

# ASSISTED DYNG IN JERSEY

Public engagement summary report

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#### 1. Introduction

#### 1.1 About this report

This report provides detail on the first phase of public engagement on assisted dying in Jersey.

It sets out an overview of engagement activity carried out during March and April 2022, summarises the hopes, thoughts and concerns that people shared and provides responses to the key questions they posed.

The report has 5 sections:

- 1. Introduction
- 2. Summary of engagement activity
- 3. Key themes approach
- 4. Key themes
- 5. Key questions

#### 1.2 Background to public engagement

In November 2021 the States Assembly decide 'in principle' to permit assisted dying and to arrange for the provision of an assisted dying service. They were the first parliament in the British Isles to do so.

The Assembly debate was informed by recommendations of the <u>Jersey Assisted Dying Citizens' Jury</u>. The Jury consisted of a group of 23 Islanders, selected at random, who were demographically representative of the Island's population.

During that debate, Assembly Members highlighted need for continued public engagement to help inform the development of the detailed proposals.

This report describes the first phase of public engagement process that took place in March and April 2022. It will be followed by a second phase of public engagement which will take place in summer 2022. This second phase of engagement will focus on the details proposal to be debated by the States Assembly in autumn 2022. Should those proposals be approved, the Assembly will debate draft legislation in, or around, Spring 2023 after which an implementation period would be required before the legislation permitting assisted dying comes into effect.

#### 2. Summary of engagement activity

This first phase of public engagement on assisted ran for four weeks between 9 March and 14 April 2022. During this period, the Government of Jersey asked Islanders to share their thoughts, hopes and concerns around assisted dying through a number of channels, both online and in-person. This activity is noted below, further detail can be found in appendix 1.

#### 2.1 In-person engagement opportunities

Islanders were invited to 'drop-in' sessions to share their views with Government of Jersey policy officers. People were requested to book online via Eventbrite, but those who did not pre-book were also welcomed at the sessions.

The sessions were advertised on www.gov.je, via social media, advertisements in the Jersey Evening Post and Bailiwick Express, radio adverts on Channel 103, digital screen advertising in public locations including Liberation Station, and through key stakeholder organisations.

Location	Date and time
St Clement Parish Hall	Friday 18 March Any time between 11.30am to 1pm
St Brelade Parish Hall	Thursday 24 March Any time between 12pm to 1.30pm
Town Library	Wednesday 30 March Any time between 4.30pm to 6.30pm
Town Library	Thursday 31 March Any time between 11.45am to 1.45pm

#### 2.2 Online engagement opportunities

In addition to in-person events Islanders could also share their views online. They could do so anonymously or provide their name, as they wished. This included:

- Emails to <u>assisteddying@gov.je</u>
- Responses to Government of Jersey social media posts
- Anonymous posts on sli.do

In total 63 responses were sent to <u>assisteddying@gov.je</u>, 50 social media comments were made and 171 people participated via sli.do, a total of 55 questions were posed and there was an engagement score of 170 (total number of questions and likes).

#### 2.3 Wellbeing and support

Assisted dying is a sensitive topic which can give rise to distressing feelings for some people. On gov.je and social media posts links were provided to mental health and wellbeing support services. This information was also available at the drop-in session plus a number of the session facilitators are Mind Jersey trained Mental Health First Aiders.

#### 2.4 Target audience for engagement

The public engagement sought to hear the views people aged 18 and over. The Children's Commissioner has advised that children aged under 18 years old should not be engaged unless by specialist experts due to the sensitive and potentially distressing nature of assisted dying.

The views of campaign groups were not explicitly sought, although contributions were received from Channel Islands Humanists, Living and Dying Well, and End of Life Choices Jersey (see appendix 2).

#### 2.5 Activity to promote participation in the public engagement

Making Islanders aware of the public engagement was extremely important. The following were used to draw attention to the engagement and to encourage people to have their say:

- Information on the Government of Jersey website (highlighted with a site-wide banner on gov.je homepage)
- Full page advertisements in the Jersey Evening Post (Appendix 1.1)
- Bailiwick Express advertisements (Appendix 1.2)
- Google advertisements (Appendix 1.2)
- Radio advertisements on Channel 103 (Appendix 1.3)
- Social media posts (Appendix 1.4)
- Digital screen advertisements at Liberation Station and the Clock Tower, King Street (Appendix 1.2)
- Leaflet distribution (see below)

To make sure that information on assisted dying proposals was accessible, information leaflets were produced in:

- English
- Portuguese
- Polish
- Romanian

These leaflets are available on <u>gov.je/assisteddying</u> and digital and paper copies were distributed via Caritas and the Association of Jersey Charities.

Summary of online and in-person responses received:

Source	Number of respondents	
In-person events	65	
Email submissions	63	
Social media comments	50	
Sli.do participants	171 participants (55 questions posed)	
Total	349	

#### 3. Key themes – approach

#### 3.1 Approach to summarising responses

The purpose of public engagement was not to gauge whether Islanders support assisted dying<sup>1</sup> – as the States Assembly has already decided, in principle, to permit it in Jersey - but to provide an opportunity for people to ask questions or share their hopes, thoughts or concerns.

This report summarises the range of views shared (see Key Themes) and questions asked (see Key Questions) but does not set out to give weight to the responses received, except by indicating the strength of response where relevant.

