:

> "There was some discussion, at an earlier stage in these proceedings, of the relevance of the petitioners' rights under article 9 of the European Convention on Human Rights. This protects the "right to freedom of thought, conscience and religion," including the freedom "to manifest his religion or belief, in worship, teaching, practice and observance". It is our duty, under section 3(1) of the Human Rights Act 1998, to read and give effect to legislation, whenever it was passed, in a way which is compatible with the Convention rights, so far as it is possible to do so. However, the article 9 right is a qualified right, which may be subject to "such limitations as are prescribed by law and necessary in a democratic society in the interests of public safety, for the protection of public order, health or morals, or for the protection of the rights and freedoms of others". Refusing for religious reasons to perform some of the duties of a job is likely (following the decision of the European Court of Human Rights in *Eweida v United Kingdom ((2013) 57 EHRR 8)* to be held to be a manifestation of a religious belief. There would remain difficult questions of whether the restrictions placed by the employers upon the exercise of that right were a proportionate means of pursuing a legitimate aim. The answers would be context specific and would not necessarily point to either a wide or a narrow reading of section 4 of the 1967

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[256] Catherine Lévesque, "Quebec College of Physicians slammed for suggesting MAiD for severely ill newborns," 11 October 2022, (*National Post*, Canada). https://nationalpost.com/news/quebec-college-of-physicians-slammed-for-suggesting-maid-for-severely-ill-newborns

[257] Brennan Leffler and Marianne Dimain, "How poverty, not pain, is driving Canadians with disabilities to consider medically-assisted death", 8 October 2022, (*Global News,* Canada) https://globalnews.ca/news/9176485/poverty-canadians-disabilities-medically-assisted-death/

Act."

Freedom of conscience, in Europe and across the globe, is under continuous attack where the practice of medicine is concerned. Ideological advocates of a right-to-die make freedom of conscience subservient to their ideological demands. The general approach appears to promote a radical understanding of autonomy concerning assisted suicide while seeking to exercise the maximum level of constraint on the autonomy of healthcare workers who conscientiously object to facilitating the death of a fellow human being.

A person's right to conscientiously object to killing innocent human beings is absolute (cf the Nuremberg Trials). To help or facilitate the killing of a human being regardless of his or her consent is cooperation (formal or at least material) in an intrinsically evil act. Conscientious healthcare workers should not be asked to be an accessory to killing the innocent. The fact that this may be the case in other jurisdictions is no reason to make it the case in Jersey.

Everyone in the healthcare profession has an obligation to protect the fundamental human rights of all human beings of which the right to life is the most basic. There is no basis for the provision of a truncated account of the freedom of conscience, particularly when the *raison d'être* for an expression of conscientious objection is based precisely on the wrongfulness of killing the innocent.

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes, the right to conscientiously object to killing innocent human beings is absolute (see the response to Q.8).

In Belgium, hospitals and nursing homes reluctant to practice assisted suicide have been "pilloried and threatened with losing their public funding".[258] In Canada, public funding was withdrawn from several hospices that refused to participate.[259]

Q.10 Do you agree that the assisted dying register should be public?

The intent of the proposal is to authorise doctors to supply lethal drugs to patients for the purpose of committing suicide. Many doctors oppose assisted suicide being part of mainstream healthcare, even if it is legalised.[260] It has not explained why doctors should take on the role of ending life. Since the time of Hippocrates in the fifth century BC, medical ethics have sought to ensure that doctors dedicate their skills completely to life and healing, not to killing and suicide. The 1949 International Code of Medical Ethics states: "A doctor must always bear in mind the obligation of preserving human life."[261] Medicine should be the last profession to be actively involved in helping people to kill themselves. Although making the register public will increase transparency, in jurisdictions where assisted suicide has been legalised, it has damaged the relationship between patients and the medical profession.

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[258] D A Jones, (ed) *Euthanasia and Assisted Suicide: Lessons from Belgium* (CUP, 2017) 40

[259] L Harding 'Delta Hospice Society envisions new private MAiD free facility.' *Western Standard*, 18 July 2021

https://westernstandardonline.com/2021/07/delta-hospice-society-envisions-new-private-maid-free-facility/

[260] Keep Assisted Dying Out of Healthcare, "Assisted Dying and the Role of Mainstream Healthcare" https://kadoh.uk/

[261] *International Code of Medical Ethics* adopted by the Third General Assembly of the World Medical Association London, England, October 1949

Q.11 Do you agree that the nine proposed steps are all necessary?

The purpose of the proposals is to relax the prohibition on doctors ending the lives of their patients. As such no safeguards can be considered capable of preventing abuses since the objective of the nine steps is by their very nature an abuse of medical ethics and human rights. The right to life is the most basic of all human rights. It is innate, universal and inalienable. Like liberty, it is not granted by governments, legislatures or courts of law. If the right to life of any category of person is diminished, regardless of their consent, then the right to life of everyone is undermined.

Changing the law to allow some individuals to be killed at their request puts the lives of vulnerable people at risk of being killed against their will. Mistakes that result in the wrongful death of a patient can never be undone – death is final.

Q.12 Do you think there are any further steps / actions that should be included?

See the response to Q.12, above.

Q.13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Lives Worth Living rejects the premise of this question as it requires an acceptance of assisted suicide to a greater or lesser extent.

Assisted suicide is unethical and dangerous. Once the law has been changed, no process, protocol or timeframe would be capable of providing vulnerable individuals with the level of protection from coercion that currently exists. Speaking in the House of Lords on 22 October 2021, Lord Herbert of South Downs argued that legislating to permit the taking of a patient's life crossed the Rubicon and warned that it would introduce "the idea that a patient's life may be taken, albeit with their consent." He stated:

> "Life, in some circumstances, is no longer to be protected by an inviolate principle, but rather by administrative safeguards and term limits. The fear is not only that those safeguards may prove inadequate, that vulnerable people may be exploited and encouraged to end their lives and that, in reality, choice over death has been given to others, or that the time limits are essentially arbitrary, it is also that the safeguards will steadily be eroded. Once the utilitarian argument has asserted itself, we will move inexorably towards a world where the worth of life is measured and questioned."[262]

Q.14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Lives Worth Living rejects the premise of this question as it requires an acceptance of assisted suicide to a greater or lesser extent. (See the response to Q.13, above.)

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[262] Assisted Dying Bill [HL] Hansard 22 October 2021, https://hansard.parliament.uk/Lords/2021-10-22/debates/11143CAF-BC66-4C60-B782-38B5D9F42810/AssistedDyingBill(HL)#contribution-96AF0981-F4DC-4E44-A668-99AEC0037BAF

Q.15 Do you agree that the law should not prohibit professionals from raising the subject of assisted dying?

No, healthcare professionals should not be permitted to raise the possibility of assisted suicide with their patients or clients. The danger of such a policy can be illustrated by the testimony of Christine Gauthier, a veteran of the Canadian armed forces and former Paralympian. Gauthier, who had suffered permanent damage to her legs and spine while training on an obstacle course, told the Canadian Parliament, Thursday, 1 December 2022, that having sought to have a wheelchair ramp installed at her home for five years, a veteran's association caseworker offered to supply the necessary equipment for her to end her life.

Roger Foley, who was hospitalised with a degenerative brain disorder in London, Ontario, told the Associated Press how healthcare workers would raise the possibility of assisted suicide with him. In one incident, the hospital's director of ethics told him continuing care would cost "north of $1,500 a day." Foley said that he found their repeated approaches to be coercive.[263]

Q.16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes, the right of everyone – regardless of their status or profession – to conscientiously object to killing innocent human beings is absolute. (See the response to Q.8).

Q.17 Do you agree that a person should only be entitled to one second opinion?

Yes. Allowing multiple possibilities for a case to be reconsidered would result in applicants "shopping" for a compliant doctor. Most physicians do not support a change in the law to legalise physician-assisted death, especially those with experience caring for terminally ill patients. Based on the 2019 survey published by the Royal College of Physicians, only 32% of doctors support the legalisation of physician-assisted death, with 43.4% of respondents opposing a change in the law.[264] If this is representative of the medical profession on Jersey, there will be so few doctors willing to participate, would lead to patients "shopping" for a compliant doctor who, inevitably, would be unfamiliar to them. In the decade following legalisation in Oregon (1997-2007), one quarter (62 out of 271) of all lethal prescriptions in Oregon were provided by just three doctors.[265] The 2020 Oregon Death with Dignity report notes that some assisted suicides were approved by doctors who had known the patients in question for less than seven days. Only three out of the 245 who died were referred for psychological or psychiatric evaluation.

Q.18 Should the law allow for confirmation of consent to proceed?

This proposal is a tacit acknowledgement that an assisted death may not be quick or painless. Experts writing in the British Medical Journal point out that: "The safety and efficacy of previous and current oral assisted dying drug combinations is not known" and that reported adverse effects of drug combinations used to induce death "include vomiting, myoclonus [sudden, brief involuntary twitching or jerking of muscles] and a prolonged dying process of up to 47 hours."[266] Dr Joel Zivot, an associate professor of anaesthesiology and

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[263] Maria Cheng "'Disturbing': Experts troubled by Canada's euthanasia laws, 11 August 2022 (*AP News*, New York) https://apnews.com/article/covid-science-health-toronto-7c631558a457188d2bd2b5cfd360a867

[264] https://www.rcplondon.ac.uk/news/no-majority-view-assisted-dying-moves-rcp-position-neutral

[265] Concentration of Oregon's Assisted Suicide Prescriptions & Deaths from a Small Number of Prescribing Physicians by Kenneth R. Stevens, Jr. MD Revised 3/18/2015

[266] "The impact on general practice of prescribing assisted dying drugs", *BJGP Life,* 28 September 2021, https://bjgplife.com/2021/09/28/the-impact-on-general-practice-of-prescribing-assisted-dying-drugs/

surgery and an expert witness writes: "I am quite certain that assisted suicide is not painless or peaceful or dignified. In fact, in the majority of cases, it is a very painful death."[267]

Q.19 Should the law allow for the option of a waiver of final consent?

By definition, advanced consent is not informed consent. Permitting final consent to be waived would not allow for changes of circumstances and therefore a possible change of heart. Such a policy could well facilitate incidents similar to the case of a 74-year-old Dutch woman whose death became the subject of international news in 2017. The woman gave advanced approval for assisted suicide before losing mental capacity due to Alzheimer's. In 2016, the woman's doctor decided to end her life, she was given coffee containing a sedative so that the lethal injection could be administered more easily. When the sedative failed to have the desired effect, the woman struggled to resist the doctor. She was then restrained by family members so the drugs could be injected. Such events should not be allowed to occur in Jersey.

Q.20 Do you agree with the two different approval routes as proposed?

The rationale for both proposed routes is fatally flawed. This was well expressed by the 1994 report of the New York State Task Force On Life and The Law when it stated:

> "The criteria and safeguards that have been proposed for assisted suicide and euthanasia would prove elastic in clinical practice and in law. Policies limiting suicide to the terminally ill, for example, would be inconsistent with the notion that suicide is a compassionate choice for patients who are in pain or suffering. As long as the policies hinge on notions of pain or suffering, they are uncontainable; neither pain nor suffering can be gauged objectively, nor are they subject to the kind of judgments needed to fashion coherent public policy. Euthanasia to cover those who are incapable of consenting would also be a likely, if not inevitable, extension of any policy permitting the practice for those who can consent."[268]

Q.21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

If the States Assembly is genuinely interested in ensuring transparency and the highest levels of ethical oversight, then all decisions should be open to review not merely those relating to Route 2.

Q.22 Do you agree that the Law should provide for appeals to the Royal Court?

Yes.

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[267] Joel Zivor, "Last rights: assisted suicide is neither painless nor dignified", *The Spectator,* 18 September 2021 https://www.spectator.co.uk/article/last-rights-assisted-suicide-is-neither-painless-nor-dignified

[268] *When Death Is Sought*, xv https://www.health.ny.gov/regulations/task_force/reports_publications/when_death_is_sought/preface.htm

Q.23 Do you agree with proposed grounds for appeal?

No, the grounds for appeal should include matters relating to the determination of the diagnosis and prognosis regardless of their consideration during the assessment process.

Q.24 Do you agree with there should be a 48-hour time period between approval and the assisted death to allow for appeals?

The recent ruling by the European Court of Human Rights which was critical of Belgium's assisted suicide laws demonstrates the importance of time and transparency in a process involving the life or death of an individual. Tom Mortier, who took the case to the ECHR only learnt about the death of his mother, Godelieva de Troyer, the day after her life was ended. A case of this kind should never be permitted in Jersey.

Q.26 Do you agree that there should be no expiry date for the approval of an assisted death?

No. A request for assisted suicide may not be as clear and settled as it may appear, therefore, it would be unwise and unsafe to provide approval without an expiry date.

Patients with a terminal condition who desire suicide or euthanasia often suffer from treatable mental health issues, most commonly depression. When these patients receive appropriate treatment, they usually abandon the wish to commit suicide. While suicidal ideation is a risk factor for suicide, many people who experience this never commit or attempt suicide. Such thoughts can be an important and normal component of coping with terminal illness.[269]

Medication for depression and effective pain relief techniques significantly change the outlook of patients who would otherwise seek to end their lives.

Q.27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Since legalised assisted suicide is shielded by doctor-patient confidentiality "in effect, any physician-assisted suicide regulation must, in the end, be physician self-regulated."[270] The presence of an Administering Practitioner may help to reduce the scenario outlined in the response to Q.28, it cannot provide an adequate safeguard for the vulnerable.

Q.28 Do you agree that a loved one should be able to support the person to self-administer the substance?

No. Changing the law to allow some individuals to be killed at their request puts the lives of vulnerable people at risk of being killed against their will. Vulnerable people could easily become the target of undue influence, subtle pressure, coercion and unintentionally be made to feel a burden. It is extremely difficult if not impossible to safeguard against these things. Allowing "loved ones" or any third party to participate in administering lethal drugs would only increase this risk.

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[269] *ibid*.

[270] Daniel Callahan and Margot White, 'The Legalisation of Physician-Assisted Suicide: Creating a Regulatory Potemkin Village' (1996) 30 *Uni Richmond Law Rev,* 1

Q.29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes, death certificates should reflect physician assisted suicide as the cause of death in every incident when that is the case. To do otherwise who be to falsify the record.

Q.30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Creating a body responsible for reporting and collecting data cannot address the potential for abuse. For example, in Oregon, doctors who supply lethal drugs to patients are required to declare this to the Oregon Health Authority (OHA) merely by ticking a series of boxes. There is no case review system to examine how requests for lethal drugs have been handled. As the OHA makes clear on its website, it does not investigate whether people who have been supplied with lethal drugs met the conditions laid down in the law. With such a closed system it is impossible to say that there has been no abuse of the law.[271]

Q.32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service?

It must be recognised that, from a psychological perspective, taking part in assisted suicide can be extremely onerous for physicians and the others involved.[272] There is no evidence that the Jersey Care Commission with be capable of the task required of it.

Q.33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (ie, that the JCC should have the powers to close the service down)

Yes, assisted suicide has no health benefits. It is not a medical procedure and should not be considered as such. Its aims are opposed to the goals of medicine, namely to cure and care but not to harm or kill patients. Unfortunately, the lack of precision in the proposals and the use of standards that cannot be objectively measured – such as "unbearable suffering…that cannot be alleviated 'in a manner that the person deems tolerable'" – means that it is highly unlikely that the Jersey Care Commission would be able to justify the closure of the scheme.

END

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[271] Living and Dying Well, "Truths & Half Truths About Assisted Dying," https://www.dyingwell.co.uk/wp-content/uploads/2021/05/Truths-and-Half-Truths-about-Assisted-Dying-A5-Final.pdf

[272] See: EXIT - "Le Droit De Mourir", https://www.youtube.com/watch?v=7iNYTj_G03k

20. Living and Dying Well

Living and Dying Well Response to Consultation on Jersey Assisted Dying proposals published Oct 2022

In November 2021, the States Assembly of Jersey agreed 'in principle' that a person could be assisted to die either by physician assisted suicide (where lethal drugs are self-administered) or voluntary euthanasia (where lethal drugs are administered by a ‘registered medical practitioner’), subject to safeguards. Following this decision, the States Assembly is seeking the opinions about its assisted dying proposal - the following is our submission to this public consultation.

About Living and Dying Well

Living and Dying well is an independent think tank, established in 2010, to examine issues at the end of life, including assisted suicide and euthanasia. Our patrons and members include experts in the law, the legislative process, medicine, mental health, ethics and other disciplines related to the end-of-life debate. We hold a range of views on all aspects of the debate, but share a common concern that public safety is of paramount importance in this area and that some of the ideas that are being put forward - for example, that doctors should be licensed by law to supply or administer lethal drugs to terminally ill patients - are not compatible with this and would put vulnerable people at serious risk of harm. We recognise that deficits in care exist but have seen no evidence that these will be ameliorated by such legislation. We fully respect the motivations of those who may take a different view but find that the evidence from other legislatures that have gone down this road confirms our conclusion that such legislation jeopardises people at a vulnerable time in their lives and undermines the professional duty of care to patients and their families.

Summary of issues specific to Jersey

Some specific issues in Jersey need to be addressed urgently in Health and Social Care. We suggest it is not appropriate for the State to provide a free death service when other services that would save life or improve the quality-of-life left are not being provided.

There is an acute shortage of manpower. General Practice has a 15% vacancy factor at present; nurse vacancies remain unfilled at all clinical grades – especially band 6 and 7- and in care homes and in the hospice; there is an acute shortage of allied health professionals with many occupational therapists resigning posts in the past two years; there are shortages in social care for patients in their own homes with no fast track to financial social services support to allow them to be cared for at home.

There is no mandatory mental capacity training for health and social care staff, yet assessment of mental capacity is a core requirement in the proposed system.

There is no ability to provide single shot radiotherapy on the island, yet for those with bone metastases such an intervention can result in dramatic improvement – consideration should be given to such a development in the new hospital construction. The new hospital, able to provide a wider range of modern medical interventions, is long overdue.

Specialist palliative care is provided in the hospice, but currently there are beds closed (only six are open at the time of writing this document) due to staff shortages. Specialist home care provision has fallen as there are now only two nurses in the team and input to the hospital has been scaled back. Modern palliative care requires adequate staffing to work through outreach into community, secondary and tertiary care including into Intensive Care. The team in Jersey is short-staffed, impeding the ability of specialist palliative care to work in conjunction with acute and longer-term treatment services. Input is therefore restricted when people are in the last phase of illness, which inevitably means opportunities for earlier improvement in quality of life are missed. Palliative care services should be equitably provided over the week (7 day working) with a dedicated helpline number 24/7 for any staff at any grades seeking expert advice on a patient. Ideally relatives should have a single point of contact if concerned as disease does not respect the clock nor the calendar. A standard should be set that referrals are seen within 48 hours with urgent referral seen faster.

The bereavement service is provided by the hospice and depends on voluntary donations, yet the proposal is for state-funded bereavement support for the relatives of those who have had assisted dying. This is inequitable across the population; in particular, this ignores the needs of children bereaved through other causes.

The recent report by Professor Hugo Mascie-Taylor (Review of Health and Community Services (HCS) Clinical Governance Arrangements within Secondary Care report) made 61 important recommendations that must be urgently addressed. The issues in governance highlighted it the report raise questions as to how current structures would have the capacity to oversee a Jersey Assisted Dying Service without serious jeopardy to oversight of services whose mission is to save life and improve quality of life. Inspection of services currently is restricted to hospital services, but the main governance risks will be in community services and mental health, neither of which are currently subject to independent inspection.

Executive Summary

This document outlines Living and Dying Well's response to the proposals laid out in the Consultation Report released in October 2022. Addressing each aspect outlined in the report, this paper highlights the serious dangers of the assisted dying proposals. The wide qualifying conditions, the vague descriptions of assessments, the lack of real-time recording, monitoring, training and key safeguards as proposed do not give confidence that an assisted dying system in Jersey would protect the best interests of vulnerable people and society at large.

This consultation response will go through each element of the proposals in sequence, covering the end-of section questions asked in the consultation document.

Importantly, several peer reviewed papers and official reports from jurisdictions that permit physician assisted suicide and/or euthanasia have been published in the last year. This evidence was not available to the Deputies at the time of debate, nor to the citizens jury. References to some of these publications are provided in this submission.

Principles

The document states that the States Assembly should not introduce an assisted dying law until they are satisfied that all Islanders can access good palliative and end-of-life services. There is no elucidation, however, on what would constitute "satisfaction". In addition, it does not define what level of palliative care would be satisfactory: **it does not specify whether islanders simply have access to or are experiencing good palliative care, and indeed whether that palliative care is general or specialist, nor whether it is rapidly responsive and integrated with other services**. The States Assembly should act on their recent review of specialist palliative services to ensure that all those who need it are receiving it before any change in the law on assisted suicide. The proposals quote Canada as a place where 82.8% of people who are requesting an assisted death are receiving palliative care. This is highlighted to suggest the synergy between the two. In Canada, however, evidence shows that only 60% of MAiD patients see a **specialist** palliative care team, and many of them (854 in 2020) who receive palliative care receive it after having requested MAiD, preventing the conclusion that people request assisted death *despite* good care.[273] [274] A recent publication from Canada also reveals that many requests originate through loneliness and/or poverty rather than medical needs perceived as refractory or which are unavailable to that person [275].

It is important that, unless the law changes the definition of suicide, assisted dying is seen as assisted suicide or euthanasia (depending on the method of lethal drug ingestion). Legally, suicide is the taking of one's own life, with or without the help of any other. Regardless of the context or intention of 'assisted dying', it is important that the language remains legally accurate. In assisted suicide the patient ingests by selfadministration (usually orally) large number of tablets (up to 200), either crushed or dissolved in a large tumbler of liquid; an alternative of a nitrogen gas 'pod' has been suggested in which the patient is sealed and

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[273] Munro C., Romanova A., Webber C., et al. Involvement of palliative care in patients requesting medical assistance in dying, *Canadian Family Physician*, vol 66 (Nov 2020); 48

[274] Gallagher R. Lack of palliative care is a failure in too many MAiD requests, *Policy Options Politiques*, October 19, 2020

[275] Wiebe E, Kelly M, Spiegel L et al Are unmet needs driving requests for Medical Assistance in Dying (MAiD)? A qualitative study of Canadian MAiD providers. Death Studies 2022 https://doi.org/10.1080/07481187.2022.2042754

dies of anoxia. In euthanasia, the clinician injects into a vein a large dose of short acting anaesthetic agent, often with or followed by rocuronium or similar to paralyse the patient who then dies of asphyxia.

Eligibility criteria

Prognosis: The proposals state (paragraph 16) that those with terminal illnesses which are "expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable" and which are expected to bring death within 6 months would be eligible for an assisted death. A prognosis of six months life expectancy is notoriously inaccurate and a probabilistic art.[276] [277] [6] Experience from the Liverpool Care Pathway found that the tools are not sensitive enough to identify reliably those who will die within hours or days.[278]

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill chaired by Lord Mackay of Clashfern heard:

- **"It is possible to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years"** – Royal College of General Practitioners

- "Prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor"- Professor John Saunders, Royal College of Physicians

A suggestion of a six-month prognosis in legislation will inevitably result in many people ending their lives very early in the mistaken belief that death is far closer than it is. A guestimate of prognosis is not a safeguard, there is no test for prognosis that can be verified. Canada has removed their "reasonably foreseeable" death criterion because of the vague nature of prognostication.

Of additional concern is the qualification of the "expectation of suffering". How is it possible to determine whether suffering can or cannot be alleviated if a decision for an assisted death has been made not based on current suffering, but the possibility of future suffering? Such expectations arise from fear or from previous experiences of witnessing failures in care in the past.

The expectation of suffering is as unpredictable as the time-prognosis of a terminal illness. **If the notion of "unbearable suffering" is self-determined by the person, then any degree of expectation of suffering cannot be judged merely by a clinician or other health professional, as suffering is not inherently linked to a condition but to an individual's subjective experience of a given condition, influenced by many social, psychological, emotional, and existential factors including the attitude of those providing care**.

Importantly, the alleviation of physical pain and suffering rests on the diagnosis of the underlying cause of the distress and appropriate administration of medicine and good care.

Paragraph 18 implies that a potentially terminal condition that would with treatment not lead to imminent death, qualifies for assisted suicide. This provision opens a grey area in the law where someone with an incurable physical condition could request assisted suicide on the basis that undergoing treatment that would delay death would cause unbearable suffering. For example, someone with complications of poorly controlled diabetes could decline to continue to use insulin, thereby becoming eligible for assisted suicide.

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[276] Hoesseini A et al. Physicians' clinical prediction of survival in head and neck cancer patients in the palliative phase. *BMC Palliative Care,* 2020; 19: 176-85. https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-020-00682-2;;

[277] Warriach HJ et al. Accuracy of physician prognosis in heart failure and lung cancer: comparison between physician estimates and model predicted survival. *Palliative Medicine*, 2016; 30(7): 684-9. https://journals.sagepub.com/doi/abs/10.1177/0269216315626048 [6] *House of Lords Report* 86-II (Session 2004-05), p730. https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm

[278] More Care, Less Pathway (publishing.service.gov.uk), 2013

Evidence from overseas shows that pain is infrequently a significant factor in requests for assisted suicide.[279] If pain does feature, it is usually the fear of pain, rather than unmanaged, painful symptoms experienced. The criteria proposed are heavily based on the potential for suffering - which, as above, is hard to define – even though the feared suffering might never be experienced and may be easily ameliorated.

Finally, given the proven link between physical and mental health, proposals which, in their current format, only apply to people with physical medical conditions could be deemed to discriminate against those with mental conditions. The interplay between mental states and physical experience means that those with mental conditions may present with physical symptoms. This "physical cause" criterion does not ensure that those with suicidal ideation from reversible mental illness will be prevented from being provided with lethal drugs.

Countries with laws which allow for non-terminal illness to qualify have seen a drastic increase in the number of assisted suicides.[280][281] The proposals risk leading to a marked shortening of life, particularly among those who feel or fear being a burden or are coerced to request an assisted death.

Assisted Dying Service

If the assisted dying service in Jersey is to be free (para 30) and therefore state funded, it should only come into force when all specialist palliative care is fully state funded for all who need it. No provision of medically assisted death should be prioritised in the public finances above the provision of care for those whose quality of life can be improved.

The Jersey Assisted Dying Service (para 29) will be delivered and managed by the Health and Community Services Department, but this risks the accusation that cost saving becomes a motive or that the hospital or hospice is a 'death house'. To avoid this the Jersey Assisted Dying Service should be completely outside the health care system for all its activities, with premises away from the hospital. Such premises could provide a place where the person takes lethal drugs (similar to Dignitas) and any bereavement service should be located in such premises, not in the Jersey Hospice. In Canada some funeral homes offer dedicated rooms for medically assisted deaths[10].

Any future private assisted suicide companies (para 33) might be able to make their own rules around provision, conscientious objection, eligibility, and reporting. Any such future initiative must be strictly regulated.

In considering staffing, where there are conflicts of interests of workforce distribution, services involved in care must be prioritised over assisted death. Staffing needs in care settings must be prioritised over assisted dying, given the duty of care on doctors to preserve and improve life.

There are important implications for the inter-disciplinary team involved with the ill person. Given the gravity of a request, any professional involved in the care or assessment of a person who has requested an assisted death should be aware of the assisted death request (para 44). This is to inform good conversations around care and ensure that **information relevant to the application** for 'assisted death' is available. It would provide clarity between professional clinical and social support teams and make sure that care to the person in clinical and social settings was adjusted correctly. Without knowledge of an assisted death request, those involved in a person's care would be ill equipped to support and provide appropriate care to that person and to other patients.

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[279] The Oregon Health Authority reports on the Dignity with Dying Act show pain as a less important factor than others.

[280] Euthanasia, Assisted Suicide, and Suicide Rates in Europe, Journal of Ethics in Mental Health, Vol 11 (2022)

[281] https://www.cbc.ca/news/canada/london/funeral-homes-pivot-to-offer-rooms-for-medically-assisted-deaths-1.6224353

Conscientious objection

An individual doctor or management board of the hospice, hospital, clinic, care home, or other facility where the person has made a written declaration to self-administer lethal drugs must also be under no obligation to participate in any part of the process.

It is important that any conscience clause in Jersey extends to organisations and not just individuals. An organisation must have the right to declare openly that it refuses to have assisted suicide or euthanasia conducted on its premises without jeopardising its funding; it is notable that in Canada hospice-closure has been reported because no provision for a conscience clause for organisations was put in place.[282]

Additionally, the law should state clearly that no recognised health body or organisation which operates in the field of health or social care can consider a doctor's refusal to participate in procedures around assisted suicide when making any determination about the employment, promotion, appointment, or career of that doctor. Under para 55, due consideration should be given to conscientious objection in cases where guidance is not complied with.

If an establishment receives funding from the public sector, legislation must stipulate that the public sector body funding cannot be withdrawn on the grounds that an organisation has a conscientious objection.

A conscience clause must also make provisions for staff at every grade. This should include judges and legal professionals, not just medical and paramedical practitioners, to abstain from any part of the practice of assisted dying. In the same way that medical professionals might have ethical or conscience objections to participating in assisted suicide, those involved in the legal process of approving and judging on individual cases should be afforded the same conscience rights. Consultations with the legal profession should be made in advance of any introduction of the proposed law as there may be significant concerns relating to the consciences of individual legal professionals.

The proposals state that a conscientious objector must inform the person of their conscientious objection. However, if the patient doesn't need to say they are requesting/have requested an assisted death this would not be possible: in such a situation, a care professional who otherwise may have conscientiously objected may unknowingly participate indirectly in facilitating a persons assisted death (e.g., conducting assessments (para 50 a.) that are used as supporting statements, delivering equipment or medical supplies).

Moreover, **if those who are opposed to participating in an assisted death on conscience grounds are obliged to declare their position, then equal rights suggest that those who are willing to participate also declare.**

Those engaged in Jersey Assisted Dying Service must all opt-in (para 56), and processes must protect against doctor-shopping.

Requirement that the lethal drugs are taken/administered in the patient's own home or dedicated Jersey Assisted Dying Service location would protect staff and other patients and allow relatives as much time as they wish with the person pre-death and the body after death. If they are a care home resident, the option of death outside the care home must be available to protect staff and other residents.

Support systems

The proposals would change the nature of bereavement support (para 71) – there should be no diversion of provision away from families and loved ones in non-assisted death cases, particularly after sudden or

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[282] Bouthillier M-E, Opatrny L. A qualitative study of physician's conscientious objections to medical aid in dying. *Palliative Medicine*, 2019; 33(9): 1212-20. https://journals.sagepub.com/doi/abs/10.1177/0269216319861921

otherwise unexpected deaths. The Jersey Assisted Dying Service should instigate their own bereavement support service to safeguard services for those not involved in such cases.

Para 64 requires the doctor to only have been fully registered for 12 months. These doctors will be very junior and while they may fulfil the competency framework of a limited training programme, their broader experience of clinical practice, disease progression, human relationships and family dynamics will be far too immature to ensure they can take on the roles envisaged. Clinicians should be at least 10 years postregistration. It will be important that a clinician with **expertise in the specific condition** has seen the person requesting assisted death as there may be reversible conditions that have been missed, misinformation about the probable course of disease and support that the generalist doctor is not aware of.

All practitioners in Jersey Assisted Dying Service should be subject to supervision for their mental wellbeing. The service should not be remunerated in such a way that it attracts doctors away from other clinical areas and thereby jeopardises the health care of other patients.

Assessment processes

There are major deficits in the proposals over the assessment process. It is essential that it is audited from real-time recording of the consultation. This can be undertaken using a body worn camera as worn by police, ambulance personnel and some emergency medicine staff in resuscitation procedures. The widespread use by the police and ambulance personnel has shown that confidentiality is not jeopardised. Such systems protect all parties from subsequent allegations and would allow the quality of the consultation to be audited to ensure that the assessor did not provide leading questions or fail to pick up important nonverbal cues. Specific steps must be laid out through which the diagnosis is verified, mental capacity is assessed by someone appropriately trained, all reversible causes of suffering have been identified and options discussed with the person, and that processes are in place to detect coercion.

Hourglass' survey in 2022 identified that 1 in 5 people over the age of 65 years have been affected by abuse, that most (37%) is financial abuse, 33% is psychological (often coercive control), and 21% is neglect. 83% of abuse occurs in the person's own home – doctors are very poor at detecting these main types of abuse. In part this is because they cannot normally ask questions about financial and other affairs, but also because the victim is usually very reluctant to disclose that their own child or grandchild is perpetrating abuse.

Assisted dying process

The short **cooling off period of 14 days (74) fails to recognise the fluctuating nature of a wish for death over weeks and even years,** as many people say they are glad they are still alive when supported out of those times of despair and when they realise they are still of value and of worth despite being ill.

Indeed, in many illnesses, some symptoms or the effects of progressive disease can take more than a fortnight to resolve. **The proposed reflection period would prevent a person from reassessing their wish to die when symptoms had settled**. In the context of someone who has been alive for at least 18 years, and given the gravity of an assisted death request, 14 days is a drastically insufficient time-frame for reflection.

Furthermore, no assessment or interaction with doctors pertaining to the assisted dying process should take place during the period of reflection. **The current proposals do not allow for true, sufficient, independent reflection**, given the ongoing assessments that would be taking place in the 14 days.

Paragraph 76a suggests that 14 days would not "unduly extend suffering". Not giving assisted suicide is not the same as prolonging suffering. Describing it as such gives the impression that a doctor is harming a patient by "forcing" them to live and would give undue pressure to complete an assisted death as soon as the 14-day period is over, rather than give as much reflection time is necessary. During the 14 days al measures should be focused on ensuring comfort and dignity.

If a person is about to die anyway, what benefit is brought on by taking away their life? Moreover, if they lose decision making capacity to consent, that means they also lose decision making capacity to withdraw consent, so reducing the reflection period opens the door to coercion and non-consensual deaths.

The proposals mention that Canada doesn't have a reflection period, with the rationale that by the time a person has made a request they have already decided on their wish to die. There is no evidence provided for that statement. Those who have given careful consideration will have registered in advance with Jersey Assisted Dying Service. **A desire for death usually fluctuates and can be dependent on the care received[283]**. No assumptions should be made at all about a person's request. Timeframes add a layer of safety to allow due consideration of the major decision to end life prematurely and allow for a therapeutic response to a therapeutic intervention.

Paragraph 77 states that simple regulation in the future can be made for the timeline to be reduced. This is an explicit proposal that will open the door for reductions and eventual removal of reflection periods. This should be removed from the proposals and only primary legislation, not regulations, should be able to shorten timeframes.

Information and referral

The imbalance between patient and doctor (84) means that the line between encouragement to suicide and an open discussion about options is entirely blurred and cannot be safeguarded against.[284] In the doctor patient relationship, there is an inherent hierarchy and advice about a course treatment is often requested by the patient. **A doctor raising assisted dying as a "treatment option" is perceived as suggesting that the patient should consider ending their life, with a subliminal message that what lies ahead is so terrible that the patient would be better off dead. Assisted dying should be entirely separate from healthcare to protect the doctor-patient relationship, leaving the patient the free choice to seek Jersey Assisted Dying Service, and removing the risk of subliminal coercion by the doctor.**

Guidance on having conversations (para 85) will not stop coercion. Licensing professionals to suggest assisted dying opens the doors to coercion. There is no safeguarding of the context in which a doctor might suggest assisted dying, for example in cases of despair or to cover up clinical error.

The suggestion that Jersey should follow the Canadian model is inherently dangerous (para 86). Doctors should not be allowed to initiate discussion of assisted death, as it results in a rapid increase in premature deaths, often for reasons of chronic illness aggravated by social isolation or financial hardship.[285] The problem of language as a barrier to Jersey Assisted Dying Service information will require all literature to be bilingual in English and Portuguese with the option of Jersey Assisted Dying Service provided translators when the person initiates contact with the service. The service should take place outside the remit of "health and social care".

Care navigator

Paragraph 88 inadequately sets out what information will be given to a person – it should not just include the principle of ending life, but the processes, potential complications, and the details of what the assessments will involve.

There are no care navigators routinely provided for other situations in health and social care, although in some cases a professional may advocate for them to receive the support, treatment or intervention they require.

However, the proposed care navigator will be coercive by steering a person through the system. It does not allow the person freedom to exercise their autonomous choice. Dignitas is a service outside Swiss healthcare and those who are determined to end their life approach Dignitas. The States of Jersey should not provide persons to steer its citizens towards an early death.

First request

It is not clarified in the proposals (para 91) how an electronic request is verified. What classifies as a clear and unambiguous gesture of confirmation? Mental incapacity is often commensurate with lack of communication. For this reason, all requests must be verbal (independently witnessed) or written.

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[283] Downman TH Hope and hopelessness: theory and reality. J R Soc Med 2008: 101: 428–430. DOI 10.1258/jrsm.2008.080193

[284] Shastri A et al Recognition and treatment of depression in older adults admitted to acute hospital in England. *Clinical Medicine* 2019; 19(2): 114-8. https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6454375/

[285] Alexander Raikin. No Other Options. Winter Essay 2023 New Atlantis. On line 16 December 2022. https://www.thenewatlantis.com/publications/no-other-options

Paragraph 96 says that a person may discontinue the process, but does not state what help a person is given to change their minds? **The doctor is not simply a tool to be used to advance the patient's medical wishes, but a health advisor who has expertise to offer in the course of the person's best interests** – they are not morally neutral, and thus must be able to offer advice throughout the course of the process about alternatives.[286]

First assessment

The proposals suggest that the first assessment should be an opportunity to explore the fears and anxieties leading to an assisted death request (100a). It is imperative that the person is required to inform those providing professional care to ensure conversations are had and that proactive action can be taken to mitigate any fears or anxieties which may *lead* to progressing an assisted death request. Jersey Assisted Dying Service must also be required to explore fears as soon as a person makes contact.

Indeed, all care, information about support and other services should be received as a pre-requisite to an assisted dying request. A person should not have to request an assisted death before those assessments of the adequacy of care provisions are made. In this way, carers and other health professionals should be informed of an assisted death request (102c) (as mentioned above): how can those who request assisted death because of failings in care change their mind or withdraw consent if the professionals involved in their care are unaware of a request, or indeed the inadequacy of the services they provide?

The proposals outline that a doctor must not speak to family or other carers without the consent of the person. **In order to sufficiently assess the person's eligibility for assisted death, it is paramount that the assessing doctor is able to talk to people close to the person to gain further understanding**.

The proposals (105b, 107) state that the person must consent to the assessing doctor seeking opinions from specialists in order to complete assessments. Given this provision is made for the situations in which a doctor cannot make an assessment without such specialist opinion, if a patient does not consent, the process must stop. The proposals do not make this clear, but **a person should not be allowed to continue in the assisted dying process if determinations of eligibility cannot be made**, especially when consent is not given for specialist assessment in the cases of doubt.