#### 3.2 Personal responses to the engagement process

Many Islanders who contributed to the engagement process shared their personal experiences of death and assisted dying, which included accounts of personal illness and bereavement. These contributions are not described in detail in this report but the themes they touch on are reflected below.

We are very grateful to all for sharing these experiences.

<sup>&</sup>lt;sup>1</sup> Research and opinion polls carried out in Jersey, in the UK and internationally suggests that a majority of the population are in favour of assisted dying. This engagement process was not attempted to replicate that work.

#### 4. Key themes

Responses to the engagement have been clustered into 6 key themes. Some reflect arguments presented in the wider ethical and moral debate on the issue, others focus on the practicalities and implications of establishing an assisted dying service in jersey.

#### 4.1 Personal and societal experiences of death and dying

#### Desire for more open dialogue around death and dying

Many responses expressed a wish for a cultural shift in the way death is considered in society. They want the subject to feel less taboo and to be spoken about honestly and openly, and not just amongst those who are close to the end of life.

This included a desire for people to discuss their end-of-life choices at an early stage, including matters related to their will, financial affairs and funeral arrangements, and matters such as lasting power of attorney and decisions related to end-of-life care, including advanced decisions to refuse treatment. Or, in future, the wish whether or not to have an assisted death.

#### Acknowledging 'bad deaths'

Personal experiences of deaths of loved ones were raised frequently during the engagement process. For some, these were stories about a 'good death' which was peaceful, including symptoms and pain being well managed, and an experience that was not unduly distressing for both the individual and their family.

However, for others, there was a need to share and publicly acknowledge that there are 'bad deaths', even with excellent support and palliative or end of life care. For these people, watching loved ones come to the end of their life, sometimes slowly, and in intolerable pain was a traumatic experience. One that they think may be alleviated in future, with the introduction of assisted dying.

#### Autonomy of choice

Some of those who expressed support for assisted dying talk about it as a something they would want for themselves, depending on their future health. Others did not necessarily see it as an option for themselves, but rather they held a view that everyone should have a right to choose what happens at the end of their life. For some this was seen in the context of choice and control over one's health and medical decisions, in the same way an individual has a choice about other health and medical treatments, for example the option to make a personal decision to not undergo chemotherapy, even if it is the recommended course of treatment.

#### Experience of assisted dying in other jurisdictions

Some shared experiences of friends and loved ones having assisted death in countries including Switzerland, the Netherlands and Canada. Those who shared their experience considered it to be a largely positive, particularly for those who were resident in that country. For those who travelled to Switzerland, the stresses of funding, travel and legal uncertainty (fear of prosecution of family members) weighed against the benefits of seeking an assisted death to end their suffering.

#### 4.2 The role and impact on medical professionals

#### The option to conscientiously object

The importance of medical professionals being able to choose whether or not to participate in an assisted dying service was seen as paramount. Some expressed a concern that even with a 'conscientious objection clause' some doctors may feel pressured to take part.

#### Availability of doctors willing to participate

Some responses queried whether any doctors on island would actually be willing to participate in an assisted dying service, others suggested health care professionals should be surveyed to gauge whether there would be sufficient numbers on island to support an assisted dying service. [As part of this engagement process, a small number of doctors did proactively make contact to express that they would be willing to participate in an assisted dying service.]

#### Tensions in the role of doctors to prevent suffering or preserve life

The tensions of the duty of doctors to both prevent suffering and sustain life were noted in submissions from those both in favour and opposed to assisted dying. Those against it, felt this tension made assisted dying an impossible choice for doctors. Others noted a legal mandate to assist a patient to die would support doctors who felt that alleviating suffering was their principal duty.

#### Clarity over role in overseeing end of life care

Some raised the issue of the unspoken practice of doctors providing high doses of pain relief to hasten a death. They felt that a legal framework for assisted dying could provide clarity over medical intervention at the end of life in such instances.

Others cited the case of Harold Shipman, noting that assisted dying legislation would not have prevented this situation. Others were clear that this example of a convicted killer is not valid and assisted dying laws would provide safeguards and guidance for health professionals participating in the process to prevent abuse.

#### Medical complications during the procedure of an assisted death

Many responding to the public engagement wanted to understand more about the actual procedure of an assisted death. Some expressed a concern for things going wrong, such as an assisted death taking longer than expected or being a distressing experience for the individual or family members. They wanted to understand more about medications taken and the role of the doctor.

#### 4.3 Eligibility for an assisted death

The States Assembly, in debating assisted dying, were of the view that more consideration should be given as to:

- whether people should be able to make an advanced decision in relation to assisted death, and
- whether assisted dying should be permitted for people aged 17 or under.

Both these subjects were discussed extensively in the drop-in sessions as well as other eligibility criteria.

#### Advance decisions

An advance decision is where a person determines what care or treatment they want or do not want in advance of requiring it. For example, some people make an advanced decision not be resuscitated if they have a heart attack.

Many who attended the in-person sessions were in favour of the introduction of assisted dying and in favour of advanced decisions. They felt the law should permit a person to make an advanced decision to have an assisted death if, for example, they lost the ability to make that decision at a later date (for example, if they were in a coma or they lost capacity due to dementia). In particular, people spoke of loved ones diagnosed with dementia who had expressed a wish early in their diagnosis for an assisted death.