Given assisted suicide involves the intentional ending of one's own life, there is likely to be a high component of suicidal ideation. Indeed, intolerable suffering, as a largely psycho-social phenomenon, cannot be assessed reliably on the basis of physical symptoms by an individual unqualified to examine mental health.[287] It follows, therefore, that **considerations of mental health and capacity should be assessed by a specialist such as a psychiatrist**, psychologist or other qualified mental health professional.

The proposals state that such experts should only be consulted in the cases of doubt, but given the integration between mental health, suicidal ideation and assisted dying requests, psychiatric assessments undertaken by mental health professionals should occur in every request.

The report written after the first request (para 110) should contain every detail of the assessment – status of care, provision of care, duration of care, ongoing plan, reasons for request, capacity assessment.

Paragraph 115 entitles a person to second opinion in the case where the first assessment has deemed the person ineligible. Given there has been an appeal, and a second opinion is being sought, **the second opinion assessment must be more rigorous**, given the issues that have arisen from an appeal about eligibility. In addition, the second assessment must take into account any appeals that were made on the basis that eligibility was not originally confirmed.

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[286] Rutherford J et al. What would the doctor prescribe: physician experiences of providing voluntary assisted dying in Australia. *Omega- Journal of Death and Dying*, 2021; July 20. https://journals.sagepub.com/doi/10.1177/00302228211033109

[287] Select Committee on Mental Capacity Act 2005- Report of session 2013-14. https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm

Regardless of whether a person is eligible or ineligible, the right care and support should be made available to them throughout the course of their illness.

Withdrawal

For every opportunity for consent given to the patient, the offer of withdrawal must also be offered. As currently laid out, the proposals state only that the patient must give consent to move forward, but doesn't provide explicit opportunity for withdrawal. Such provision is necessary to prevent coercion by the doctor.

In the event of withdrawal (para 138), reasons for withdrawal must be noted for monitoring and reporting processes. If there is another request following a withdrawal (para 140), due consideration must be given to the fact there was a withdrawal and its reason.

Consent to proceed

The provision of consent to proceed is deeply problematic (para 142). A doctor is supposed to uphold best interests – they cannot do this whilst euthanising a person who might have otherwise lived and has no capacity to respond or withdraw consent. What is a best interest when someone is supposed to be dying but isn't dying – to keep them alive or to actively bring about their death?

Under paragraph 144 - it is unclear what provision is put in place if there is no consent to proceed with ending the patient's life, but there are complications? Should the person be managed in a life-saving way (clear the airway of vomit etc) when the aim is death?

The proposals under the "consent to proceed" section demonstrate that any assisted dying process should not be undertaken by doctors, given the contradictions between upholding best interest decisions and procuring and administering death.

Waiver of final consent

It is good that advanced decisions are not included in the proposals. The waiver of final consent, however, is problematic (para 148). The waiver of final consent still gives rise to the problems that arise from an advanced decision: **how can a determination be made that a person has not changed their mind about an assisted death if there is a period of time between a waiver of final consent and the assisted death taking place**. No assumption should be made that a person might not want to change their mind, regardless of how short the period of time in between a request and death.

Part of the process outlined in the consultation document is the emphasis on consent to move forward with the next step of the process, and that the process is entirely in the patient's hand. This is inherently undermined if provision is made for consent to no longer be necessary in the cases of persons who do not have capacity to give (and therefore, not give) final consent to an assisted death. It would enable serious cases of abuse and deep uncertainty in the reporting of assisted deaths.

Including this provision could lead to coercion, and would cover over any abuses. Consent to proceed should always be affirmed. Any action other than actively signalled agreement to proceed to death should be taken to indicate doubt and the process deferred or revisited at a later time. it is not safe enough to leave the extent of 'objection' to the judgement of onlookers. **Assumptions of consent, especially when it comes to the ending of life, must not be made.**

Paragraph 151c could lead to pressure to waive final consent; persons being told they are at risk of not being able to consent to assisted death, so they must do it before it is too late. This would make it very hard to judge if a person was pressured or coerced into assisted suicide based on of a medical prognosis that may be inaccurate.

Decisions relating to the withdrawal of treatment should not be made by doctors in the assisted dying service, but by palliative and other attending doctors in normal healthcare settings. Conflating treatment refusal with the assisted dying process would confuse the aims and understanding of end-of-life care in the public eye, and undermine the confidence of those not wishing an assisted suicide.

Supporting opinions

It is concerning that the proposals do not require an expert in the person's condition to be consulted for Route 1 patients. **How can proper assessments be made of a condition in which an assessing doctor is not an expert**? Indeed, what assurances are there that an assessment, not undertaken by an expert, which deems a person eligible, has been made with full appreciation of the specificities of the given disease and how they may affect capacity and prognosis?

At least one assessing doctor should be a specialist in the condition, given that eligibility is connected to prognosis, and prognosis is dependent upon specialist knowledge about a disease.

Whilst anyone providing a supporting assessment may not be required to have undergone assisted dying training (159), it should be paramount that they understand the reason for which they are giving an opinion, which should impact their assessment accordingly.

If no determination can be made, and the person does not consent to a further opinion, then the request should be treated as ineligible. Given the gravity of the choice, the assumption should be ineligibility, not eligibility.

To prevent abuses, any law should state that a coordinating doctor should not be allowed to judge a person eligible if any opinions he or she has received indicate that the person is ineligible (para 164). Indeed, any disputes in medical opinion should be settled by an independent judge in a court or tribunal having examined the evidence. The current proposal allows a coordinating doctor to forego the advice offered by experts, which would allow abuses to occur and go unreported.

Second formal request – written declaration

The ability to review and revise wishes in the case of a person who retains decision making capacity (para 186) discriminates against those who might want to review wishes but appear to have lost some capacity, whether or not they have signed a waiver of final consent. This is why assisted dying is problematic and opens a path to abuse, coercion, and involuntary euthanasia.

Approval process

Concerns were raised with any court's involvement placing an unnecessary burden on the person requesting an assisted death and resulting in an unnecessary cost. However, something is only unnecessary if carrying it out has no valid benefit. **The courts can consider personal and social factors in an individual's life beyond that which is recorded in the clinician record** (and beyond those which doctors have access to) and are able to ensure that individuals do not fall victim to abuses of the system. This means the court can balance the rights of some against the protection of others. There is great benefit to society in having the court protect in this sphere and in this way. The majority of Citizen's Jury members (77%) recommended involvement of a Court or Tribunal (para 188); this should not be ignored, especially not for the reason of keeping up with other jurisdictions as quoted.

Decision making

Objectivity and subjectivity

Any assessment of 'time remaining' cannot be exact, as the consultation acknowledges. This is true in both R1 and R2 situations. By separating the two it is all too easy to presume it is complicated in the latter and easy in the former. Since it is often a terminal diagnosis which is the trigger for an assisted death, the need to consider the prognosis as accurately and as carefully as possible is significant. Either consciously or unconsciously, a doctor may feel pressured to alter their prognosis to qualify the individual for an assisted death. The participation of a court or tribunal provides protection against this and should be encouraged when it is matters of life and death at play. This rationale is provided by the consultation when it comes to R2 cases, but remains the same in R1 cases. As in R2 cases, there is no remedy for a faulty assessment in R1 cases unless the court is involved and can provide such a remedy.

To provide these much-needed safeguards the court needs to go beyond merely reviewing the doctor's confirmation. The court's assessment is otherwise already influenced by the doctor's bias. Instead, they need to approve or disapprove the assisted dying requests themselves, by objectively reviewing the same evidence that has been put in front of the doctor. This points to the quality of the evidence put before the court being significant in the quality of a judgement, and therefore also safeguard, they are able to provide. For this reason, the relevant information should include oral statements from doctors, other health and social care professionals family and friends from the start and not just if the tribunal is not satisfied with the information initially provided. The medical member of the tribunal should not just have relevant experience but be an expert within the field. The person requesting the death must be heard and the process should end if they don't give consent to the court to make the determination. Only if all these elements are realised can potential abuses of the system be spotted.

This safeguard provided by the court is even more significant given that under the current proposal the law will not provide a fixed framework to understand suffering through. Although suffering is subjective and does depend on a number of factors, the law is not easily swayed by this. It has defined 'harm', an equally subjective subject, as it has 'loss'. The law is not intimidated by the difficulties and complexities of human emotion but provides a much needed and clear overlay so that they can be properly assessed for legal purposes. Without this, eligibility for assisted dying will struggle to provide consistency and fairness and be influenced instead by subliminal biases of a doctor in an individual case.

With any framework created to define suffering, a fear of disease progression and deterioration should not move an individual closer to an assisted death. Instead, it should prompt conversations about care and the support available. It would otherwise be a capitulation and abandonment of the principles of care and care provision to allow the fear of pain to qualify someone for death.

Appeals

Given that in medical disputes, private citizens and medical professionals (under the auspices of healthcare organisations) may initiate legal proceedings and appeal medical decisions made by doctors, it should follow that appeals may be made on the grounds of prognoses given by doctors, and the level of care that is or isn't being provided to a person requesting an assisted death. These grounds should be included, as well as those outlined in paragraph 244a and 244b.

With regards to the expiry of approval, whilst there may be risk that an expiry date may induce some pressure to end their life, it would provide an opportunity for a person to think carefully about whether or not to go ahead with an assisted death. **Moreover, if the eligibility criteria are based around unbearable suffering, an approval that is not acted upon throws doubt upon the "unbearableness" of the suffering**. Indeed, suffering that is unbearable should not be remediable by the palliation of approval (as described in 255c). Fear of suffering should not be seen as unbearable and certainly should not form the basis of a law. **The option to have an assisted death should not be given as a medicine - comprehensive, accessible, specialist palliative care should fulfil that function**.

Finally, if approval is given on the basis of a time-specified prognosis (less than 6 months), then a person who outlives the prognosis which contributed to the approval in the first place should have that approval nulled and voided, and be subject to reassessment if they wish. A person requesting an assisted death, for example, told they will die within 6 months, and remaining alive several months later should not be able to undergo an assisted death under the same approval. Approval should be made on the basis of a prognosis given at the time of the assessment, that, once outlasted, should give rise to reassessment.

An expiry date on approvals should, therefore, be put in place to protect against unnecessary deaths and deaths occurring from redundant assessments.

Planning and Preparation

Hospitals have always been, and should remain, places of healing and restoration. Allowing them to become possible places for an assisted death undermines and contradicts their purpose. **A lack of distinction between places of treatment and places of deliberately ending life would undermine confidence in the hospital system both by the individual patient (when they witness assisted suicides on their ward) and by the population in general.**

The possibility of failure to die in an assisted death (para 276) must be addressed. There is no need for a health care professional to be present when the lethal drugs at ingested. The desired outcome is death, but supposing the patient vomits and starts choking or when fitting occurs? In such situations the healthcare professional is expected to clear the airway etc, but in this situation this would resuscitate the patient. In the context of assisted dying the normal “care” that a doctor might show by managing a patient whose assisted death may be going wrong could be considered as harm and contrary to the patient’s wishes, with the doctor deemed to have failed to “care” for the patient. In Oregon nine patients have reawakened after taking lethal drugs, but did not proceed to a second attempt at assisted suicide. If a fatal injection had been administered as they awakened, that would have been contrary to their wishes following their first attempt, **In this scenario, the line between that which constitutes harm and that which constitutes help becomes very complex, and demonstrates again that assisted dying should not take place in healthcare, as it contradicts and manipulates the medical profession’s duty of care.**

Assisted dying substance

While much is made in the consultation about the holding of substances securely, which is to be supported, little is made of which substances are to be used. **In other jurisdictions, the lethal drugs used have never been subject to proper scientific scrutiny**.[288] [289] [19] Previously, large doses of barbiturate were used, but a shortage of supply and escalating prices have meant different drug combinations are now being tried to induce sedation with toxic levels, precipitating a heart arrhythmia and death by asphyxia. In Oregon, a mixture of four different classes of drug have been used over the last seven years, but have resulted in longer median times to death.[290]

In the Oregon reports, information on complications is only reported when a physician or other health professional is present at the time of death. These reports, from 42% of Oregon’s assisted deaths, record a complication rate of 6.3% over 23 years, with a complication rate of 8% in 2021.[291] This rate suggests a different picture to the ‘idealised death’ portrayed by those campaigning for such legislation.

The suggestion of pharmacy training is positive, although guidelines for this training need to be published in advance so they can be scrutinised and strengthened by a range of stakeholders. There is currently no indication that this will be the case. Avoiding drug error by the wrong patient being given lethal drugs will be decreased if the drugs can only be supplied to a patient in their own home.

End of Life

The proposals state (para 290) that if the person “demonstrates a refusal or resistance to the administration of the substance by words, sounds or gestures” the process will end, regardless of whether there is a waiver of final consent. It also says that reflexes and involuntary movements would not constitute refusal.

This gives rise to several problems. Firstly, resistance may indicate grief, pain or fear, despite the presence of consent. Wincing or struggling in pain may not constitute a withdrawal of consent (particularly if someone has requested assisted dying ***because*** of their pain). Thus, resistance may be hard to distinguish. Secondly, given that in other circumstances (such as initially requesting assisted dying) gestures would constitute

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[288] Smets T et al. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis or reported and unreported cases. BMJ, 2010; 341: c5174. https://www.bmj.com/content/341/bmj.c5174.short;

[289] Raus K et al.. Euthanasia in Belgium: shortcomings of the law and its application and of the monitoring of practice. Journal of Medicine and Philosophy 2021; 46: 80-107. https://academic.oup.com/jmp/article-abstract/46/1/80/6118631; [19] Kotalik J. Medical assistance in dying: challenges of monitoring the Canadian program. Canadian Journal of Bioethics, 2020; 3(3): 202-9; https://www.erudit.org/en/journals/bioethics/1900-v1-n1-bioethics05693/1073799ar/abstract/

[290] Worthington A, Finlay I, Regnard C. Efficacy and safety of drugs used for ‘assisted dying’. *British Medical Bulletin*, 2022, 1–8 https://doi.org/10.1093/bmb/ldac009

[291] Oregon Death with Dignity Act, 2021 Data Summary

approval/consent (para 91), it seems inconsistent that certain gestures as laid out in para 290 should be disregarded or assumed to be reflexes.

This raises the issue that gestures are hard to interpret, particularly in the case where someone cannot verbally communicate or has lost decision making capacity. Gestures which signify refusal should be acted on – but identifying the line between involuntary movements, movements which signify pain but in keeping with consent (like wincing under a voluntarily-taken cold shower) and actual movements communicating refusal are blurred. In cases of assisted dying, these determinations cannot be mistaken.

The proposals state that the administering practitioner does not have to be in the same room as the person while they take the substance (294b). This would lead to grave oversights and gaps in the data collected in reporting. **The practitioner should be in the same room to monitor the process, the person and any complications.**

Finally, it is a dangerous assumption to state that supporting self-administration would be an "extension of care" (para 295). There should be clear regulations set out as to who, if anyone, the person consents to have to help them administer the lethal substance, should the need arise.

After assisted death

If a change in the legality of assisted dying aims not only to change the law but also to reduce stigma around death and dying, it needs to do so not by hiding its reality but by proclaiming it openly. Assisted suicides should be recorded as such.

While the law will be legalising assisted dying, it is not seeking – nor should it seek– to change the definition of 'suicide', as this would have far-reaching consequences beyond those which have been consulted on. **For this reason, the explicit cause of death should be labelled as 'suicide' since it is the intentional ending of one's own life.**

Aside from the details of reporting in individual cases, transparency in data publication is significant for medical research. Data in public documents, including the MCFCD, should record assisted deaths as suicide by lethal drugs. Otherwise, **data on fatality rates and prognoses of diseases will be skewed: if the underlying condition is recorded as the cause of death**, the data on this disease, over time, artificially changes, making it hard for medical research to assess the nature of the disease.

Verification of death can occur in the persons own home after the person bringing drugs and removing any unused drugs has left the dead person's home.

Regulation oversight

Regulation and monitoring need to be robust and maintain a high level of scrutiny, particularly with regards to who it is that is being given, and is giving, lethal drugs and the background to that decision. Other countries have struggled in this area: 40% of cases going unreported in Belgium and data in Oregon being disposed of after a year. Since it is easy for forms of abuse or coercion to arise, in an area dealing with the difference between life and death, the need for strong regulation cannot be understated.[292]

The law should prescribe the content of the administrative review to include care history, length of relationship with the administering doctors and a review of all the relevant assessment documents.[293] This is to avoid a situation where completing the administrative review becomes a quick and meaningless tickbox exercise which fails to evaluate and assess the assisted death. The current proposals lack these details and equate to a poorly detailed legislative framework.

The same need for prescription arises in relation to the annual report that the Jersey Care Commission will be required to publish. This report must include an identification of groups of people with similar characteristics.

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[292] Smets T et al. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis or reported and unreported cases. BMJ, 2010; 341: c5174. https://www.bmj.com/content/341/bmj.c5174.short

[293] Worthington A, Regnard C, Sleeman K, Finlay I . Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. BMJ Supportive & Palliative Care 2022;0:1–7. doi:10.1136/spcare-2022-003944

This should be based on ethnic background, reason for requesting assisted dying, complications, length of relationship to the doctor, drugs used and the length of time between ingestion and death. The JCC annual report should be published every year, including any years where there are no assisted deaths in Jersey. The latter situation provides an opportunity to review and assess the requests made and the assessments that have led to disapproval.

While the current proposal suggests that committee members may be experts in end-of-life care, medical ethics or social care, it must be assured that each member is an expert in one of these fields. Without this, the regulative process will not provide the necessary knowledge and expertise needed for a weighty review.

The need for careful consideration when setting out a legal test on capacity should not be underappreciated. The Mental Capacity Act 2005 came into being after a lengthy period of scrutiny and review and is regularly updated by a mental capacity forum which provides up to date assessment guidelines. It seems doubtful that a robust legal test addressing the same area can be made within 18 months. More detail needs to be provided on the test, who will be drafting it and the level of scrutiny that will be given to it. Significantly, any change within this area of the law will have consequences for mental capacity more generally and alter the law on consenting to harm - an already contested area of the law.

An example of the complexity of this area can be found in assuming that an assisted dying decision can be communicated through gestures or other means. These same gestures are interpreted as involuntary when it comes to the administration of drugs and not used to stop the assisted dying process at this stage. Consistency in what is seen to amount to ‘capacity’ is paramount.

Final comments and conclusion

A proposed bill is not going to solve deficits in care, but it may result in people not being offered the care that they need at the end of life. Inadequate integration of palliative care with acute services leaves many patients unable to benefit from modern techniques - such as palliative radiotherapy or opioid rotation - which could benefit them. Advanced pain management techniques such as nerve blocks are also likely underutilised. Diverting resources away from these areas to involve staff in processing eligibility and providing lethal drugs will only worsen this situation.

The evidence in jurisdictions where assisted suicide and euthanasia has been in place for some time, such as the Benelux countries, reveals that many doctors have changed their minds and become critical of the reality of implementation. Doctors have reported a major emotional toll from such involvement. The health workforce is exhausted and demoralised; it does not have capacity or resilience to take on additional complex legal responsibilities to end life when all efforts during the pandemic have been to enhance and protect quality of life, while accepting the inevitability of death.

Recent evidence from Canada has revealed difficulties in monitoring an assisted dying service. [294]

It is our concern that sufficient safeguarding cannot be achieved in Jersey’s current health and care system to make an assisted dying law workable safely, and that the proposals have been arisen through fear and a reaction to deficits in care. We suggest there has been inadequate consideration of the factual evidence that points to the inherent dangers, particularly recent evidence for other jurisdictions.

Route 2

The track 2 proposals should be abandoned completely. Suffering is a complex subjective experience with many interacting domains (physical, social, psychological, grief and loss, anger, loneliness, poor self-worth, spiritual issues, social and financial problems, etc.). This proposal destroys Jersey’s recent suicide prevention

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[294] J Kotalik. Medical Assistance in Dying: Challenges of Monitoring the Canadian Program *Can J Bioeth / Rev Can Bioeth.* 2020;3(3):202-209

initiatives, allows Jersey to abandon its developing mental health services and will abandon any meaningful rehabilitation and support services.

Living and Dying Well

10th January

21. Medical Ethics Alliance

Q1. Questions on sharing your responses:

We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation.

Do you give permission for your comments to be quoted?

Yes, attributed

Name or organisation to attribute comments to, if applicable:
Medical Ethics Alliance

A coalition of six medical and nursing bodies who look to the Abrahamic and Hippocratic traditions

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q3. If yes, do you think assisted dying:

Should not be permitted

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No

Please tell us the reason for your response
In reality prognosis is not possible. Most doctors have patients who outlive their prognosis. My wife outlived her "best prognosis" by 17 years

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism". It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

No

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

No

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Don't know

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes - they should have the right to refuse

Please tell us the reasons for your response
The conditions of the World Medical Association should apply. These include no provision for referral to a doctor agreeing to kill or assist suicide.

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes - they should have the right to refuse

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Don't know

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

No

Please tell us the reasons for your response
No such process should take place at all

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

No

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

If yes, please detail the further steps or actions you think should be included.
There is no way a health professional can know the family dynamics that could lie behind a request. Inheritance is an obvious consideration.

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under 'Route 1 (terminal illness) 90 days minimum those eligible under 'Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Don't know

Please tell us the reasons for your response
See answer above.

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Don't know

Please tell us the reasons for your response
This term is undefinable

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Yes - I agree

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

Please tell us the reasons for your response
It would damage the doctor patient relationship

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Please tell us the reasons for your response
It would undermine the doctor patient relationship

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

Don't know

Please tell us the reasons for your response
See above

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

No - I do not agree

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

No - the law should not allow for a waiver of final consent

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Other (please specify):
It is inappropriate for any health professional to take part

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Don't know

Please tell us the reasons for your response
See earlier answers.
Police are investigation deaths in the Gosport Memorial Hospital and some families taking family members to the Dignitas Clinic in Switzerland.
Does Jersey really want to go down this dangerous road ?

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

No

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person's wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

No

Please tell us the reasons for your response
With predictions that over a million cases of dementia will affect U K citizens this is an impossible task for any court.

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

No– I do not agree, there should be a time period longer than 48-hours

Please tell us the reasons for your response
see above

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

No

Please tell us the reasons for your response
see above

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

No - I disagree, there should be an expiry date

Please tell us the reasons for your response
see above

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

No

Please tell us the reasons for your response
see above

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

No

Please tell us the reasons for your response
This would lead to unresolvable family conflicts

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Please tell us the reasons for your response
The extent of the killing is of national and international concern

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

No

Please tell us the reasons for your response
see above

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Please tell us the reasons for your response
The extent of the killing is of international concern

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

No

Please tell us the reasons for your response
see above

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

Yes - I agree, it should not be considered an essential service

Please tell us the reasons for your response
It is negating millennia of medical ethics.

Hippocrates ended the prior practice os physician assisted poisoning and in time this became the cornerstone of western medical ethics. Is Jersey really going to reverse this ?

22. My Death, My Decision

My Death My Decision
campaigning for assisted dying

My Death, My Decision
39 Moreland Street,
London, EC1V 8BB

www.mydeath-mydecision.org.uk

Contact: trevor.moore@mydeath-mydecision.org.uk

9th January 2023

We are pleased to make our submission to the Assisted Dying in Jersey Consultation. Alongside End of Life Choices Jersey and others, My Death, My Decision was a co-founder of the Assisted Dying Coalition.

Our answers to the consultation questions are set out in the table below, but we should like to make two initial points:

1. Most importantly, we consider the proposals confusing in relation to those who are terminally ill. Paragraphs 16.a and b of the report suggest that only those who meet the prognosis timeframes (six or twelve months) and for whom the condition is *expected* to give rise to unbearable suffering, can follow the shorter Route 1 - not if they are *currently* so suffering.

If adopted, this would mean that a terminally ill person who meets those timeframes and is *currently* suffering would have to follow the extended Route 2, (paragraph 22.a of the report - on the basis that an incurable condition, by definition, includes a terminal one). We do not think that can have been intended, surely those suffering 'now' should be able to follow the shorter Route 1? This could easily be addressed in the suggested wording in paragraphs 16.a and b of the report, by altering it to read "... is causing or is expected to cause unbearable suffering..."

2. In paragraph 12c of the consultation report there is a statement that the final report to Members is expected to ask them 'to agree, in principle, that legislation permitting assisted dying should not be brought into force until the Assembly is satisfied that all Islanders can access good palliative and end-of-life services'. The definition of what constitutes 'good palliative care and end of life services' will always be changing as medical knowledge advances. It will also depend on individual, not generic, circumstances. There is a concern that this proviso could postpone the law's introduction indefinitely, on the basis that care could always be better. A more workable approach is to ensure that any applicant has been offered the best services then available. The funding of those services is of course for the government to decide upon.

Q. 1 Do you give permission for your comments to be quoted?
Yes, attributed

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes

Q.3 If yes, do you think assisted dying:

should be permitted

Q.4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

Yes

Please tell us the reasons for your response:

Please see answer to Q.14 - i.e. someone who is terminally ill (including neurodegenerative) and *currently* experiencing unbearable suffering must be able to apply under Route 2

Q. 5 Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes

Please tell us the reasons for your response:

We understand why Jersey might want to adopt this restriction but it would be a huge act of kindness to the people of the UK if they felt able to include them.

Q.6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes

Please tell us the reasons for your response:

This is consistent with the age of majority in Jersey

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all the criteria?

Yes

Please tell us the reasons for your response:

It would not provide equality of access if there was any question of a person who meets the criteria being unable to proceed on financial grounds

Q.8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Don't know

Please tell us the reasons for your response:

Depending on the input needed by the Assessing Doctor, refusal by a key specialist could render the right to an assisted death illusory for some applicants. If refusal is allowed, as a minimum the clinician will presumably be required to follow para 52 of the GMC's *Good Medical Practice*", viz: *"You must explain to patients if you have a conscientious objection to a particular procedure. You must tell them about their right to see another doctor and make sure they have enough information to exercise that right. In providing this information you must not imply or express disapproval of the patient's lifestyle, choices or beliefs. If it is not practical for a patient to arrange to see another doctor, you must make sure that arrangements are made for another suitably qualified colleague to take over your role."*

Q.9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises.

Please tell us the reasons for your response:

The resident may well have lived there for years and regard the premises as their home - indeed they may have nowhere else to go. One of the beneficial aspects of an assisted death is choosing to die where you wish. It would be callous and possibly life-threatening to move them.

Q.10 Do you agree that the assisted dying register should be public?

Yes

Please tell us the reasons for your response:

If assisted dying is to be included as part of the spectrum of end of life choices, allowing practitioners to be anonymous will serve only to perpetuate the idea of an assisted death as somehow separate from other options. It could also inhibit practitioners from speaking in public on issues relating to assisted dying.

Q. 11 Do you agree that the nine proposed steps are all necessary?

Yes

Please tell us the reasons for your response:

We agree with the steps but have concerns about the Tribunal (the extra step for Route 2), see below

Q. 12 Do you think there are any further steps / actions that should be included?

No

Please tell us the reasons for your response:

We think that the 9 steps provide a workable and robust set of requirements. Any further steps could render the right to an assisted death almost illusory. In particular, we would be concerned if any further steps such as prospective approval by the court in all cases were to be proposed (as in the Westminster Assisted Dying Bill [HL] which fell in May 2022).

Q.13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes

Please tell us the reasons for your response:

But see answer to Q.14 in relation to possible 'gap' created by proposed definition for Route 1. Any protocols should require that the relevant professionals work so far as practicable to meet the timing wishes of the applicant, subject to the minimum.

Q.14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Yes

Please tell us the reasons for your response:

A longer period is appropriate for Route 2 cases where the person is not terminally ill – the longer timeframe is likely to be dictated by practicalities if e.g. a specialist opinion or assessment is required. This is the same time period as now required for analogous cases in Canada, where it seems to be working in practice.

We think there is however a confusion in the proposals in relation to those who are terminally ill and *currently* experiencing unbearable suffering, compared to those where the condition '*is expected to* result in unbearable suffering'). The confusion is compounded because paragraphs 76b and 209 of the consultation report refer to Route 2 as only applying to those who are not terminally ill. See our introductory paragraph at the outset of this memorandum.

We should be happy to run through this fundamental point in greater detail, possibly orally, if that would be helpful.

Q. 15 Do you agree that the law should not prohibit professionals from raising the subject of assisted dying?

Yes

Please tell us the reasons for your response:

The law is not an appropriate or an effective way of shaping conversations between health care professionals and their patients. Similarly to our response to Q10, to prohibit this would serve only to keep assisted dying as separate from the other end of life choices for a patient. In Victoria, Australia, palliative care specialists fought for the prohibition but now some are changing their minds because ambiguities can arise in discussions with patients. See *Working with palliative care physicians to prepare for voluntary assisted dying legislation* - Australian Psychiatry 2022, Vol. 0(0)1–3

Q. 16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

No

Please tell us the reasons for your response:

As explained in relation to Q10 and Q15, to separate out assisted dying in this way will serve only to delay the time it takes for it to be normalised as an end of life option. Further, the exercise of the right to an assisted death should not be dependent on the arbitrariness of how well-informed a person is. This could amount to discrimination.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

Don't know

Please tell us the reasons for your response:

The risk is that someone is referred to a specialist who is very conservative in their view of when AD is appropriate and so refuses, denying them their right to an assisted death.

Q. 18 Should the law allow for confirmation of consent to proceed?

Yes

Please tell us the reasons for your response:

But any law should allow the option of health practitioner administration (lethal injection) in any event – and for practical and reassurance reasons this is likely to be the preferred choice for most (cf Canada - well over 10,000 of 10,064 so chose in 2021 and, in its first period of operation, 56 of 66 in New Zealand).

Q. 19 Should the law allow for the option of a waiver of final consent?

Yes

Please tell us the reasons for your response:

This is an option introduced in Canada and seems appropriate. Otherwise a person could be denied the assisted death they wish due to unforeseen changes in circumstances. This would be arbitrary and disproportionate.

It is however important to ensure there is a public understanding of the difference between this option, which would apply only late in the approval process, and an Advance Decision requesting an assisted death at some time in the future should the person lose mental capacity. We are aware of confusion in people's minds about these two quite different scenarios.

Q. 20 Do you agree with the two different approval routes as proposed?

No – all approvals should be by the Coordinating Doctor based on their assessment and that of the Independent Assessing Doctor only (ie. no requirement for a Tribunal)

Please tell us the reasons for your response:

There is good evidence from those jurisdictions that already have an assisted dying law that the process of two assessments on two occasions is sufficient. Introducing a Tribunal as an additional prospective step is likely to cause greater stress and anxiety, as well as time delays (and costs). There should however be the ability for the Coordinating Doctor and the independent Assessing Doctor to refer to a panel or specialist if they have any matters on which they require a further assessment.

At para 188 of the consultation report, reference is made to the (fallen) Meacher Bill and its proposal that a High Court Order be required for an assisted death in England & Wales – that this had in part influenced the jury's views. Professor Penney Lewis cogently analyses why such a requirement is not only unworkable but also inappropriate in the circumstances: *International Perspectives on End-of-Life Law* Ch 6 *Should Assisted Dying Require the Consent of a High Court Judge?*

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Don't know

Please tell us the reasons for your response:

Because as per Q20 answer, a Tribunal should not be required for any cases.

Q22. Do you agree that the Law should provide for appeals to the Royal Court?

No

Please tell us the reasons for your response:

The rules and protocols applicable to approvals for an assisted death and likely [criminal?] sanctions should be so structured as to obviate the need for further challenge on a prospective basis. Adding a further step is inappropriate in the same way as a Tribunal (see Q.20).

In particular, we do not consider that a family member should be able to challenge decisions made – in some cases, applicants will not want to involve family members, who may disagree with assisted dying or the applicant's decision to have an assisted death. The exclusion of lobby groups is easily circumvented by such groups funding appeals by family members, for example – this has happened in high profile cases of withdrawal of life-sustaining treatment for children; assisted death decisions by competent adults are quite different and should not be subject to direct or indirect lobby group pressure.

Q23. Do you agree with proposed grounds for appeal?

Don't know

Please tell us the reasons for your response:

We do not consider that appeals are appropriate (Q.22)

Q.24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Don't know

Please tell us the reasons for your response:

We do not consider that appeals are appropriate (see Q.22)

Q. 25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Don't know

Please tell us the reasons for your response:

We do not consider that appeals are appropriate (see Q.22)

Q.26 Do you agree that there should be no expiry date for the approval of an assisted death?

Yes

Please tell us the reasons for your response:

If the eligibility criteria are met it should then be for the applicant to decide. Other jurisdictions show that, once approved, many of those eligible often do not proceed to the assisted death in the year in which approval is given.

Q.27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes

Please tell us the reasons for your response:

This will rule out concerns about incorrect administration by the individual. But we think that administration by a health practitioner should be allowed and would be the overwhelmingly preferred option (see Q.18).

Q.28 Do you agree that a loved one should be able to support the person to self administer the substance?

Yes

Please tell us the reasons for your response:

Especially if an Administering Practitioner is present or nearby (see Q.27).

Q.29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Please tell us the reasons for your response:

There should be no stigma attaching to an assisted death. It is also important for ongoing public confidence that there is full transparency about the scale of and reasons for assisted deaths

Q. 30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Please tell us the reasons for your response:

This will help ensure public confidence.

Q.31 Do you agree that post-death administrative review of each assisted death is required?

Yes

Please tell us the reasons for your response:

This will help ensure public confidence

Q. 32 Do you agree that the Jersey Care Commission should independently regulate and inspect the Assisted dying service

Yes

Please tell us the reasons for your response:

This will again ensure public confidence in the service, but they should not be able to regulate or direct in ways that could make the service unworkable and thus illusory

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)

No– I disagree, it should be considered an essential service

Please tell us the reasons for your response:

The Assisted Dying Service will have been approved through the democratic process, so no separate body should have the ability to stop its operation.

23. National Secular Society

challenging religious privilege

January 2023

Assisted dying in Jersey consultation: National Secular Society input

This response is made on behalf of the National Secular Society.

The NSS is a not-for-profit, non-governmental organisation founded in 1866, funded by its members and by donations. We advocate for separation of religion and state and promote secularism as the best means of creating a society in which people of all religions and none can live together fairly and cohesively. We seek a diverse society where all are free to practise their faith, change it, or to have no faith at all. We uphold the universality of individual human rights, which should never be overridden on the grounds of religion, tradition or culture.

More information about our organisation can be found here:
https://www.secularism.org.uk/about.html

The National Secular Society's position

We believe that patient autonomy includes the right of mentally competent adults to make a voluntary and settled decision regarding the time, setting and manner of their death. We recognise there is scope for reasonable disagreement on the eligibility criteria for accessing assisted dying.

Island Global Research polling found 90% of islanders support a law to allow terminally ill, mentally competent adults to avail themselves of assisted dying and only 3% believe that Jersey should wait for Westminster to act first.[295]

The vast majority of terminally ill patients do not avail themselves of assisted dying, even in jurisdictions where it has been decriminalised. As such, assisted dying should be correctly understood as complementary to rather than in competition with high quality palliative care. It is entirely consistent to believe that assisted dying should be legal while well-funded, gold-standard palliative care should be available to all.

But is it undeniable that even the best palliative care cannot alleviate all suffering in all cases. This suffering can come in many forms, including but not limited to: physical pain, nausea, immobility, incontinence and indignity.

It is well known that, even where access to high quality palliative care is available, serious illness is associated with a higher risk of suicide. A 2022 Office for National Statistics analysis found, for example, that the suicide rate in English patients with low survival cancers was 2.4 times higher than the general population.[296] There is no reason to believe this data would not be replicable in Jersey.

Marjorie Wallace CBE, chief executive of mental health charity SANE, has said traditional suicide prevention measures "are not an appropriate response" for those who are nearing the end of life and wish to ease the dying process, because their motivation is "to shorten death, not shorten life".[297]

The potential criminalisation of assisted dying increases the risk of botched suicides amongst this group. Without the assistance of a medical professional, these individuals lack the means and expertise to end their lives in a peaceful and dignified manner. Furthermore, the lack of an explicit legal framework exposes those who might seek to assist such patients, even when motivated entirely by compassion, to prosecution.

Those with substantial financial means may elect to travel to Dignitas in Switzerland to receive medical help in ending their lives. Indeed, since 2002, almost 500 Britons have resorted to travelling to Dignitas in Switzerland.[298] At an average cost of £10,000, however, this option remains out of reach for many.

Accessing assisted dying abroad is not only problematic because it excludes the less well off in our society: Travelling to Dignitas necessarily requires an individual to be at a stage in their illness where they are still physically able to travel. This means some patients will feel forced into availing themselves of assisted dying abroad earlier than they otherwise would were it legal domestically.

Thus, the current law is pressurising patients into ending their lives prematurely in an alien setting, away from their home, family and friends.

By contrast, assisted dying was legalised in Oregon 1997 for terminally ill, mentally competent patients. Available evidence suggests it has been implemented safely and effectively.[299] Of the 36,498 deaths in Oregon in 2017 only 143 resulted from assisted-dying. It has not, as opponents have suggested, lead to "widespread euthanasia".

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[295] https://www.islandglobalresearch.com/View?id=2232

[296] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplediagnosedwithseverehealthconditionsengland/2017to2020

[297] https://www.dignityindying.org.uk/news/hundreds-of-terminally-ill-brits-take-their-own-lives-in-uk-eachhttps://www.dignityindying.org.uk/news/hundreds-of-terminally-ill-brits-take-their-own-lives-in-uk-each-year-latest-estimates-suggest/year-latest-estimates-suggest/

[298] https://www.statista.com/statistics/1095576/dignitas-accompanied-suicides-from-gb/

[299] https://cdn.dignityindying.org.uk/wp-content/uploads/DiD_ASSISTED-DYING-INhttps://cdn.dignityindying.org.uk/wp-content/uploads/DiD_ASSISTED-DYING-IN-OREGON_REPORT_AW_9_SINGLE-PAGES.pdfOREGON_REPORT_AW_9_SINGLE-PAGES.pdf

Indeed, in 35% of cases, individuals prescribed aid-in-dying medication did not ultimately use it. Rather it served as peace of mind that it would be available were their suffering to become intolerable – a form of so called “emotional insurance”.

And, as of 2018, Disability Rights Oregon, a state-based disability advocacy group, had not received a single complaint of actual or attempted abuse under the Oregon Death with Dignity Act.

Furthermore, the implementation of a safe and effective assisted-dying framework has not come at the expense of high quality palliative care. In 2019, the Center to Advance Palliative Care ranked Oregon’s palliative care system 12th in the country with an A grade, scoring of 88.9 out of a possible 100.[300]

The NSS believes everyone should have their say when it comes to assisted dying reform. However, religious dogma should not be considered a rational, compassionate, or legitimate basis for policy making. It is not for the state to impose religious dogma on citizens. Furthermore, religious groups should not resort to fearmongering and misinformation in their efforts to oppose assisted dying.