Whilst there was a lot of support for advanced decisions people acknowledged they are very difficult to provide for, in particular they recognised the importance of an individual giving their consent, and having the opportunity to change their mind, at every stage of the process. For example, a person may decide in advance that they want an assisted death if they get a certain condition but change their mind at a later stage but lack the ability to communicate that.

#### Under 18 years old

There was no definitive view as to whether children under 18 years old should be permitted an assisted death. Some people thought that those aged under 18 may not have the maturity to make such a decision. Others felt children and young people should not be denied an option afforded to adults. Overall, the majority view was to legislate for adults aged over 18 years only and potentially reconsider in future.

#### Residents only

The majority expressed the view that an assisted dying service should only be available to residents, and that Jersey should not become a destination for 'suicide tourism'. Views varied on how a 'resident' should be defined, and what length of time an applicant may need to have lived in Jersey to be eligible. A minority felt it would be more equitable if Jersey provided for anyone who wanted an assisted death and others noted the potential financial benefits of providing assisted dying to non-residents.

#### Terminal illness

Whilst some agreed that 6 months felt to them an appropriate timeframe for those diagnosed with a terminal illness to request an assisted death, others – both those in favour and opposed to assisted dying- were not comfortable with a specific time-period for defining terminal illness. They noted comments from many medical practitioners on the difficulty in accurately predicting life expectancy. Others noted the Canadian terminology that deaths that were either 'reasonably foreseeable' or 'not reasonably foreseeable.'

#### Defining unbearable suffering

The decision made by the Assembly to allow those experiencing unbearable suffering to have an assisted death, even where they do not have a short life expectancy, was welcomed by most who attended the in-person sessions, although some felt it should be restricted to those who were already near to the end of their life.

Many acknowledged that suffering was ultimately a personal and subjective experience, and the individual concerned was the only person who could determine whether their experience was unbearable. For some, this raised questions over how this would feature in the application and assessment process. Others questioned the interaction between mental and physical health and how the cause of suffering was determined.

#### 'Slippery slope' of eligibility vs. responding to societal views

Several online submissions articulated a concern that over time criteria for eligibility would inevitably widen (for example, allow for those aged under 18 or those whose only medical condition is a mental illness) citing jurisdictions such as Canada where eligibility criteria have widened over time. Some also expressed a concern that numbers requesting an assisted dying would continually increase.

Others stated that if, in time, a decision was taken by the States Assembly to widen eligibility criteria, this would be in response to evolving societal views at the time the decision is taken.

#### 4.4 Safeguards and approval process for an assisted dying service

#### Navigating the process

Participants clearly articulated the need for an assisted dying service to be designed around the patient i.e., the service should be straightforward and equitable to access and should support the individual (and their family) at every stage of the process. There was some concern that an overcomplicated process may deter those who are eligible, given they will be in a vulnerable position and experiencing suffering.

#### Court or Tribunal involvement in the pre-approval process

Concerns were raised at the in-person events about including the courts or a tribunal in the decisionmaking process. Some people thought it would be an unnecessary burden, increasing the time taken to determine requests for an assisted death. Conversely, others noted that judicial involvement was an important safeguard which added integrity and accountability to the process, a benefit both for applicants and the medical professionals involved.

#### Detecting coercion

The concern most frequently expressed during the engagement process was the fear of an individual being coerced into requesting an assisted death. Some felt that no safeguard could mitigate against this risk (for example, where there was implicit pressure that it would be better for other family members if death was sooner rather than later), particularly in instances of 'covert' coercion. People were also unsure as to whether doctors would be able to detect coercion. Others felt that a robust assessment process, which included family members, would be sufficient to identify coercion.

#### Role of the family

Many cited the importance of involving family members in the assessment process, both in order to safeguard against incorrect assessments of eligibility, but also in order to support family members as well as the patient throughout the process in terms of both practical and emotional support. Some noted the need for this support to extend beyond the death of their loved one.

#### Fluctuating circumstances and decisions

Whilst the 'in principle' decision made by the States Assembly notes that a request for an assisted death must be 'settled', some responses to the public engagement raised concern over those whose health conditions fluctuated in terms of 'peaks' and 'troughs' in their physical and mental health. There was a concern that they may choose an assisted death, even though in future, their condition - and suffering - may improve.

#### Impact on suicide rates

Comments online (via sli.do) raised a concern about a possible rise in suicide rates with the introduction of assisted dying. Others raised concerns that without assisted dying, suicide rates amongst those with health conditions that result in unbearable suffering could rise. (See the Key Questions Section below)

#### Pre and post death scrutiny

Online contributions noted the importance of oversight and clear record keeping both during the assessment process and once an assisted death has taken place.

4.5 Funding, personal financial implications and provision of end-of-life services

#### Funding for all end-of-life provision

Most contributions signalled the need for continued improvements and funding for all end-of-life care services, both those provided by government and by other organisations. It was very clear that people believe that assisted dying should be a 'real choice', one that is made by a person who wants

some control over the end of their life, as opposed to a 'false choice', one that is made by a person who believes they will not receive the care they need.

Some expressed a fear that the introduction of assisted dying would lead to a decline in the funding or quality of other services, 'fund and support living, before you fund and support dying'.

#### Issues with accessing other services

Some submissions expressed concern that inadequate provision, or limited access, to other related services were more important, for example, mental health services and domiciliary care. A sense of *'other things need fixing first'*, before assisted dying can be introduced to Jersey.