Religious opposition to assisted dying reform in Jersey

Philip Eagan, Catholic bishop of Portsmouth, wrote in a 2021 pastoral letter: “[l]et there be no death-clinics in Jersey”.[301] He said legalised assisted-dying would be “difficult or impossible to control” despite compelling evidence to the contrary from Oregon, Australia and New Zealand.

His claim that those at the end of life need “support, comfort and care, good pain control” fails to confront 2019 Office of Health Economics data from England which shows that even with universal access to hospice care, 6,394 people a year experience no pain relief in the final three months of their life.[302] This equates to 17 people every day.

In 2022, the Christian Institute falsely claimed that Jersey had voted to “legalise euthanasia”, even though assisted dying and euthanasia are materially distinct medico-legal concepts.[303] Its article added that Jersey residents would “be able to request to be killed in cases”. Again, this appears to be a wilfully misleading account of what assisted dying entails: the patient must self-administer aid-indying medication. It cannot be administered by a doctor.

The Institute’s Ciarán Kelly invokes a sanctity of life style argument by claiming that the legalisation of assisted dying would “deny the value of every person as an individual made in the image of God”. It is undeniable that the religious sanctity of life view – the idea that God created human life, only God has the right to end it – is a key driver of opposition to greater patient choice at the end of life.

While individuals are entitled to their theological positions, they cannot be used as a cudgel to restrict the end of life decisions of mentally competent, terminally ill adults.

Some religious groups in Jersey, however, have come to recognise that theological objections to assisted dying increasingly fail to resonate with the public, and have sought to cloak their religious arguments and, indeed, the religious nature of their opposition to assisted dying in secular terms.

‘Jersey Dying Well’, for example, is chaired by John Stewart-Jones. [10] Its website notes he is a “retired GP”. It fails to mention, however, that he is also a prominent member of the Jersey Evangelical Alliance – which opposes assisted dying on religious grounds - and a pastor at Freedom Church.[11]

Furthermore, Jersey Dying Well fails to declare on its website its links with the Westminster all party parliamentary group on dying well, which is chaired by evangelical Christian Danny Kruger MP and funded by Christian Action Research Education (CARE).

In opposition to the most recent attempt at legislative reform in England and Wales, Danny Kruger claimed Baroness Meacher’s bill, which allowed for assisted dying only in terminally ill, competent adults, would lead

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[300] https://reportcard.capc.org/

[301] https://www.cbcew.org.uk/bishop-egan-asks-jerseys-catholics-to-oppose-plans-to-legalise-assisted-dying/

[302] https://www.ohe.org/publications/unrelieved-pain-palliative-care-england#

[303] https://www.christian.org.uk/news/jersey-consults-on-dangerous-assisted-suicide-and-euthanasiahttps://www.christian.org.uk/news/jersey-consults-on-dangerous-assisted-suicide-and-euthanasia-proposals/proposals/

to “widespread euthanasia of the elderly and disabled”. CARE falsely claim that legalising assisted dying would “impose on doctors a duty to kill”.[304]

The Jersey Evangelical Alliance has also sought to conflate assisted dying and euthanasia.[305] It appeals to the protection of the “vulnerable in our society, including people with disabilities” despite 2015 Populus polling which showed, in fact, support for assisted dying amongst the disabled community (86%) exceeded that in the general public (84%).[306]

The Alliance’s reverend Drew Walker gave a presentation to the assisted dying citizen’s jury in 2021 which included unnuanced and misleading claims such as “Assisted Suicide is not the best course of care” and “Assisted Suicide opens the door to the abuse of the most vulnerable”.[307]

This is to ignore, deliberately or otherwise, that the absence of a legal framework includes no prospective safeguards for patients: a patient found to have availed themselves of assisted dying only has their wishes examined retrospectively. The motivations of their family members are only scrutinised after the patient’s death comes to light. The clinical opinion of the patient’s doctor is only solicited after the fact.

In the same evidence session, professor David Albert Jones of the Anscombe Bioethics Centre falsely claimed that there is “broad consensus between very different religions on this issue”. In fact, 2013 YouGov polling showed 72% of Anglicans; 69% of Jews and Sikhs; and 56% of Catholic support legalisation of assisted dying.[308]

Furthermore, a 2019 Populus poll showed 80% of religious people support the legalisation of assisted for mentally competent, terminally ill adults.[309] Separate polling suggests 53% of religious people believe it is wrong for religious leaders to campaign against assisted dying.[310]

Jones’s claims that faith leaders broadly oppose assisted dying reform is further undermined by the existence of the “religious alliance for dignity in dying”, which enjoys support from prominent clerics such as the former archbishop of Canterbury, George Carey. Carey has said his views are “in step with the vast number of Christians who see the need for change”.

The group's chair, Rabbi Dr Jonathan Romain, has said: "We must puncture the myth that religious people oppose assisted dying. Anti-choice religious leaders and groups don't speak for the majority. We must work together to make the compassionate case for assisted dying."

In the course of a 2021 debate in the States Assembly, the dean of Jersey, the very rev Mike Keirle, raised concerns that legalisation of assisted dying could erode the trust between doctors and patients.[311] On the contrary, it is the *absence* of an explicit legal framework that is more likely to endanger the doctor-patient relationship and inhibit frank conversation on end of life decisions. This is because patients who wish to discuss a desire for assisted dying with their doctor may be reluctant to broach the topic if they fear their doctor could be prosecuted.

Finally, the Church of England is the established church in Jersey and, while Jersey has its own legislature, it is nonetheless worth nothing the views expressed by some of the 26 Anglican Bishops who enjoy seats in the UK’s House of Lords by right.[312]

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[304] CARE for Assisted Suicide | CARE

[305] https://static1.squarespace.com/static/5d2346b25e98b80001fb6187/t/6149e75a284e044a6fcca43e/1632233309762/Assisted+Suicide+Leaflet.pdf

[306] https://www.dignityindying.org.uk/news/poll-assisted-dying-support-84-britons/

[307] https://www.gov.je/Caring/AssistedDying/pages/citizensjuryonassisteddying.aspx

[308] https://yougov.co.uk/topics/politics/articles-reports/2013/12/16/three-four-support-changing-assistedhttps://yougov.co.uk/topics/politics/articles-reports/2013/12/16/three-four-support-changing-assisted-dying-lawdying-law

[309] https://yonderconsulting.com/poll-archive/Dignity-in-Dying-GB-poll-11-24-March-2019-Q1-Q2-tables-forhttps://yonderconsulting.com/poll-archive/Dignity-in-Dying-GB-poll-11-24-March-2019-Q1-Q2-tables-for-publication.pdfpublication.pdf

[310] https://www.thetimes.co.uk/article/dying-with-dignity-faith-leaders-are-out-of-touch-on-assisted-dying-sayhttps://www.thetimes.co.uk/article/dying-with-dignity-faith-leaders-are-out-of-touch-on-assisted-dying-say-followers-pphx3wg87followers-pphx3wg87

[311] https://www.dailymail.co.uk/news/article-10243041/Jersey-paves-way-legalise-assisted-dying.html

[312] https://www.jerseydeanery.je/about

Martin Warner, bishop of Chichester, used his *ex officio* position in a 2021 debate on assisted dying to opine: "God does not inflict evil on people". Speaking on the National Secular Society podcast, Baroness Meacher recalled a conversation with an unnamed lord spiritual in which he said "I don't know that I believe in autonomy."[313]

Conclusion

The law concerning assisted dying should seek to uphold the right to exercise a genuinely autonomous choice. The religious views of some, however sincerely held, should not restrict the freedoms and choices of others.

We recognise that there is scope for reasonable disagreement on this issue and welcome intellectually honest debate around it. We urge the States Assembly to be mindful of theological opponents of assisted dying obfuscating their language, motivations and funding.

24. Quennevais Evangelical Church

Q1. Questions on sharing your responses: We are asking these questions so we can process your data correctly and understand more about who is responding to this consultation. Do you give permission for your comments to be quoted?
Yes, attributed **Name or organisation to attribute comments to, if applicable:** Quennevais Evangelical Church

Q2. Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?
Yes

Q3. If yes, do you think assisted dying:
Should not be permitted

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[313] https://www.secularism.org.uk/podcast/2021/09/ep-56

Q4. Key questions on Section 3 - eligibility criteria

Life expectancy for neurodegenerative diseases (see consultation report paragraphs 16-19)

The States Assembly agreed in principle that assisted dying should be available to a person who has been diagnosed with a terminal illness, which is expected to result in unbearable suffering that cannot be alleviated and is reasonably expected to die within six months.
It is proposed that for those with a neurodegenerative disease this should be extended to people with a life expectancy of 12 months or less.

Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months or less?

No

Please tell us the reason for your response
Vulnerable people who are suffering may not be thinking straight, they may be suffering from depression. They may feel a burden to family and society. They need care and support, not killing. Also - if unbearable suffering is the measure - how is unbearable suffering measured? Is there an objective measure? Someone having a bad day may make a pessimistic and fatal decision.

Q5. Resident definition (see consultation report paragraphs 25 & 26 and note ‘Jersey resident’ on p.17)

The States Assembly agreed, in principle, that assisted dying should only be available to Jersey residents in order to avoid ‘death tourism". It is proposed that a person will only be considered ‘resident’ if they have ordinarily resident in Jersey for at least 12 months immediately before requesting an assisted death.

This means that a person who was born in Jersey, but has been living elsewhere, would not be eligible for assisted death unless they had returned to live in Jersey for the 12 months prior requesting an assisted death.

Do you agree that the definition for Jersey resident should only include those ordinarily resident in Jersey for 12 months?

Don't know

Please tell us the reasons for your response
The question is badly worded. I don’t want to imply support for assisted dying by answering yes, I don’t want to imply that there should be no safeguards in place by answering no. Assisted dying should not be allowed. If it is it should be made very difficult indeed to do so, including avoiding suicide tourism is important.

Q6. Eligibility – age (see consultation report paragraphs 25 & 26 and note ‘Age limit’ on p.17)

Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes

Please tell us the reasons for your response
Parental responsibility is an important factor for life, though 18 is arbitrary a line needs to be drawn somewhere. What about those not mature enough at 18 to make such a decision and in an informed manner. What about those with learning difficulties or mental illness without the maturity or capability to make a decision - more reason n it to go ahead, to legislate for all the gray areas seems impossible.

Q7. Key questions on Section 4 - Assisted Dying Service

Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and meet the criteria?

Don't know

Please tell us the reasons for your response
If people had to pay for it this would make it more difficult to access - meaning less would choose it, which is a good thing.

what is the situation with palliative care? If assisted suicide is the cheaper option that would appear to force poorer and more vulnerable people into a decision based on financial pragmatism.

Q8. Conscientious objection – Supporting assessments (see consultation report paragraph 50)

The Law will explicitly provide that no person can be compelled to directly participate in the assessment, approval or delivery of an assisted death.

In drafting the law, consideration will be given as to which tasks or activities constitute direct participation in assisted dying (such as undertaking a specified role in the process such as 'Coordinating Doctor' or being present at the time of administration of the assisted dying substance), as opposed to tasks which are ancillary to the provision of an assisted death service (such as related administrative tasks such as booking an assessment or the delivery of equipment or medical supplies.)
It is proposed that the provision of supporting opinions or assessments requested by an Assessing Doctor to help support their determine of whether a person is eligible for an assisted death would be considered as direct involvement, for example: professional opinion provided by a specialist on the person's prognosis or life expectancy pulmonary function tests, carried out by a physiotherapist assessment to determine decision-making capacity by a psychiatrist or psychologist

Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person's eligibility for an assisted death?

Yes - they should have the right to refuse

Please tell us the reasons for your response
It seems impossible to protect this - again, we should not be going down the route of assisted suicide. Even if granting exemptions for conscientious objectors early on, legislation and practice in other areas suggests that these protections are eroded over time. Can medical practitioners still opt out of abortion and related actions? Rather than opt out it would give more clarity to enable practitioners to opt in to be "licenced to kill" if such services are to go ahead.

Q9. Conscientious objection -Premises owner right of refusal (see consultation report paragraph 50)

Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)

Yes - they should have the right to refuse

Please tell us the reasons for your response
Assisted dying should not be allowed. If it does go ahead then to prevent this situation specific places should be licenced to kill, which should be made clear to residents before going there.

Q10. Public or private register (consultation report paragraphs 56-59)

It is proposed that assisted dying practitioners, who can demonstrate the necessary competencies, and who have undertaken the necessary training, will be required to register with the Jersey Assisted Dying Service. Registration will be the mechanism via which they ‘opt-in’ to be an assisted dying practitioner.

The registers for healthcare and medical practitioners, as held by the Jersey Care Commission, are currently public registers i.e.. anyone can search the register to find out about the qualifications of a named practitioner. This is to ensure transparency.

Do you agree that the assisted dying register should be public?

Yes

Please tell us the reasons for your response
This gives clear accountability.

Q11. Key questions on Section 5 - assisted dying process: request and approval

Request and approval process

Page 33 of the consultation report includes a diagram of the nine proposed steps in the assisted dying process:

Step 1 - First request
Step 2 - First assessment
Step 3 - Independent assessment
Step 4 - Second request
Step 5 - Request approval
Step 6 - Planning and preparation
Step 7 - Prescribing the substance
Step 8 - End of life
Step 9 - After the death

Do you agree that the nine proposed steps are all necessary?

Don't know

Please tell us the reasons for your response
It seems disgraceful to consider such a process of death. But if you are to go ahead with assisted suicide there does need to be great care. Arguably there should be more steps and more independent assessments for such a significant decision.

Q12. Do you think there are any further steps / actions that should be included?

(Please note, further Sections of this document include more detailed questions about specific steps)

Yes

If yes, please detail the further steps or actions you think should be included.
Include family considerations.
Include a legal assessment - will this be a legal death.

Q13. Period of reflection (see consultation report paragraphs 72-79)

The States Assembly agreed, in principle, that the assisted dying assessment process should allow a period of reflection, hence the proposed the minimum amount of time between the first request (step 1) and the end of life (step 8): 14 days minimum for those eligible under ‘Route 1 (terminal illness) 90 days minimum those eligible under ‘Route 2 (unbearable suffering)

Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Don't know

Please tell us the reasons for your response
These numbers seem arbitrary. There should be delay, but how do you possibly legislate for each case - every situation is different.

Q14. Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days?

Don't know

Please tell us the reasons for your response
How do you measure unbearable suffering? People have expressed unbearable suffering, and would have ended life if possible, yet survived and gone on to lead a good life.

Q15. Key questions on Section 5 - assisted dying process: request and approval

Duty on professionals to tell patients / not tell patients about assisted dying (see consultation report paragraphs 84-87)

It is proposed that the law neither prohibits health and care professionals from raising the subject of assisted dying with their patients or clients, nor requires them to do so. This means, for example, a GP could raise the subject with a terminally ill patient without waiting for them to raise the subject first or, conversely a GP could choose not to tell their patients about assisted dying.

Do you agree that the law should not prohibit professionals for raising the subject of assisted dying?

No - I do not agree

Please tell us the reasons for your response
To inform a patient of the option of assisted suicide appears to be in direct contradiction to the Hippocratic oath.

Q16. Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes - I agree

Please tell us the reasons for your response
The medical profession should be about preserving life not ending it.

Q17. Second opinion (see consultation report paragraphs 116-122)

It is proposed that the law sets out that a person, who has been found to be ineligible for an assisted death is entitled to ask for one second opinion. This can be after the assessment by the Coordinating Doctor, if they are found ineligible at this stage OR after assessment by the Independent Doctor, if they are found ineligible at this stage, but not at both stages of the process as this would indicate that the person did not clearly meet the criteria.

Do you agree that a person should only be entitled to one second opinion?

No - I do not agree

Please tell us the reasons for your response
We should not help people to commit suicide.

Q18. Confirmation of consent to proceed (see consultation report paragraphs 143-146)

It is proposed that the law provides for the person to complete a ‘confirmation of consent to proceed form’, allowing the Administering Practitioner to take an appropriate intervention such as administering the substance intravenously, if, for example, a person who has self-administered the substance was to lose consciousness part way through ingesting the substance and hence does not die.

Should the law allow for confirmation of consent to proceed?

No - I do not agree

Please tell us the reasons for your response
This could be abused.

Q19. Waiver of final consent (see consultation report paragraphs 147-156)

It is proposed that the law should include the option for the person to complete a ‘waiver of final consent’.

This is a document that is completed after the assessment process that confirms that the person wishes to proceed with an assisted death should they lose their decision-making capacity AFTER their request for an assisted death has been approved (Step 5) but BEFORE they are due to give their final consent (Step 8).

Should the law allow for the option of a waiver of final consent?

No - the law should not allow for a waiver of final consent

Please tell us the reasons for your response
This could be abused.

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

No - all approvals by the Coordinating Doctor should be confirmed by a Tribunal (i.e. a Tribunal involved in all cases)

Q20. Key questions on Section 5 – approval process

Routes for approval (see consultation report paragraphs 189-203)

It is proposed that there are two different approval routes:
a. Route 1 (terminal illness) which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments)
b. Route 2 (unbearable suffering), which will entail approval by the Coordinating Doctor based on their assessment and that of the Independent Assessment Doctor (ie. two doctor assessments), and then confirmation of that approval by a specialist tribunal
Do you agree with the two different approval routes as proposed?

Please tell us the reasons for your response
It should be made as difficult as possible for a life to be ended. The more qualified people seeing the request the better. Furthermore - is there a pastoral (not just medical/legal) assessment made?

Q21. Tribunal (see consultation report paragraphs 211-235)

It is proposed that the Tribunal: always reviews a decision of a Coordinating Doctor to approve a Route 2 assisted dying request (on the basis that it provides an additional safeguard) does not review a decision of a Coordinating Doctor not to approve as assisted dying requests (on the basis there can be an appeal to Court).
Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Yes

Please tell us the reasons for your response
The aim should be to preserve life. Tribunal only needs to be involved if the request is to end life.

Q22. Appeals (see consultation report paragraphs 236-255)

Do you agree that the Law should provide for appeals to the Royal Court?

No

Please tell us the reasons for your response
The aim should be to preserve life not take it.

Q23. It is proposed that the law will provide for appeals to the Royal Court on the following grounds: whether the person has, or has not, been ordinarily resident in Jersey for at least 12 months a determination by either of the Assessing Doctors that the person has or does not have the decision-making capacity to request an assisted death OR the person’s wish is, or is not, voluntary, clear, settled and informed a failure, or perceived failure, to make determinations or act in accordance process set out in law
Do you agree with proposed grounds for appeal?

Yes

Please tell us the reasons for your response
Only to overturn a decision to kill.

Q24. Timeframe for appeals

It is proposed that there is at least 48 hours between a request being approved (Step 5) and the final review before the assisted death (Step 8) in order to allow an interested person to make an application for an appeal, if they think an assisted dying request should not have been approved, whilst avoiding protracted delay or distress for the person who has requested the assisted death.

Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

No– I do not agree, there should be a time period longer than 48-hours

Please tell us the reasons for your response
This may not give enough time for an interested party to intervene - how will an interested party find out? Will family be informed? What about weekends / bank holiday / other times when fewer staff / other issues may be missed.

Q25. Who can appeal

It is proposed that an appeal can be made by the person (or their agent) or an interested person (ie. a person who the Court is satisfied has a special interest in the care of the person such as a family member or close friend). It would not include a third party, such as a representative of a lobby group.

Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Yes

Please tell us the reasons for your response
There is the right to a private life, however, how will "special interest" be defined? This could be whittled down in future.