#### 'False choice' of an assisted death

As set out above, people expressed concern about assisted dying being a 'false choice'. Not just in relation to an individual's ability to accessing the health and care services they need but also with regard to other external factors, beyond their health, that may impact their suffering, for example inadequate housing. Some people sought assurance that the assessment process would take into account factors behind a request for assisted dying, to ensure these related only to the suffering caused by the health of an individual.

#### Cultural and societal pressure for an assisted death

Similarly to 'false choice', some participants were concerned about individuals choosing an assisted death for the 'wrong reasons'. For example, if someone diagnosed with a terminal illness chooses to shorten their life in order to save care costs so they may pass an inheritance to children or grandchildren. Others were worried about people choosing an assisted death to avoid being a burden on family members in their final months.

#### 4.6 The process of legalising assisted dying in Jersey

#### Make it happen

Those in favour of assisted dying who contributed to the public engagement were keen that progress was made at pace. Some felt they had already 'waited too long' or were concerned that the legislation would come too late for their personal circumstances. Others worried about that politicians would block the progression of the legislation, 'don't ignore public opinion'.

#### Learning from elsewhere

At the in-person sessions, some people stated that Jersey must learn from the experience of jurisdictions that have already introduced assisted dying. Some were positive about Jersey leading, not 'following' the rest of the UK.

#### Keep the public informed at every step

Many reiterated the need for continued public engagement as the legislation is developed, and for effective and wide-reaching information campaigns in the event an assisted dying service is established. Participants considered it extremely important that people know their rights and the options available to them. This was felt to be of particular importance for certain groups, including those with English as an additional language and those with other barriers to accessing information, for example those with sight impairment.

#### 5. Key questions

The questions below were frequently asked during the public engagement process. They are grouped into the same themes used Section 4. As the engagement process continues to roll-out <u>www.gov.je/assisteddying</u> will be updated with the additional questions and answers.

#### 5.1 Personal and societal experiences of death and dying

#### Q. What does assisted dying mean?

A. Assisted dying is where a person who has a terminal illness, or experiences unbearable physical suffering, chooses to end their life with the help of a medical professional.

Assisted dying is not the same as suicide. Assisted dying is a service provided to people in certain limited circumstances that will be set out in law.

Those who choose an assisted death may self-administer drugs to end their life or be supported by a medical professional who administers the medication.

#### Q. How do I request an assisted death?

At present, the legislation is not in place to request an assisted death in Jersey. This is likely to be an option in the future if the States Assembly approve legislation to permit this. However, in the meantime you may wish to discuss your end of life wishes in advance with your family. This may include other decisions and legal decisions not directly related to assisted dying, but that can be made in advance, including lasting powers of attorney and an <u>advance decision to refuse treatment</u>.

Q. will I be able to decide in advance that I want an assisted death?

A. Current proposals for assisted dying in Jersey do not allow for someone to make an advance decision about requesting an assisted death. Those who are considering an assisted death will need to make a request to the assisted dying service at that time.

#### 5.2 The role and impact on medical professionals

Q. Can doctors and other professionals conscientiously object to assisted dying?

A. Yes. The States Assembly have decided that any nurse, medical practitioner or other health professional would be able to conscientiously object and would not be under any legal duty to participate in assisted dying.

Proposals currently being considered would allow for health and care professionals to make a decision to 'opt in' to participating in an assisted dying service. However, other health professionals may be asked to provide an assessment or professional opinion for an assisted dying service assessment (again, with the provision of the option to conscientiously object).

#### Q. If professionals do choose to participate in assisted dying, how will they be supported?

A. Experience from other jurisdictions where assisted dying is permitted suggests that supporting an assisted death can have an emotional impact on health and care professionals involved, even where those professionals firmly believe that they should participate in the process.

With this in mind, proposals being developed will include provision for wellbeing and peer support for health professionals who do opt in to work in an assisted dying service.

#### Q. How many doctors on Island are willing to participate?

A. A small number of health professionals have either publicly or privately said that they would optin to supporting people with an assisted death in Jersey. Others have said they support assisted dying in principle but would not actively participate, and others are clear that they do not support assisted dying in any form.

Should assisted dying legislation be approved, as part of the implementation phase, detailed work will be carried out to develop the pool of health care professionals needed to deliver the service. This may need to include a combination of professionals who live and work in Jersey and others who are brought in on an ad hoc basis.

#### Q. What if my doctor doesn't support assisted dying?

A. Proposals being developed will look to ensure that anyone who meets the criteria in law can access an assisted dying service. This may include allowing people to directly contact a centralised assisted dying service, without being referred by a doctor in the event a doctor does not support assisted dying.

#### Q. How does the process of an assisted death work and what drugs are used?

There are two ways that an individual may have an assisted death. Either they may choose to selfadminister medication or they may choose to have a medical practitioner administer the medication that will end their life.

Before the event, an individual would be supported to plan the day, time, and location for their assisted death, as well as other decisions such as who will be present at the time of the procedure.

On the day of the procedure, a registered medical practitioner or registered nurse will be present. They will confirm that the individual has capacity and consents (fully agrees) to the procedure. After this final confirmation, the assisted death can take place.

For a self-administered assisted death, the individual will ingest oral liquid medications. For a practitioner administrated assisted death, several medications are injected intravenously. The first medication will cause the individual to fall into a deep sleep, after which they will become unaware and stay unaware until their death.<sup>2</sup>

The length of time this process can take varies with each individual. Based on data from other jurisdictions, the average time for self-administered oral medication from ingestion to unconsciousness is 5 minutes. And an average of 32 minutes between ingestion and death.<sup>3</sup> The median time from administration to death, where medication is injected intravenously is 9 minutes.<sup>4</sup>

The exact medications, combinations and dosages differ across the countries where assisted dying is currently permitted. Typically, a combination of three types of medications are used to bring about death:

- The first drug deeply relaxes the person, and they begin to lose consciousness.
- The second drug puts the person into a deep coma.
- The third drug stops their breathing and heart, and results in death<sup>5</sup>

For example, in Oregon, USA the medications most frequently prescribed for oral self-administration is a combination of diazepam, digoxin, morphine sulfate, and amitriptyline. In Canada, where medications are more commonly administered by practitioners intravenously, the combinations of medications most commonly used is midazolam (an anxiolytic, sometimes called anti-anxiety

<sup>&</sup>lt;sup>2</sup> Medical Assistance in Dying (MAID) (nshealth.ca)

<sup>&</sup>lt;sup>3</sup> <u>DWDA 2021 (oregon.gov)</u>

<sup>&</sup>lt;sup>4</sup> Medications and dosages used in medical assistance in dying: a cross-sectional study | CMAJ Open

<sup>&</sup>lt;sup>5</sup> FAQ – CAMAP (camapcanada.ca)

medications or tranquilizers); propofol (an anaesthetic coma-inducing agent); and rocuronium or cisatracurium (neuromuscular blockers to stop respiration).<sup>6</sup>

#### *Q. What if an assisted death goes wrong?*

A. As with all medical procedures, it is possible that complications may occur. If this were to happen, it would most probably result in an individual taking longer to die than anticipated. For this reason, an important safeguard is that a registered medical practitioner is present at all assisted deaths, even if the individual chooses to self-administer the medication, so that they can intervene if things do not go to plan. Protocols will be established to provide practitioners with clear guidelines on what to do if complications do occur.

#### 5.3 Eligibility for an assisted death

#### Q. Who will be eligible for an assisted death in Jersey?

A. The States Assembly have decided, in principle, that a person who could choose to have an assisted death would be a Jersey resident who:

- is aged 18 or over
- has the capacity to take a decision to end their life
- has been diagnosed with a terminal illness and has a life expectancy of 6 months or less, or has an incurable physical condition that causes enduring and unbearable suffering

The person's decision to access assisted dying must also be:

- voluntary, the decision would be their own choice, freely made with no pressure or coercion from others.
- continuing, meaning that their choice is settled and stays the same.
- fully informed, the person must be well-informed about their disease and their care and treatment options

#### Q. If someone expresses a wish for an assisted death in advance, will this be taken into account?

A. An advance decision can guide medical treatment decision-making for people if they lose the ability to make their own medical decisions. Current proposals state that a person could not request assisted dying in advance. It was decided that people requesting assisted dying need to have decision-making ability throughout the entire process to make sure their decision remains voluntary and consistent.

<sup>&</sup>lt;sup>6</sup> Medications and dosages used in medical assistance in dying: a cross-sectional study | CMAJ Open

#### Q. Can someone with dementia access assisted dying?

A. Having dementia on its own is unlikely to make a person eligible for assisted dying. By the time the disease is advanced the person will usually no longer have decision-making capacity.

However, a person diagnosed with dementia may be eligible if they meet the eligibility criteria in relation to a different disease, illness or medical condition. Like anyone else, people who have dementia must still have the ability to make and communicate a decision about their wish for assisted dying throughout the process.

# *Q.* What if an individual has both physical and mental health conditions that result in unbearable suffering?

*A.* The States Assembly have agreed that an individual may only be eligible for assisted dying due to a physical health condition. However, the suffering resulting from this physical condition may also result in psychological suffering or a diagnosis of a mental health condition. If this were to be the case, it is likely that as part of the assessment process, the individual would be required to undergo a psychiatric assessment to determine if the mental illness had an effect on their decision-making capacity to request an assisted death.

#### Q. How can you define 'unbearable suffering'?

A. 'Unbearable suffering' is ultimately a subjective and personal term. In jurisdictions, such as Canada, the law sets out that that an eligible person must have an illness that "causes them enduring physical or psychological suffering that is intolerable to them and that cannot be relieved under conditions that they consider acceptable." The Canadian assessment process requires the medical practitioners to determine this, and if the doctor assessing does not have expertise in the condition causing the patient's suffering, they must consult with a practitioner who does.

In addition, the Canadian law sets out that the person reviewing the request for assisted dying must agree that the person requesting must have given serious consideration to all other means of alleviating their suffering in the first instance, including accessing counselling services; mental health and disability support services; hospice and palliative care services.

#### Q. Doesn't the introduction of assisted dying place a value on the lives of disabled people?

A. The proposed eligibility criteria does not propose a list of eligible health conditions, impairments or disabilities; or place a value judgement on them. It places a focus eligibility due to the unbearable suffering of an individual. Such 'unbearable suffering' may be felt both by those who do, and do not identify, as having a disability.