Q26. Expiry of approval (see consultation report paragraphs 256-258)

It is proposed that there is no expiry date for an approval for an assisted death as a person should not feel pressured into ending their life on the basis that their assisted dying approval may expire.

Do you agree that there should be no expiry date for the approval of an assisted death?

Yes - I agree, there should be no expiry date

Please tell us the reasons for your response
It should be as hard as possible to end life. People should not feel under pressure.

Q27. Key questions on Section 6 – assisted dying process – planning and delivery of an assisted death

Administering the substance (see consultation report paragraphs 295-302)

It is proposed that an Administering Practitioner needs to stay with the person, or nearby the person, at the time of administration as an additional safeguard in the unlikely event that something goes wrong.

Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes

Q28. It is proposed that a loved one (ie. friend or family member) may support the person to self-administer the substance as an extension of the care they may have been providing over previous days or weeks. This is to ensure the person is supported by their loved ones up until their last moment, albeit it is recognised that not all jurisdictions permit loved ones to be involved.

Do you agree that a loved one should be able to support the person to self-administer the substance? substance?

No

Please tell us the reasons for your response
Family members may feel coerced into ending their life, when unscrupulous family members are involved.
This will be traumatic for the surviving family.

Q29. Recording the cause of death (see consultation report paragraphs 314-318)

It is proposed that the medical certificate of the facts and causes of death would reference the administration of the assisted dying substance as the cause of death. This would, in turn, be recorded in the register of deaths which is a public document.

Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying?

Yes

Please tell us the reasons for your response
But also list the diagnosis that lead to assisted suicide being allowed.

Q30. Key questions on Section 7 – Regulation and oversight

It is proposed that three distinct structures / systems are put in place to ensure the safety and quality of the assisted dying service. These structures include: an HCS Service Delivery and Assurance Board an assisted dying review committee to undertake a post-death administrative review of each individual assisted death independent regulatory oversight by the Jersey Care Commission.
Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes

Please tell us the reasons for your response
If assisted suicide is to go ahead it's administration must be kept separate to the health and social system so as not to allow for pragmatic or financial decisions to kill rather than to care for.

Q31. Do you agree that post-death administrative review of each assisted death is required?

Yes

Please tell us the reasons for your response
Accountability.

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Don't know

Q32. Do you agree that the Jersey Care Commission should independently regulate and inspect the assisted dying service?

Please tell us the reasons for your response
Having health and social care in the same hands as the death team may blur the lines too much - leading to pragmatism.

Q33. Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e. that the JCC should have the powers to close the service down)

Yes - I agree, it should not be considered an essential service

Please tell us the reasons for your response
The medical profession has thrived this long with out killing people intentionally. Our emphasis should be on care not killing.

25. Royal College of Psychiatrists

Assisted Dying in Jersey
Response to Consultation
Royal College of Psychiatrists
13 January 2023

The College and its members

The Royal College of Psychiatrists ("RCPsych") is the professional medical body responsible for supporting psychiatrists. We work to secure the best outcomes for people with mental illness, intellectual disabilities and developmental disorders by promoting excellent mental health services, supporting the prevention of mental illness, training outstanding psychiatrists, promoting quality and research, setting standards and being the voice of our members and the profession. We represent over 20,000 members, including those who work in Jersey, and work in all four nations of the UK. We also support members internationally.

Response to proposals

Our response to the assisted dying proposals in Jersey, as set out in the consultation report, is informed by our members, including those who work in Jersey and in areas that are directly affected by the proposals.

It is important to note, the RCPsych does not have an established position of neutrality, support, or opposition to the practice of assisted dying. We consider assisted dying to be a complex matter and that the proposed changes to law, in this instance, are for the Jersey Assembly and people of Jersey to consider. In line with our role as the voice of our members and the profession of psychiatry, our response below advises on matters set out in the proposals that relate to persons suffering from mental disorders or who lack mental capacity.

Specifically, our response covers, in a limited manner, some points of principle expressed by our members and focuses on how the implementation of certain aspects of the report may require psychiatric input, as well as the potential impacts that operationalising the proposed assisted dying service in Jersey may have on services psychiatrists in Jersey operate.

Questions

Q. 1 Do you give permission for your comments to be quoted?

No ☐

Yes, anonymously ☐

Yes, attributed ☒

Name to attribute comments to: N/A

Organisation to attribute comments to, if applicable: Royal College of Psychiatrists

Q. 2 Do you, or the organisation on whose behalf you are responding, hold a strong view on whether or not assisted dying should be permitted?

Yes ☐

No ☒

Prefer not to say ☐

While acknowledging that the RCPsych does not have a position on the practice of assisted dying itself, it is important to note that we do hold views on aspects of the proposals that are relevant to persons suffering from mental disorders or who lack mental capacity, as well as the impact that their implementation may have on the services our members in Jersey operate.

Q. 3 If yes, do you think assisted dying:

should be permitted ☐

should not be permitted ☐

We offer no further comment on this point.

Section 3 – eligibility criteria

Q. 4 Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy or 12 months or less?

Yes ☐

No ☐

Don’t know ☒

Please tell us the reason for your response:

We have selected ‘Don’t know’ as we do not hold a view on whether the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of 12 months of less. We do, however, wish to comment on the consultation report’s inclusion of neurodegenerative disease within the eligibility criteria, and on its definition of such conditions as physical.

We note that mental disorder, mental disability or mental incapacity are not included within the proposals’ eligibility criteria. Should there ever be any re-evaluation of this aspect of the proposals, we would expect to participate comprehensively in this process. We wish to point out, however, that physical conditions commonly co-exist and interact with mental health conditions.

Psychiatrists are often the primary treating clinicians for people with dementia, brain injuries of various forms, and functional neurological illness. Acknowledging that psychiatrists may become involved in such cases as a result, clarity on precisely how psychiatrists in Jersey may be required to participate in the process for patients with neurodegenerative illness, brain injury or functional illness is required.

Q. 5 Do you agree that the definition for jersey resident should only include those ordinarily resident in Jersey for 12 months?

Yes ☐

No ☐

Don’t know ☐
Other, please state ☒: No comment.

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 6 Do you agree that assisted dying should only be permitted for people aged 18 or over?

Yes ☐

No ☐

Don’t know ☐
Please tell us the reasons for your response:

We offer no comment on whether assisted dying should only be permitted for people aged 18 and over. However, should there ever be any re-evaluation of this aspect of the proposals, we would expect to participate comprehensively in any consultation as this would impact the services our members operate, as well as people who use these services.

<u>Section 4 – Assisted Dying Service</u>

Q. 7 Do you agree that the Jersey Assisted Dying Service should be free to people who want an assisted death and who meet all criteria?

Yes, it should be free ☐

No, it should be paid for ☐

Don’t know ☐
Please tell us the reasons for your response:

We offer no comment on this point.

Q. 8 Do you agree that health professionals should have the right to refuse to undertake a supporting assessment (or provide their professional opinion), if that information may be used by an Assessing Doctor to make a determination on the person’s eligibility for an assisted death?

Yes, they should have the right to refuse ☒

No, they should not have the right to refuse ☐

Don’t know ☐
Please tell us the reasons for your response:

We understand that, where a coordinating doctor is unable to determine matters relating to a person's illness, health condition, prognosis, life expectancy and treatment options, or their decision-making capacity when determining a person's eligibility for assist dying, then they must, with the person's consent, seek the opinion of another relevant professional with appropriate skills and training to support them to make a determination. As a result, psychiatrists may be asked by a coordinating doctor to make a judgement regarding a person's decision-making capacity in complex cases.

While paragraph 47 of the consultation report states that the law "will explicitly provide that no person can be compelled to directly participate in assessment, approval, or delivery of an assisted death," consideration is yet to be given as to which tasks or activities constitute direct participation in an assisted death. Therefore, the report does not specify whether a psychiatrist's role in the process would constitute "direct involvement" in an assisted death.

It is our view that carrying out a capacity assessment for a person who has applied for assisted dying constitutes direct involvement in the process. While the consultation report makes it clear that it is the assessing doctor who is ultimately responsible for determining whether a person is eligible for an assisted death, it also makes it clear that other relevant professionals will only be contacted to provide a supporting opinion should the assessing doctor be unable to determine a person's eligibility. A psychiatrist, for example, would only be asked to conduct an assessment of a person's decision-making capacity should the assessing doctor be unable to make this determination themselves. Such an assessment, then, would likely have a direct influence on the assessing doctor's determination of eligibility.

Psychiatrists must be afforded the right to conscientiously object to undertaking a supporting assessment, such as an assessment of a person's decision-making capacity. We expect that anyone who conscientiously objects to participating in the process be afforded the right to do so, and that this right be extended to all clinicians who may be called on to participate in the process.

Given our clear expectation of conscientious objections being allowed, a robust process for clinicians opting out of this care should be included in drafting the law on this issue, and in the implementation of an assisted dying service in Jersey. Doing so would ensure that the obligation to meet the patient's needs falls on the system, rather than the individual clinician. Clarity on when a clinician refuses to participate, and whether they are obligated to find a replacement, is required.

There would also need to be consideration given to the additional demands this would place on mental health services where one or more staff members conscientiously object to participating in the process. In areas with limited specialist staffing, this could create significant issues in providing that capacity assessment in a timely fashion. In essence, any system must be flexible to an individual's wishes, while also accounting and delivering the patient's wishes as a systems obligation.

It is not yet clear whether a different threshold for capacity would be required than is already in law in Jersey. There needs to be clarity as to what level of capacity is felt to be appropriate to make such a decision, and whether a higher threshold would be required. Additionally, despite there being an expectation that non-mental health focused clinicians are trained in adults with incapacity legislation, our members have previously reported that there is a general uncertainty around using it that can translate to patients needing to be seen by psychiatrists and other mental health professionals unnecessarily. Consideration must be given to any additional training required to ensure clinicians are prepared to assess capacity more widely and in these particular scenarios.

We also note that the development of guidance on assessing capacity is the responsibility of the proposed HCS Service Delivery and Assurance Board. We expect that any guidance, and any relevant legislation, specifies which professionals may be called on to provide capacity assessments. Clearly defining who these professionals would be will help ensure that, for what is a highly significant assessment, only those with sufficient expertise to make such a decision are utilised. We would urge, though, that psychiatrists would not expect to be routinely asked to be involved in determining whether people are able to make the decision about assisted dying.

Focusing on the services in which psychiatrists operate, we expect the impact to fall on mental health services to the extent that additional capacity assessments will be required. This impact would need to be assessed prior to implementation, including implications for staffing. Doing so would ensure any additional staff needed to deliver provisions could be contracted ahead of time.

Q. 9 Do you think that conscientious objection clause should provide a premise owner / operator the right to refuse an assisted death on their premises (for example, a care home provider may choose not to permit a resident to have an assisted death in their room, even though it is the person's place of residence or care)?

Yes, they should have the right to refuse ☐

No, they should not have the right to refuse if the person who wants an assisted death is resident or being cared for in the premises ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 10 Do you agree that the assisted dying register should be public?

Yes ☐

No ☐

Don't know ☒

Please tell us the reasons for your response:

We have selected 'Don't know' as we do not hold a view on whether such a register should be made public. An opt-in register of who was willing to participate, including psychiatrists, would need to be carefully considered. It would not be out of the question for organisations vehemently opposed to the proposals to attempt to access that register in order to personally target clinicians who engage in the process.

<u>Section 5 , Part 1 – assisted dying process: request and approval</u>

Q. 11 Do you agree that the nine proposed steps are all necessary?

Yes ☐

No ☐

Don't know ☒

Please tell us the reasons for your response:

We have selected 'Don't know' as we do not hold a view on whether the nine proposed steps are necessary. From the perspective of our members and the services in which they operate, ensuring any resulting activities of the proposals do not significantly increase demand on mental health services to the detriment of other patients is important. The sustainability of services, and the impact of these duties on the workforce, should be considered.

Q. 12 Do you think there are any further steps / actions that should be included?

Yes ☐

No ☐

Don’t know ☒

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not hold a view on whether further steps or actions should be included.

However, our members have noted that psychiatrists’ involvement in the process may include assessing and treating mental illness in someone who has requested assisted dying, and that it is possible that psychiatrists may be asked to support a person, and their friends and family, while they go through the proposed steps. We would expect that any future legislation and implementation plans take this into account.

Q. 13 Do you agree with the proposed minimum timeframe for those with a terminal illness of 14 days?

Yes – I agree ☐

No – I do not agree ☐

Don’t know ☒

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not have a view regarding the proposed minimum timeframe of 14 days for those with a terminal illness.

Consideration will need to be given to the additional demands the implementation of the proposals may have on the health system, with specific attention paid to mental health services where one or more staff members conscientiously object to participating in the process, particularly for cases relating to people with neurodegenerative illness requiring supporting assessments from psychiatrists.

Additionally, 14 days from first request to assisted death might put our members under undue pressure to form an opinion. We would expect that any future legislation and implementation plans explicitly ensure that specialists employed to provide further assessments, advice or information, such as psychiatrists, are not placed under undue pressure to provide opinions without adequate time.

Q. 14 Do you agree with the proposed minimum timeframe for those with unbearable suffering of 90 days? *Yes – I agree* ☐

No – I do not agree ☐

Don’t know ☒

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not have a view regarding the proposed minimum timeframe for those with unbearable suffering as set out in the consultation report. However, further consideration does need to be given to the additional demands that may be placed on mental health services where one or more staff members conscientiously object to participating in the process. In areas with limited specialist staffing, this could create significant issues in providing supporting assessments in a timely fashion.

Q. 15 Do you agree that the law should not prohibit professionals from raising the subject of assisted dying?

Yes – I agree ☐

No – I do not agree ☐

Don’t know ☒

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not have a view regarding whether professionals should be prohibited from raising the subject of assisted dying. However, should the law not prohibit professionals from doing so, we would expect that, in drafting the law on this point, provisions be set out to ensure that this would not supersede discussions focused on relieving suffering, improving quality of life, or treating mental illness.

Q. 16 Do you agree that the law should not place an explicit requirement on relevant professionals (e.g. those working in GP surgeries or hospital departments) to tell people about the assisted dying service?

Yes – I agree ☒

No – I do not agree ☐

Don’t know ☐

Please tell us the reasons for your response:

The proposals currently require relevant professionals who receive a request for assisted dying to refer the person for an assessment, even if they conscientiously object to the process. In practice, such a requirement may mean that relevant professionals would have to refer any person for an assisted dying assessment if requested to do so, including for patients who do not meet the criteria. Under the current proposals, a psychiatrist, for example, may be asked to do so by a suicidal adult they are caring for. This may impact a psychiatrist’s ability to establish a therapeutic relationship with the patient and treat the person for a mental disorder. There needs to be clarity as to whether it is the duty of the clinician to refer every patient who requests it, or if discretion can be used in instances when it is clear that a person does not fulfil criteria for assisted dying.

As previously stated, we expect that anyone who conscientiously objects to participating in the process be afforded the right to do so, and that this right be extended to all clinicians who may be called on to participate in the process. A robust process for clinicians opting out of this care should be included in drafting the law on this issue, and in the implementation of an assisted dying service in Jersey. Doing so would ensure that the obligation to meet the patient’s needs falls on the system, rather than the individual clinician. Clarity on whether a clinician is obligated to find a replacement in such instances would also be very helpful.

Q. 17 Do you agree that a person should only be entitled to one second opinion?

Yes ☐

No ☐

Don’t know ☐
Please tell us the reasons for your response:

We offer no comment on this point.

Q. 18 Should the law allow for confirmation of consent to proceed?

Yes ☐

No ☐

Don’t know ☒
Please tell us the reasons for your response:

We offer no comment on this point.

Q. 19 Should the law allow for the option of a waiver of final consent?

Yes – the law should allow for a waiver of final consent ☐

No – the law should not allow for a waiver of final consent ☐

Don’t know ☐
Please tell us the reasons for your response:

We offer no comment on this point.

Q. 20 Do you agree with the two different approval routes as proposed?

Yes ☐

No – all approvals should be by the Coordinating Doctor based their assessment and that of the Independent Assessing Doctor only (i.e. no requirement for a Tribunal) ☐

No – all approvals by the Coordinating Doctor should be confirmation by a Tribunal (ie. a Tribunal involved in all cases ☐

Don’t know ☒
Other, please state ☐ _______________________

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not have a view on the two approval routes as set out in the consultation report.

However, we note that paragraph 195 of the consultation report states that “there are distinct parallels with the assessment and decision-making processes that doctors currently make when alleviating suffering, knowing that it may hasten death.” We wish to note that palliative care interventions, including mental health interventions, are not intended to shorten life. We would therefore expect this point to be amended in drafting any future legislation.

Q. 21 Do you agree that the Tribunal should only review decisions of the Coordinating Doctor to approve Route 2 assisted dying requests?

Yes ☐

No ☐

Don't know ☒

Please tell us the reasons for your response:

We have selected 'Don't know' as we do not hold a view as to whether the tribunal should only review the decision of the coordinating doctor in instances where a person has been approved though route 2.

It would be helpful for the potential role of psychiatrists in relation the Tribunal to be clarified. Given the small number of psychiatrists in Jersey, we would expect that the implementation of the Tribunal considers the impact of its members potentially assessing an application of a person they may have treated or known for a long time.

Q. 22 Do you agree that the Law should provide for appeals to the Royal Court?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 23 Do you agree with proposed grounds for appeal?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 24 Do you agree with there should be at 48-hour time period between approval and the assisted death to allow for appeals?

Yes ☐

No – I do not agree, there should be no minimum time period for appeals ☐

No – I do not agree, there should be a time period longer than 48-hours ☐ *Don't know*

☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 25 Do you agree that the right to appeal should be restricted to the person (or their agent) or a person with special interest?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 26 Do you agree that there should be no expiry date for the approval of an assisted death?

Yes – I agree, there should be no expiry date ☐

No – I disagree, I think there should be an expiry date ☐

Other, please state ☒ Don't know

Please tell us the reasons for your response:

We have selected 'Don't know' as we do not hold a view as to whether there should be an expiry date for the approval of an assisted death. However, our members have raised the point that, as mental capacity and psychiatric condition can fluctuate, it may be sensible to have an expiry date on any given approval to account for changes to decision making capacity.

Section 6 – assisted dying process: planning and delivery of an assisted death

Q. 27 Do you agree that there should be an Administering Practitioner with the person or nearby?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 28 Do you agree that a loved one should be able to support the person to self-administer the substance?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 29 Do you agree that the medical certificate of the fact and cause of death, and hence the register of deaths, should accurately record the cause of death as assisted dying? *Yes* ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Section 7 – Regulation and oversight

Q. 30 Do you agree that an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the assisted dying service?

Yes ☐

No ☐

Don't know ☒

Please tell us the reasons for your response:

We do not hold a view on whether an HCS Service Delivery and Assurance Board is needed to provide oversight of the safety and quality of the proposed assisted dying service in Jersey.

However, RCPsych members in Jersey have raised that a range of training, education materials, and assessments would need to be developed for psychiatrists prior to the implementation of an assisted dying service in Jersey. We would expect that any implementation plans allow enough time for such training, assessments, and education materials to be developed.

Q. 31 Do you agree that post-death administrative review of each assisted death is required?

Yes ☐

No ☐

Don't know ☐

Please tell us the reasons for your response:

We offer no comment on this point.

Q. 32 Do you agree that the jersey Care Commission should independently regulate and inspect the Assisted dying service?

Yes ☐

No ☐

Don’t know ☒

Please tell us the reasons for your response:

We have selected ‘Don’t know’ as we do not hold a view on whether the Jersey Care Commission should independently regulate and inspect the proposed assisted dying service. As such, we make no comment on whether this body should operate within a pre-existing agency or needs to be separate and distinct.