#### 5.4 Safeguards and approval process for an assisted dying service

#### Q. Who would be responsible for oversight and regulation of an assisted dying service?

A. The Jersey Care Commission is Jersey's independent care regulator. It is broadly equivalent the UK's Care Quality Commission. The law would be amended to place a legal duty on the Care Commission to regulate and inspect any assisted dying service in Jersey.

In addition to Commission inspecting the service, the health professionals involved in its delivery would be subject to oversight from their professional registration bodies, for example, the doctors must operate in accordance with the professional standards set by the General Medical Council with whom they must be registered. The Government of Jersey is in discussion with professional registration bodies about assisted dying.

#### Q. Where will assisted dying take place?

A. The Assembly have decided that assisted dying can only take place in pre-approved locations. This is to help ensure the service can be controlled and supervised. It is likely that law will provide that pre-approved locations will include both health and care facilities as well as people's private homes. The approval process will be set out in the detailed proposals currently under development.

#### Q. What if people request an assisted death but change their mind beforehand?

A. Proposals will include the ability for anyone who has made a request for an assisted death to change their mind and withdraw their request at any time.

In addition, to ensure the decision to have an assisted death is settled, there will be a mandatory period of reflection built into the process, sometimes referred to as a 'cooling off period'. This is a minimum time period between the day an initial request for an assisted death is made and the day when the assisted death takes place. In countries where assisted dying takes places already, this is typically around 15 days for those who are terminally ill, or between 1 month and 90 days for those whose death is not reasonably foreseeable. However, where the individual is expected to die in a very short period of time, the 15-day period may be reduced.

#### Q. How will it be decided whether people have capacity to make the decision?

A. A decision on whether someone has the capacity to request an assisted death will form part of the assessment and eligibility process.

Capacity already plays a key role in end-of-life decision-making. People with capacity can refuse treatment, even if that is likely to result in their death.

The Capacity and Self Determination (Jersey) Law 2016 is a legal framework that exists to support doctors and other health professionals to assess capacity.

If a doctor doubted a person's capacity to make the decision at any point in the process, they would have to refer them to another professional, such as a psychiatrist.

#### Q. Can family members request an assisted death?

*A.* No, only the person seeking the assisted dying can ask for an assisted death. This is an important part of making sure the person's decision is entirely voluntary.

#### Q. What if family members don't agree with the decision?

A. The decision to have an assisted death rests with the person. The permission of family members is not required, and they cannot 'override' a person's decision.

However, if the family were concerned that the person's eligibility (for example, they thought they were being coerced) this would be considered as part of the assessment process and could result in the request for an assisted death not being approved.

#### Q. Can family members be actively involved in an assisted death?

A. The States Assembly decided that only registered medical practitioners and registered nurses may be involved in the direct assistance of an assisted death. So whilst family members and loved ones would usually be at the person's bedside, only the medical professionals could provide or administer the medication to bring about an assisted death.

#### Q. Will the introduction of assisted dying increase suicide rates?

A. A number of studies have been undertaken of jurisdictions where assisted dying is permitted to gauge whether it results in increased rate of suicide. These studies reach different conclusions.<sup>7</sup> <sup>8</sup>Recent data shows that suicide rates increased in the US and the Netherlands after the introduction of assisted dying but declined in Belgium and Canada.

<sup>&</sup>lt;sup>7</sup> <u>The effect of assisted dying on suicidality: a synthetic control analysis of population suicide rates in</u> <u>Belgium | SpringerLink</u>

<sup>&</sup>lt;sup>8</sup> How does legalization of physician assisted suicide affect rates of suicide? - St Mary's University Open Research Archive (stmarys.ac.uk)

#### Q. Will the introduction of assisted dying reduce suicide rates?

A. The UK's Office of National Statistics (ONS) recently published data which indicates elevated suicide rates in the UK amongst those with severe health conditions.<sup>9</sup> It is suggested that access to assisted dying may reduce the number of suicides in this population i.e., that these people who were seriously ill and dying may not have chosen to end their life by suicide if a legal alternative was available.

#### 5.5 Funding, personal financial implications and provision of end-of-life services

*Q.* Is there a danger someone will ask for assisted dying because they cannot get palliative or end of life care?

A. Assisted dying is not an alternative to palliative care or end of life care. It is choice that some people who are receiving palliative care or end of life care may make.

Palliative care and end of life services are widely available in Jersey. Jersey Hospice is currently working in partnership with Government and other care agencies on the development of a new end of life care strategy which is anticipated to be published in the autumn. The aim of this partnership work is to ensure that all islanders with a life limiting illness have access and informed choice to the right care, by the right person, at the right time and in the right place.

#### Q. Will funding be diverted away from other health services, including palliative care?

A. The report and proposition considered by the States Assembly in November 2021 - P.95/2021-Assisted dying- was clear that resources currently allocated for palliative care or associated services would not be re-directed to assisted dying.

It is anticipated that the 2023 Government Plan, which will be debated at the end of 2022, will include additional monies to support the development of palliative and end of life care services.

#### Q. Will palliative care provision also be written into law?

A. The Council of Ministers will be asked to consider whether the law should be amended to place a legal duty on the Health Minister to provide end of life and palliative care services. Details will be set out in the proposals to be considered by the Assembly in autumn 2022.

9

https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicide samongpeoplediagnosedwithseverehealthconditionsengland/2017to2020

#### Q. Is assisted dying being introduced as a cheaper option to end of life care?

A. No. Assisted dying is being introduced to allow people, who meet the criteria in law, to have more control over the manner and timing of their death. It is not proposed as alternative to end of life care.