However, there must be an effective monitoring system that monitors and implements safeguards to ensure that any future legislation is only used as prescribed. The ability to enable someone to end their life is a new concept and requires a statutory body with the ability to report on and act against any abuses of the system.

We seek greater detail on the reporting body, and how this would be constituted to monitor the use of the proposals. It would also be valuable to ensure clinicians involved in this process are given access to support and, potentially, care for their wellbeing following what may well be a personally traumatic experience for them.

Our members in Jersey have expressed specific concerns regarding the six principles of safeguarding, noting that the medical community in Jersey is small with only 12 psychiatrists. Regarding palliative care, members in Jersey have also raised the point that there is only one hospice in Jersey, and that there are no specialist dementia care homes. To staff an assisted dying service in jersey, clinicians would likely need to be taken from other services. This impact would need to be assessed prior to implementation, including implications for staffing. Doing so would ensure any additional staff needed to deliver provisions could be contracted ahead of time

Members in Jersey have also expressed concern that there is no regulatory body akin to the CQC in Jersey, and that it is unclear whether the necessary infrastructure currently exists to support the setting up and monitoring of an assisted dying service. We would expect that any future legislation, and plans to implement such a change in law, would require the development of robust governance processes to ensure that practices come under sufficient professional scrutiny.

Q. 33 Do you agree the Jersey Assisted Dying Service should not be considered as an essential service? (i.e., that the JCC should have the powers to close the service down)

Yes – I agree it should not be considered an essential service ☐

No – I disagree, it should be considered an essential service ☐

Don’t know ☐

Please tell us the reason for your response:

We offer no comment on this point.

26. The Christian Institute

The Christian Institute is a non-denominational Christian charity with 60,000 supporters across the British Isles, including in Jersey. We are opposed to assisted suicide and euthanasia as a matter of principle, and firmly believe that the proposals for an assisted dying service in Jersey will do far more harm than good.

There is simply no safe way to legalise euthanasia or assisted suicide. Once introduced, so-called safeguards will inevitably be eroded over time. Changing the law sends the message that suicide is an acceptable option for some, and endorses killing someone as a reasonable choice to make in the face of suffering.

Misuse of language

The consultation document states: "Assisted dying is not the same as suicide" (para. 11). This is unhelpful and misleading. Using the language of 'assisted dying' gives the public the impression that what is being proposed is broadly equivalent to palliative care – that it is about helping people in their dying moments. This is simply inaccurate and distorts the reality that the proposed law would permit medical professionals to kill their patients. That is a radical departure from doctors' duty of care and pledge to do no harm. In Canada, where both assisted suicide and euthanasia are legal, over 99% of deaths under the law are euthanasia.[314] It is vital that the public are fully aware of what is being proposed.

All life is valuable

Introducing euthanasia and assisted suicide will inevitably affect how, for example, elderly and disabled people view their own worth, and how they are viewed by others. It would plant the idea in the minds of some of the most vulnerable in our society that they are worth less than others.

The value of a human life is not based on perceptions of someone's autonomy, contribution or capacity. Once we start ranking the value of people's lives in this way, we breach a fundamental principle which protects everyone: that all lives are of equal value. Conceding this principle will have far-reaching consequences for our society. The law must not affirm the idea that some lives are not worth living. It sends the terrible message to suffering and vulnerable people that they have a duty to die.

Many disabled people are understandably fearful about what the future may hold for them and do not want the law changed.[315] The Chief Executive of Scope, which campaigns for the rights of disabled people, has said that many disabled people "too often" are looked on as a burden and as if it is not worth their being alive.[316] Where assisted suicide or euthanasia are legal, concerns about being a burden become a matter of life and death. Over half of those in Oregon who died by assisted suicide in 2020 and 2021 cited the fear of being a burden on others as a reason for ending their lives.[317]

Assisted suicide advocates give the impression that in order to have a death free from pain you must end your life. That is not the case. Palliative care experts Dr Carol L Davis and Baroness Finlay of Llandaff explain: "with modern analgesia pain is much easier to control than once it was". They concluded: "It is high time that the

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[314] *Third Annual Report on Medical Assistance in Dying in Canada 2021*, Health Canada, July 2022, page 19; *Second Annual Report on Medical Assistance in Dying in Canada 2020*, Health Canada, June 2021, page 13

[315] Not Dead Yet UK briefing note, February 2019, see http://notdeadyetuk.org/wp-content/uploads/2019/02/not-dead-yet-uk-briefing-note-as-polls-feb-2019-final.pdf as at 12 January 2023; 'Disabled people like me fear legal assisted suicide: it suggests that some lives are less worth living', Jane Campbell, *The BMJ Opinion,* 6 February 2019, see https://blogs.bmj.com/bmj/2019/02/06/disabled-people-like-me-fear-legal-assisted-suicide-it-suggests-that-some-lives-are-less-worth-living/ as at 12 January 2023

[316] Scope, Press Release, *Scope concerned by reported relaxation of assisted suicide guidance*, 20 January 2018

[317] *Oregon Death with Dignity Act: 2021 Data Summary,* Oregon Health Authority Public Health Division, February 2022, page 13

argument that ‘assisted dying’ is necessary to avoid a painful death is exposed as a fallacy.”[318] Data from Oregon reveals that concerns about pain or lack of control of pain are well down the list of reasons given by people seeking fatal drugs.[319]

More effort should be put towards ensuring high-quality specialised palliative care. But legalising euthanasia and assisted suicide will reduce investment in this kind of end-of-life care. Caring for terminally or chronically ill people is expensive. In US states that have legalised assisted suicide, terminally ill patients have seen medical insurance companies refusing to fund their treatment but offering to fund assisted suicide.[320]

And it is clear from the picture on the mainland that more needs to be done. Although the UK has some of the best palliative care in the world[321], Hospice UK estimated that in 2017 118,000 people who needed palliative care could not access it.[322] Access to proper, specialised palliative care is essential to relieve suffering, and must be prioritised in Jersey.

Eligibility criteria

The experience of other countries which have legalised euthanasia or assisted suicide is that the number of deaths under the laws increase year on year and eligibility criteria expand over time. This would inevitably be the case in Jersey as well. The proposals are already worryingly broad.

Under route 2, a person only needs to have an “incurable physical medical condition, that is giving rise to unbearable suffering that cannot be alleviated in a manner the person deems tolerable”. This is very subjective.

The law in the Netherlands also uses the phrase “unbearable suffering”, but the evidence shows it is not a desirable model to follow. There has been a marked increase in euthanasia cases for dementia (from 12 in 2009 to 215 in 2021) and for patients with psychiatric disorders (from 0 in 2009 to 115 in 2021).[323] Hundreds of euthanasia cases have involved elderly people who were not seriously ill but had conditions associated with normal old age.[324] Euthanasia has become so accepted that there are attempts to open it up to those who are simply “tired of life”.[325]

International evidence show that the legal criteria also expand, sometimes very quickly.

Canada legalised euthanasia in 2016, and cases have jumped significantly each year. There were 10,064 medically assisted deaths reported in 2021, a jump of 32% compared to 2020, which itself was 34% higher than 2019.[326] But already it has scrapped the requirement for a person’s death to be ‘reasonably foreseeable’ and has voted to widen the law to include people with mental illness, although the implementation of this has been delayed.[327] A court ruled that to restrict euthanasia to the terminally ill was ‘incompatible’ with Canadian

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[318] *The Times,* 6 November 2020

[319] *Oregon Death with Dignity Act: 2021 Data Summary,* Oregon Health Authority Public Health Division, February 2022, page 13

[320] *The Telegraph online,* 20 February 2009, see https://www.telegraph.co.uk/comment/personal-view/4736927/Right-to-die-can-become-a-duty-to-die.html as at 12 January 2023; *New York Post online*, 24 October 2016, see https://nypost.com/2016/10/24/terminally-ill-mom-denied-treatment-coverage-but-gets-suicide-drugs-approved/ as at 12 January 2023

[321] Finkelstein, E A, Bhadelia, A, Goh, C et al, ‘Cross Country Comparison of Expert Assessments of the Quality of Death and Dying 2021’, *Journal of Pain and Symptom Management*, 63(4), April 2022, pages 419-429

[322] *Sky News online,* 2 August 2017, see https://news.sky.com/story/more-than-100-000-terminally-ill-patients-denied-hospice-care-10970074 as at 12 January 2023

[323] *Regional Euthanasia Review Committees: Annual Report 2021,* March 2022, page 10; *Regional Euthanasia Review Committees: Annual Report 2009,* May 2010, page 5

[324] *Regional Euthanasia Review Committees: Annual Report 2021,* March 2022, page 13

[325] *The Sunday Times online,* 19 July 2020, see https://www.thetimes.co.uk/article/dutch-mp-backs-euthanasia-for-over-75s-who-are-tired-of-life-z8bdp6685 as at 12 January 2023

[326] *Third Annual Report on Medical Assistance in Dying in Canada 2021*, Health Canada, July 2022, pages 18-19

[327] *Global News online,* 17 March 2021, see https://globalnews.ca/news/7703262/canada-senate-passes-bill-c-7/ as at 12 January 2023; ‘Should Mentally Ill Patients Have the Right to Euthanasia?’, *Psychology Today,* 21

human rights and equality laws.[328] A parliamentary committee is currently looking into expanding the law to include children, and the Quebec College of Physicians has even suggested euthanasia for disabled babies.[329] There have been worrying cases reported in recent months showing how dangerous Canada's law is for the most vulnerable in society:

- Alan Nichols was accepted for euthanasia despite the only health condition listed on his application being hearing loss.[330]
- Joannie Cowie is considering euthanasia because of her poverty. She is physically disabled and has cancer. She lives with her disabled daughter on benefits, with no family support.[331]
- Rosie Ashcraft, 37, has Ehlers-Danlos syndrome and experiences chronic joint pain. Despite her belief that surgery will make her more comfortable, she has not been able to get an appointment with a neurosurgeon after four years. As a result, she is now contemplating euthanasia.[332]
- 'Denise' has medical approval for euthanasia after seven years of applying for affordable housing in Toronto. She suffers from a condition known as Multiple Chemical Sensitivity which means she develops rashes, suffers severe headaches and even temporary paralysis or anaphylaxis if exposed to common chemicals in things like washing powder and air fresheners. She is also a wheelchair user after an upper spinal cord injury.[333]
- Retired Canadian Forces Corporal and Paralympic athlete Christine Gauthier permanently injured her knees and spine after jumping into a deep hole while training. She describes how, while relating her condition over the phone to a Veterans Affairs employee, they said: "Well, you know that we can assist you with assisted dying now if you'd like."[334]
- Amir Farsoud has back pain, depression and anxiety, and has received medical approval for euthanasia. The house he shared was up for sale and he couldn't afford anywhere else.[335]

In 2014, Belgium became the first country to permit euthanasia for children, with no lower age limit, having initially only legalised it for adults in 2002. Euthanasia is now used much more broadly than in its early years. It is now applied to people with the first symptoms of chronic diseases like Alzheimer's, patients suffering from depression, and older people suffering a combination of complaints.[336] Euthanasia has become embedded in end-of-life care in Belgium and is increasingly seen as a reasonable choice. In 2021, there were over eleven times the number of euthanasia deaths than in the first full year (2,700 versus 235).[337]

We urge the Government of Jersey not ignore the overwhelming evidence that assisted suicide and euthanasia laws are dangerous and only get worse over time.

April 2021, see https://www.psychologytoday.com/ca/blog/finding-purpose/202104/should-mentally-ill-patients-have-the-right-euthanasia as at 12 January 2023

[328] *The Globe and Mail online,* 11 September 2019, see https://www.theglobeandmail.com/life/health-and-fitness/article-quebec-court-strikes-down-parts-of-laws-on-medically-assisted-death/ as at 13 January 2023

[329] 'Medical assistance in dying', *Government of Canada,* see https://www.canada.ca/en/health-canada/services/medical-assistance-dying.html as at 11 January 2023; *National Post online,* 11 October 2022, see https://nationalpost.com/news/quebec-college-of-physicians-slammed-for-suggesting-maid-for-severely-ill-newborns as at 11 January 2023

[330] *National Post online,* 11 August 2022, see https://nationalpost.com/news/experts-see-canadas-euthanasia-laws-as-threat-to-disabled as at 11 January 2023

[331] Global News Youtube video, 8 October 2022, see https://www.youtube.com/watch?v=ZD0O_w3HzJg as at 12 January 2023 (see from 1:23)

[332] *CTV News Vancouver,* 28 May 2022, see https://bc.ctvnews.ca/after-years-waiting-for-surgery-b-c-woman-considering-medically-assisted-death-1.5922445 as at 12 January 2023

[333] *CTV News Toronto,* 15 November 2022, see https://toronto.ctvnews.ca/toronto-woman-in-final-stages-of-maid-application-after-nearly-a-decade-long-search-for-housing-1.6145487 as at 12 January 2023

[334] *CTV News,* 3 December 2022, see https://www.ctvnews.ca/politics/paralympian-trying-to-get-wheelchair-ramp-says-veterans-affairs-employee-offered-her-assisted-dying-1.6179325 as at 12 January 2023

[335] *City News Ottawa,* 14 October 2022, see https://ottawa.citynews.ca/local-news/ontario-man-applying-for-medically-assisted-death-as-alternative-to-being-homeless-5953116 as at 12 January 2023

[336] Jones, D A, Gastmans, C and MacKellar, C (Eds), *Euthanasia and assisted suicide: lessons from Belgium,* Cambridge University Press, 2017, page 102

[337] *Dixième Rapport aux Chambres Législatives (années 2020-2021)*, Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie, page 2; *Premier Rapport aux Chambres Législatives: 22 September 2002 – 31 Décembre 2003*, Commission Fédérale de Contrôle et d'Evaluation de l'Euthanasie, page 7

Conscientious objection

A change in the law risks seriously undermining the rights of medical professionals. In Canada a care home in British Columbia lost $1.5 million of Government funding and was evicted from the building it rented because it refused to allow euthanasia.[338] In Belgium the law was changed to require care homes to allow euthanasia on their premises.[339]

Doctors, healthcare professionals and clinics must not be forced into participating in euthanasia or assisted suicide. Freedom of conscience on such controversial matters of life and death must be upheld.

No medical professionals or healthcare staff who object to euthanasia and assisted suicide should be obliged to participate in *any* part of the process. The Government should take note of the World Medical Association's position, which states that doctors should not be required to participate in assisted suicide or euthanasia deaths and "nor should any physician be obliged to make referral decisions to this end".[340]

Informed consent

The consultation document says that a person must have a "voluntary, clear, settled and informed wish to end their own life". However, the reality is that it is impossible to guarantee this. In fact, it is likely that in many cases there will be at least some element of compulsion felt by the patient, whether external or internal. The very fact of making assisted suicide and euthanasia legal means that it will always be an option which many people will feel they have to consider. The only way to guarantee the absence of coercion and duress is not to make it an option in the first place.

People can change their minds on any issue at any point. People who have terminal or chronic illnesses need a clear, firm law to protect them in their darkest moments. They certainly do not need the law to affirm their belief that their life is not worth living.

After the initial diagnosis of a serious illness, a person may well have immediate feelings of despondency, which could lead to suicidal feelings. But given time patients can get used to living with a serious illness or disability, and even regain a quality of life. A study of over 8,000 Irish adults showed that, over time, people who express a wish to die do change their minds, and the likelihood of a change in mind increases as time goes on.[341]

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[338] *CBC News online,* 14 April 2021, see https://www.cbc.ca/news/canada/british-columbia/delta-hospice-reopens-1.5987698 as at 12 January 2023; *LifeSiteNews,* 20 May 2021, see https://www.lifesitenews.com/news/health-authorities-terminate-35-year-lease-for-bc-hospice-that-refuses-to-euthanize-patients/ as at 12 January 2023

[339] *European Institute of Bioethics,* 21 February 2022, see https://www.ieb-eib.org/en/news/end-of-life/euthanasia-and-assisted-suicide/breaking-news-the-belgian-constitutional-court-rejects-the-appeal-relating-to-the-2020-law-on-euthanasia-2086.html?backto=search as at 12 January 2023

[340] 'WMA declaration on euthanasia and physician-assisted suicide', *World Medical Association,* 23 November 2021, see https://www.wma.net/policies-post/declaration-on-euthanasia-and-physician-assisted-suicide/ as at 12 January 2023

[341] Briggs, R, Ward, M and Kenny, R A, 'The 'Wish to Die' in later life: prevalence, longitudinal course and mortality. Data from TILDA', *Age and Ageing*, 2021, 50, pages 1321-1328

27. The Nursing and Midwifery Council (NMC)

Assisted dying public consultation

Government of Jersey

Ground floor

19-21 Broad Street

St Helier

JE2 3RR

By email to: AssistedDying@gov.je

12 January 2023

Dear Consultation Team,

Assisted dying in Jersey consultation

The NMC is the independent regulator of nursing and midwifery professionals in the UK. We welcome the opportunity to contribute to the consultation on the full proposals for assisted dying in Jersey. Assisted dying is an issue on which we adopt a neutral stance meaning that we neither support nor oppose attempts to change the law on assisted dying.

Our response focuses on aspects of the consultation that we view as particularly relevant to registered nurses, and where we can best offer our experience and support in our role as regulator. We have therefore set out our response in a letter rather than using the response template.

Regulation of nurses in Jersey

1.1 The NMC is responsible for setting education and professional standards, maintaining the register of professionals eligible to practise in the UK and taking regulatory action to protect the public where individual nursing and midwifery professionals do not practise in line with the NMC Code and standards.

1.2 Jersey is a Crown Dependency and not part of the UK. The Jersey States Assembly specifies that all nurses and midwives working in Jersey must be registered with the NMC.

1.3 The NMC and the Government of Jersey have signed a Memorandum of Understanding (MOU) which provides a commitment to consult one another

on any issues which might have significant implications and to refer fitness to practise concerns about nurses and midwives to the NMC.

23 Portland Place, London W1B 1PZ
020 7333 9333
www.nmc.org.uk

We're the independent regulator for nurses and midwives in the UK, and nursing associates in England.
Our vision is safe, effective and kind nursing and midwifery that improves everyone's health and wellbeing.

Registered charity in England and Wales (1091434) and in Scotland (SC038362)

1.4 All registered nursing and midwifery professionals are required to uphold the requirements the NMC Code at all times. The Code specifies registrants must "keep to the laws of the country in which they are practising"

(paragraph 20.4). All forms of assisted dying are currently illegal in the UK; therefore it would be unlawful for any nursing and midwifery professional to participate in assisted dying in the UK.

1.5 As Jersey is a separate jurisdiction from the UK, professionals practising in Jersey are expected to follow the law of Jersey. Therefore, the NMC Code will not prevent a nurse from participating in assisted dying in Jersey if it becomes lawful to do so under Jersey law.

1.6 Any nurse participating in lawful assisted dying in Jersey would be required to follow the NMC Code and the guidance and procedures established by the Assisted Dying Service. We would expect the assisted dying service in Jersey to have processes in place to support assisted dying practitioners in practice, to act first to deal with any concerns about a practitioner, and to refer concerns to us where there is a need for regulatory action to protect the public. We would be happy to work with you to develop a plan for managing concerns involving registered nurses and when you may need to make a referral to us.

Role of nurses in the Jersey Assisted Dying Service

2.1 The consultation proposes that the role of Administering Practitioner (AP) will be undertaken by a doctor or registered nurse who meet the qualifying criteria and in most instances the AP will prescribe the assisted dying substance. Only professionals on our register who have completed an NMC approved prescribing programme and have their qualification annotated on the NMC register are legally permitted to prescribe. As on 31 December 2022 there were 953 nurses on our register with an address in Jersey, of whom 63 had recorded one or more prescribing qualification (Community Practitioner Nurse Prescriber or Nurse Independent/Supplementary Prescriber).

2.2 We support the proposal to require assisted dying practitioners to have completed training prior to working in the Assisted Dying Service and to demonstrate the skills required for the scope of their role. This aligns with the expectation and professional standards in our Code (paragraphs 6.2, 13.5, 18 and 22.3). Nurses are required to keep their skills and knowledge up-to-date and be able to demonstrate this through our revalidation process.

2.3 Currently the consultation proposals limit assessment to medical doctors. Should the Government of Jersey wish to extend this we see no regulatory reason why suitably qualified and experienced nurses should not be able to participate in the assisted dying assessment as well as the delivery process. Our standards equip professionals with a wide range of professional knowledge and clinical skills, including assessing needs and planning care, and many nurses practise in highly complex and specialized roles.

Conscientious objection

3.1 Assisted dying is a sensitive topic that provokes a range of views among the public and health and care professionals. We support the proposal that the new law will provide for a conscientious objection clause so that professionals are not under a legal duty to participate in assisted dying. A legal right to conscientious objection already exists in the UK in two areas, for abortion and human fertilisation. Our Code makes provision for conscientious objection (paragraphs 4.4 and 20.7), and we have also published conscientious objection guidance.

3.2 We do not have a view about which tasks should be included in the scope of the conscientious objection clause. However, we agree that a nurse could not refuse on the basis of conscientious objection to carry out tasks which are within the normal range of their work, and which are not directly related to the assessment or delivery of an assisted death. It would be helpful if guidance on this area could be developed to support healthcare professionals.

Conducting conversations on assisted dying

4.1 We support the development of guidance for all health and care professionals to manage conversations around assisted dying and end-oflife options particularly as nurses may be approached first by someone raising the issue of assisted dying.

4.2 We expect individuals on our register to provide holistic and person-centred care. They must maintain a professional relationship with people in their care and keep the communication paths open so that they can continue to express their personal feelings, ideas, needs, concerns and expectations. We expect registered professionals to document all conversations and share any insights with colleagues as set out in our Code (paragraphs 8.6 and 16.4).

4.3 Paragraph 37 of the consultation states that the professionals required to deliver the Jersey Assisted Dying Service may include on-island and off island locums and agency professionals. The consultation does not address whether any aspect of the assisted dying process (e.g. conducting conversations on assisted dying or prescribing the substance) could be provided remotely. This issue should be addressed unambiguously in the final legislation and guidance for professionals. Because assisted dying is unlawful in the UK, a registered nurse would not be permitted to participate remotely (e.g. by video conference) in an assisted dying process in Jersey.

Doing so would be in breach of the NMC Code and may be a criminal offence in the UK.

Waiver of final consent

5.1 We agree with the proposal that the law should include the option for the person to complete a waiver of final consent. The Code requires registrants to act in the best interest of people at all times. They must make sure they have obtained and recorded informed consent before carrying out any action. If an individual does not have the capacity to give consent, registered professionals should keep to all relevant laws about mental capacity that apply on the country in which they are practising.

5.2 In our view, if a registered nurse is following the national laws of Jersey, then they should be able to meet the professional standards and the requirements in relation to ‘informed consent’.

As your proposals develop, we would be keen to feed back on the legislative drafting and we would be happy to work with you to develop guidance and supporting information for nurses, if that would be helpful.

I do hope you find our comments helpful. Please feel free to contact us if we can help any further.

Yours faithfully,

Matthew McClelland

Executive Director, Strategy and Insight

Policy@nmc-uk.org

28. Tōtara Hospice

Submission to the UK Parliament Health & Social Care Committee-Inquiry into Assisted Dying

Submitter:

Tina McCafferty
Chief Executive
Tōtara Hospice I Te Kahu Pairuri o Tōtara
Auckland
Aotearoa New Zealand

Reasons for submission

The submission responds to question 2: *What can be learnt from the evidence in countries where assisted dying/assisted suicide is legal?*

It is made in support of patient choice in healthcare. In support of patient rights and human rights where they pertain to the terminally ill and in support of excellent palliative care and assisted dying services being a complimentary continuum not opposing ideologies.

Having first-hand experience as a specialist palliative care provider Organisation who also hosts assisted dying to terminally ill patients who meet the legal criteria, we hope to offer some useful insights.

Introduction

Tōtara Hospice **I** Te Kahu Pairuri o Tōtara (TH) is an Aotearoa New Zealand (ANZ) registered charity (CC2168) and specialist palliative care provider (SPCP) offering inpatient, outpatient and at home hospice care across the districts of south and southeast Auckland, serving a community of approximately 600,000 people.

Now in our 40th operating year, we are one of ANZ's largest Hospices and its most culturally diverse; both in workforce and in community served. We actively collaborate across a range of care partnerships with secondary care, tertiary care, general practice, aged residential care and Māori and Pacific providers as well as service alliances with other Hospice providers across our region.

We have provided a hosting assisted death service (HADS) since November 2021.

Background

In October 2020 New Zealanders were given the opportunity to vote in a binding referendum on the End-of-Life Choice Bill 2019, which proposed to give those with a terminal illness (who met certain criteria including cognitive competence) the option of an assisted death. The referendum result was a majority 'yes' vote of 65.1% for the right of individuals with incurable disease to access assisted dying across Aotearoa New Zealand. On November 7th, 2021, the Bill became an Act of Parliament.

https://www.legislation.govt.nz/act/public/2019/0067/latest/DLM7285905.html

As a leadership team of a SPCP (CEO, General Manager Clinical Services, Head of People &

Capability, Medical Director, Nursing Director, Clinical Lead for Allied Health and Head of Cultural & Social Support) we had prepared for this outcome for a number of years (3 previous bills had gone through the NZ Parliament) and we chose to acknowledge and respect it. For a number of years in our belief and commitment to specialist palliative care providers working to destigmatise death and dying we ran a regular series of death cafes called the 'Departure Lounge'. We supported the use of Advanced Care Plans. We knew from conversation every other week with patients that this question of 'being able to legally choose' was sitting just under the surface (and often above it).

Contemporaneously, incrementally extensive training, debate information and education forums occurred for all staff (clinical and support) in the 24 months prior to implementation. Information and advice were provided to all volunteers.

The change management process was fundamental, critical and necessary. We had to be and were 100% transparent, we enabled judgment free debate, set clear expectations, recruited and retained for attitude and values. We were and remain explicit about how assisted dying fits with palliative care principles and practices, our service, our culture, our values and philosophy.

We would not have had a successful first year if we had not taken this approach. Clinical managerial leadership partnerships were so vital. Robust debate, inquiry, constructive challenges and the ability to find change campions. Equally vital. All entirely do-able. Not always easy. Totally worth all effort.

We drew upon the Ministry of Health resources, created our own. We developed our own policy and procedure in keeping with the Act. We have been and remain clear with all stakeholders that as an organisation:

- TH expects that any person under its care may ask about assisted dying services or choose to access this service. When a person asks for information about or access to assisted dying services, staff at TH will help the person to access this information or service (within the framework of the Act).

- A person must make their own choice to access assisted dying services and should do so without pressure from anyone else. Staff should be careful to avoid directly or indirectly encouraging someone to choose assisted dying.

- Equally staff should be careful to avoid directly or indirectly discouraging a person from choosing assisted dying. Staff should carry out their responsibilities under the Code of Health and Disability Services Consumers' Rights and ensure that a person is not prevented from accessing lawful medical care.

- Staff should use a person-centred approach during conversations about assisted dying. During these conversations, staff should keep in mind Ngā Paerewa: Health and Disability Services Standard NZS 8134:2021. In particular, they should consider the criteria in Section 1.4: E whakautetia ana ahau | I am treated with respect and in Section 1.6: Ka kitea ngā whakawhitiwhitinga whai hua | Effective communication occurs.

- If a staff member is not sure about how to respond or feels uncomfortable with something a person has talked to them about, they should speak to their direct line manager in the first practical instance or any of the Clinical Senior Leadership Team.

We studied other jurisdictions and understood that roughly less than 6% of eligible patients apply for an assisted death and only a very small sub percentage of those actually proceed. We understood that this was about autonomy, choice, safeguarding and the desire to control the means within the inevitable. We developed a network of peers from other jurisdictions (Canada, Australia and within ANZ). We knew from the working relationships formed with providers in other jurisdictions that there was little to no evidence of a thin end of the wedge or atrocities being committed. It was not a slippery slope.

In partnership with our Board the decision was made to go public with our deeply considered position via ANZ's most preeminent current affairs news programme:

https://www.youtube.com/watch?v=ztFwS6hBDrs

We commenced a formative evaluation with an independent researcher on lessons from the first year of implementation (results due March 2023).

Our position was contra to that of our peak body and to all other Hospices across ANZ. In summary we stated:

1. As an Organisation we did not conscientiously object to anyone accessing their rights under the Act/the law. We expected and respected differences to occur amongst people and organisations; we would focus on the needs of our patients and their loved ones. We remained united with our sector in our shared view that great palliative care should be accessible

2. We did not believe that the introduction of legal assisted dying had no place in palliative care, nor did we believe that these approaches were in competition or counter ideologies. Both were intervention options in the menu of services for the terminally ill.

3. Our firm support that patient centred care puts the patient in control of their choices regarding their care pathway, including their pathway at the end of their life.

4. Our firm belief that The EOLC Act 2019 has an important place in, and relationship with contemporary Hospice palliative care.

5. Our belief that the W.H.O. definition of palliative care should be updated to reflect societal changes across the world as this pertains to Assisted Death. We acknowledged that the spirit or intention of the definition is to promote palliative care as care that accepts death as inevitable and is not a curative paradigm. We do not accept that this statement was intended to prohibit patient choice or prohibit palliative care professionals and services working within societal changes/changes to norms/changes in the Law.

Key aspects of the Act that led to our position were that:

a. Only those with a physical terminally ill could access it. This meant that this was an act for the Hospice population. How could we be a Hospice and ignore this or deny patients choice? We shouldn't.

b. Only adults could access it.

c. Cognitive competence was a requirement

d. Transparency levels and the range of controls

e. Assisted death would not be a crime

f. Preventing/prohibiting or abusing patient choice would be a crime

g. The NZ voting public had made their views and their democratic voice clear

Of great significance to us was that the Act did not use the terminology 'suicide/assisted suicide'. This was critical. Patients who could access the service were already dying/ were terminal. They did not want to irrationally kill themselves. They wanted dignity and control in how they would die. Suicide has much stigma for the person and their loved ones and is an irrational act. Suicide prevents the fair pay out of insurance. Suicide should not be on the death certificate of someone who is terminally ill choosing an assisted death as the means of their inevitable death. Significantly we had experienced three suicide attempts from patients over the last couple of years because they could not access an assisted death service. One was successful and the others left the patient and their loved ones in a worse state. Such suffering. This could be prevented in the future. Work on suicide in the terminally ill has just been published in the British Medical Journal, (*BMJ* 2022;377:o1014) and makes grim reading on the consequences of lack of options around dignity, control and choice for the terminally ill.

The feedback from community was overwhelmingly positive. We received hundreds of phone calls, letters, emails, texts from the general public, healthcare providers, palliative care providers, academics and even clergy. All thanked us for having the courage to support patient choice and the leadership to implement services. There was a general backlash of various strengths regarding Hospices to objected to assisted dying. This was a shock to them but not to us. Hospices operate within democratic societies. ANZ is a progressive democracy. Hospices often found their roots in religious values. We accepted this and the reality that we TH are a Hospice for all, a progressive Hospice providing contemporary, patient centred palliative care in a complex and socially progressive environment.

Out of all the feedback we received only three (out of hundreds) expressed their disappointment (or stronger) that we would implement HADS. Two were from far right / religious /conservative organisations and one from an individual member of the public.

What has occurred to date

We provided our first HADS in January 2022 and in total have provided HADS to eleven very relived terminally ill, cognitively competent adults to the period closing 31st December 2022.

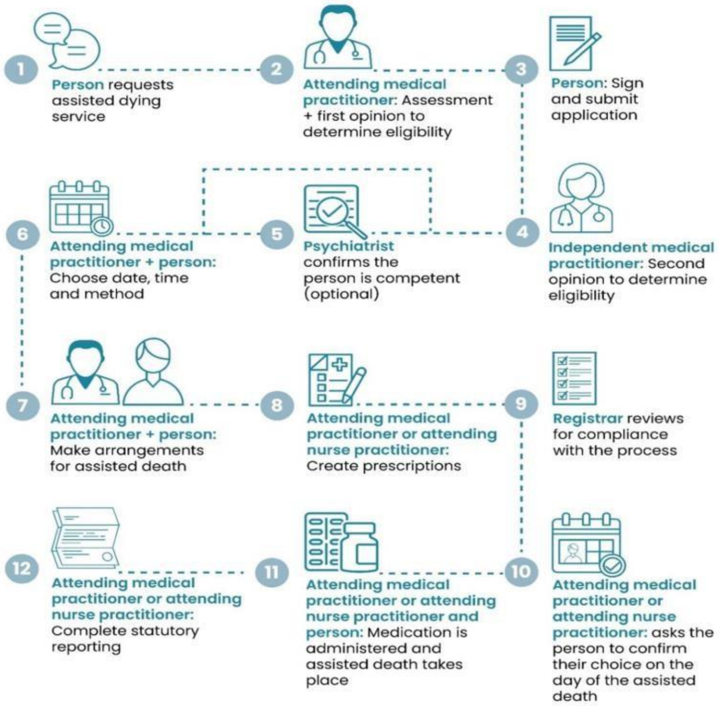
	AD Date	Age	Ethnicity	Gender	Condition
1	01/22	67	NZ European	F	MND
2	02/22	68	Fijian Indian	F	Cancer
3	02/22	58	NZ European	F	MSA
4	04/22	68	South African	F	Cancer
5	04/22	74	Chinese	M	Cancer
6	06/22	68	Dutch	F	Cancer
7	06/22	76	NZ European	F	Cancer
8	06/22	86	NZ European	F	COPD
9	08/22	54	NZ European	F	Cancer
10	11/22	80	NZ European	F	Cancer
11	12/22	72	NZ European	M	Cancer

This shows the number through to final act, not the number who have inquired or inquired and applied but who have died before approval or denied due to cognitive competency. The age range and ethnic/cultural backgrounds have been diverse. Gender is interestingly at this point more female.

We have discussed our position in public forums, conferences, with stakeholders and families, academic institutions. Cultural competence is of great importance. We are thankful to have a number of cultural liaison positions and an expectation of cultural competency in practice from staff as well as a diverse staff. Many Māori patients and family/whānau have been interested and we are supporting independent research on access for Māori. The only group to not appear broadly in the stats across ANZ is Samoan – which may be due to the strong religious orientation of this cultural group of people. It is ethically and socially just and important that wishing an assisted death is now as protected as not wishing one. No-one has to have an assisted death. However, importantly one person's 'no' cannot override another person's 'yes'. Patient choice is paramount.

Our Medical Director, Nursing Director, General Manager Clinical Services, have hands on intimately supported the provision of the eleven assisted deaths. They are supported to ensure a total care approach with patients and support loved ones via the Clinical Lead for Allied Health and the Head of Cultural and Social Support. We are supportive of any eligible TH employee undertaking an AMP role/providing assisted death directly. We actively partner with a network of Attending Medical Practitioners Medical and Nurse Practitioners who provide assisted death.

We are crystal clear on our process for individual conscientious objection both under the Employment Relations Act 2003 and under the End-of-Life Choices Act 2019. In summary our HADS service is provided within the following framework:



At the time of a person's assisted death, our HADS approach ensures that staff who are willing to participate can help make appropriate arrangements and encourage and support a person in arranging what is important to them. This includes understanding and considering needs specific to the person's culture and identity, such as needs related to religious beliefs and Te Ao Māori tikanga (e.g., kawa, blessing of rooms, rākau rongoā, mirimiri, karakia).

Staff, including me, have been involved in a number of ways:

- Providing access to a private room with space for whānau or family throughout the time the assisted death is taking place. Making this room available to whānau or family after the assisted death and making them aware of how long this room will be available to them after the person has died.

- Being present at a person's assisted death and participating/providing direct assistance to the external AMP if needed for the assisted death to take place and ensuring required supports are present for care of the person or their whānau/family, including to undertake post-death care. Staff who are present at an assisted death should have an opportunity to debrief.

- Talking to whānau or family about any cultural practices or rituals they would like to take place before, during or after the assisted death, and supporting these to take place.

- Arranging times and venues with external AMPs to provide care within our facility.

- Our specialist clinical team providing debriefing and supervision to providers with the assisted death provider network.

We are clear that our Duty of Care to a dying person from the process of inquiry, through to service provision of an assisted death does not replace or prevent the specialist palliative care a person is already getting. Instead, it provides another option for terminal patients receiving specialist palliative care.

As the concept-reality gap closed we had a turnover of circa 10% longer serving staff. Yet we had more applications for clinical roles than we ever had in our history. This has continued. Our workforce understands our research approach, and many have participated in providing the independent researcher with views, examples and information. Our research is guided by strict protocol.

Having been directly involved as a leadership team, I can say, with the backing of my team, that for these patients this is the right thing to do and is not at all at odds with our palliative care values, approach and principles. We have been privileged to be with them, support them, help them have their wishes met.

The network of practitioners is compassionate, patient centred, professional. All assisted deaths have occurred in a calm, loving, supported environment – just what a Hospice should do.

An outcome we did not predict was that we would be contacted by patients and providers from all over the country – not only our own coverage area. We have acted more than 50% of the time to provide service to those patients who legally meet the criteria but who have come up against conscientious objection at Organisation level. Who have access to a provider but do not have a venue e.g., they have been denied their right within aged residential care, a hospice, care facility etc. or are homeless or renting accommodation or are in such poverty they are overcrowded and under resourced.

We have been thanked by the Ministry of Health for our stance as otherwise we have been informed these patients were being told to rent a motel room, use a care park, basement or funeral parlour. Horrific.

We remain very well supported by patients, families and wider stakeholders. We are recognised as a pioneering Hospice service for ANZ by many. Other Hospices are beginning to engage with us and inquire about what we do, what it looks like, the response from staff and patients. We welcome this dialogue and hope to see the network expand.

We will be involved in the first-year review with the Ministry of Health's The End-of-Life Review Committee and we will be publishing our own research on organisational impact.

Concluding remarks

Our standard palliative care got better as assisted death made us question and review everything we do.

We had some turnover of staff from very traditional, conservative or religious backgrounds. We recruited and retained great staff also.

We acknowledge the right of conscientious objection of individuals and ensure we have a process. Everyone can have their view. Everyone must know and work with our Organisation approach within the Act and within our policy and procedure. Everyone must respect that we are a pro patient choice Organisaiton. The sky has not fallen in. There has been no drama.

- We must keep talking, training, refreshing, inquiring– maintaining the culture and the reasons are vital.
- Not having suicide at all levels as mentioned above has been fundamental.

- In pushing and leading change, we have respectfully forced conversations across our own and other sectors – we aim to have this continue. Some partner Hospices are now providing social support. It is a beginning

- Ethical questions and forums are critical to progress and change.

- Change management is vital.

- Transparency is vital.

- Education and information are vital. Misinformation is rife and emotive.

Having been directly involved as a leadership team, I can say, with the backing of my team, that for these patients this is the right thing to do and is not at all at odds with our palliative care values, approach and principles. We have been privileged to be with them, support them, help them have their wishes met.