It is anticipated that only a very small minority of those approaching the end of their life will consider as assisted death. Based on experience of other jurisdictions it is estimated that between 2 and 38 people per year may seek an assisted death in Jersey.

#### Q. How much will assisted dying cost?

A. It is anticipated that access to assisted dying would be free to anyone who is already entitled to free health care in Jersey.

#### Q. Would assisted dying be treated like suicide with regard to life insurance?

A. Many other countries explicitly state in their legislation that assisted dying should not be considered as suicide. As a result, it does not impact on life insurance policies in those places. Work is ongoing to understand the possible implications on personal insurance in Jersey with regard to assisted dying. Ultimately, however, any individual requesting an assisted death in Jersey may need to check any exclusions on their personal insurance policies.

#### 5.6 The process of legalising assisted dying in Jersey

#### Q. What are the next steps towards legalising assisted dying in Jersey?

A. Following their 'in principle' decision, the States Assembly's next steps are to consider more detailed proposals on assisted dying in November 2022. See the timeline below:

Timeframe	Action
November 2021	The States Assembly approved assisted dying 'in principle'
Spring to Summer 2022	Talk to islanders, ask questions, share thoughts
November 2022	States Assembly debate on detailed assisted dying proposals
November 2022 to March 2023	Preparation of draft legislation
May 2023	Draft legislation debated in States Assembly
May 2023 onwards	Implementation of assisted dying service in Jersey (if legislation is passed), including training of health professionals

#### Q. When will assisted dying become available in Jersey?

A. Detailed assisted dying proposals will be considered by the States Assembly this autumn. If they are approved, it is hoped that legislation will be debated in Spring 2023. There will be a minimum 18-month implementation period before the law comes into effect in order to set up the assisted dying service and ensure the necessary training, safeguards, regulation and oversight is in place. This means that the earliest date that assisted dying could be available in Jersey is late 2024 or early 2025.

#### Appendix 1.1 – Jersey Evening Post

The Jersey Evening Post has approximately 58,649 daily readers and website views.

Full page advertisements were placed in the Jersey Evening Post on 11, 21 & 26 March, below is a sample.

# ASSISTED DYING IN JERSEY

In November 2021 the States Assembly became the first parliament in the British Isles to decide 'in principle' to permit assisted dying.

An 'in principle' decision means the States Assembly wants to receive more information before confirming how an assisted dying service in Jersey should operate. The next step is for the States Assembly to consider more detailed assisted dying proposals. Between now and Autumn 2022, we want to know your views on how assisted dying should work in Jersey.

MONDAY 21 MARCH 2022 JERSEY EVENING POST 3

What safeguards should be in place and what should an assisted dying service look like?

You can ask questions or share your hopes, thoughts and concerns in the following ways:

Ask your questions at: sli.do using the code: AssistedDyingJSY

Email us: AssistedDying@gov.je

#### Or book in and visit us:

St Brelade Parish Hall Thursday 24 March 12:00-13:30 Book via Eventbrite Town Library Wednesday 30 March 16:30-18:30 Book via Eventbrite Town Library Thursday 31 March 11:45-13:45 Book vio Eventbrite

Government of Jersey

Visit gov.je/AssistedDying for more information and to book in to visit us Appendix 1.2 – Advertisements: Google and digital screens

**Google ads** generated 671 clicks, and 170,000 impressions (the total number of times the ad was seen) between 13 march and 1 April.

Digital screens displayed advertisements at:

- Liberation Bus Station between 15 and 20 March and 28 March to 3 April
- Clock Tower, King Street between 21 and 28 March

Sample:



#### Appendix 1.3 – Radio advertisements

Radio adverts were played on Channel 103 between 12 March and 11 April, between 2 and 4 times a day. The advert was played a total of 101 times. 59% of Jersey's population listens to Channel 103 each week, reaching 54,400 people in Jersey each week. A sample script was as follows:

"The Government of Jersey would like to hear your questions, thoughts, hopes or concerns about assisted dying, to help inform more detailed proposals. On Wednesday 30 March between 4.30pm to 6.30pm and Thursday 31 March between 11.45am to 1.45pm, we will be at the Town Library where you can drop in and chat to our team. To find out more and to register visit our website <u>gov.je/assisteddying</u>."

#### Appendix 1.4 - Social media posts

Below is a summary of the social media activity relating to the assisted dying public engagement. All posts were published on the Government of Jersey account.

- **reach:** The number of people who saw your post at least once. Reach is different from impressions, which may include multiple views of your post by the same people. This metric is estimated
- engagement: The number of reactions, comments, shares, and clicks on your post
- **impressions:** The total number of times your post has been seen.

	Facebook		
Date	Image	Text	Engagement
9 March	SASSISTED DUBLE DUBLE Sk us your questions, or share your hopes, thoughts and concerns		Reach: 12,385 Engagement: 520 Impressions: 12,385
13 March	ASSISTED DYING DN JERSEY Ask us your questions, or share your hopes, thoughts and concerns		Reach: 12,709 Engagement: 372 Impressions: 12,709
16 March	ASSISTED DYING IN JERSEV Assisted Dying drop-in session: St Clement Parish Hall Friday 18 March, 11:30-13:00		Reach: 19,914 Engagement: 918 Impressions: 30,128

#### Facebook

18 March	ASSISTED DYING IN JERSEY Assisted Dying drop-in session: St Clement Parish Hall Friday 18 March, 11:30-13:00	We want to know your thoughts, questions and concerns on Assisted Dying. Ask us your questions, or share your hopes, thoughts and concerns. We are hosting a series of events where you can drop in and chat to our team, the first takes place today at St Clement Parish Hall from 11:30am - 1pm. To find out more and to register, visit gov.je/AssistedDying	Reach: 10,045 Engagement: 86 Impressions: 10,386
22 March	ASSISTED DY INC IN JERSEY At us your questions, or share your hopes, thoughts and concerns	We want to know your thoughts on Assisted Dying. Ask us your questions, or share your hopes, thoughts and concerns about an assisted dying service in Jersey. A series of events will take place over the coming weeks to help Islanders find out more information. The next event will take place at St Brelade Parish Hall on Thursday 24 March from 12pm - 1:30pm. Book your place to join us in person via https://bit.ly/36zDdXN	Reach: 4,578 Engagement: 171 Impressions: 4,582
23 March	<section-header><text></text></section-header>	We want to know your thoughts on Assisted Dying. Ask us your questions, or share your hopes, thoughts and concerns about an assisted dying service in Jersey. A series of events will take place over the coming weeks to help Islanders find out more information. The next event will take place at St Brelade Parish Hall tomorrow (Thursday) from 12pm - 1:30pm. Book your place to join us in person via https://bit.ly/36zDdXN	Reach: 7,527 Engagement: 283 Impressions: 7,855
28 March	ASSISTED DYING IN JERSEY ASSISTED DYING IN JERSEY ASSISTED DYING IN JERSEY	What are your views on Assisted Dying? We are hosting a series of events for you to ask questions, or share your hopes, thoughts and concerns about an assisted dying service in Jersey. The final 2 drop in events take place this week on Wednesday and Thursday at the Town Library. Book your place to join us in person via http://bit.ly/36zDdXN	Reach: 12,917 Engagement: 427 Impressions: 12,917
30 March	<section-header><section-header><section-header></section-header></section-header></section-header>	What are your thoughts on Assisted Dying? Ask us your questions, or share your hopes, thoughts and concerns about an assisted dying service in Jersey. A series of events will take place over the coming weeks to help Islanders find out more information. The next event	Reach: 5,929 Engagement: 56 Impressions: 6,033

2 April	<complex-block></complex-block>	will take place at the Town Library today from 4:30pm - 6:30pm. Book your place to join us in person via https://www.eventbrite.co.uk//town- library-30-march The Assisted Dying team are available for you to comment, ask questions, share your hopes, thoughts or concerns by: Visiting sli.do (code: #AssistedDyingJSY) Email: assisteddying@gov.je	Reach: 5,929 Engagement: 56 Impressions: 6,033
7 April	SASSISTED DYING DYING DY JERSEY Ask us your questions, or share your hopes, thoughts and concerns	The Assisted Dying team are available for you to comment, ask questions, share your hopes, thoughts or concerns by: Visiting sli.do (code: #AssistedDyingJSY) Email: assisteddying@gov.je	Reach: 7,702 Engagement: 36 Impressions: 7,702

#### Twitter



Sample text: What are your views on Assisted Dying?

We're hosting a series of events for you to ask questions, or share your hopes, thoughts and concerns about an assisted dying service in Jersey. The final 2 events take place on Wednesday and Thursday.

Book your place http://bit.ly/36zDdXN

Twitter	
Date	Impressions
9 March	3,413
13 March	3,575
16 March	6,542
18 March	4,431
22 March	2,666
23 March	1,649
30 March	1,688
2 April	1,687
7 April	1,441

#### LinkedIn





**Sample text:** We want to know your thoughts, questions and concerns on Assisted Dying. Ask us your questions, or share your hopes, thoughts and concerns.

We are hosting a series of events where you can drop in and chat to our team, the next information event takes place tomorrow at St Brelade Parish Hall from 12pm - 1:30pm.

To find out more and to register, visit <u>https://bit.ly/36zDdXN</u>

LinkedIn	
Date	Impressions
9 March	627
13 March	673
18 March	352
23 March	689
30 March	237
7 April	441

#### Instagram



Ask us your questions, or share your hopes, thoughts and concerns

In November 2021 the States Assembly became the first parliament in the British Isles to decide 'in principle' to permit assisted dying. An 'in principle' decision means the Assembly wants to receive more information before confirming if, and how, assisted dying should be permitted.

The next step is for the Assembly to consider more detailed assisted dying proposals in November 2022. Between now and then, we want to know your views on how assisted dying should work in Jersey. What safeguards should be in place and what should an assisted dying service look like?

Tell us by commenting below, submitting on sli.do or find more info on gov.je/AssistedDying

Instagram	
Date	Accounts reached
9 March	2,1014
13 March	1,693
23 March	1,666
28 March	1,288
7 April	1,180

# END OF LIFE CHOICES POLICY STATEMENT 1 OF 5

# TOPIC: UNBEARABLE SUFFERING

Not all suffering is bearable. Every patient should receive the best possible palliative care, and Jersey should continue to develop the high quality of this service. That being understood, hard cases will remain.

In deciding who is eligible for assistance to die, unbearable suffering must be the key criterion, even more than terminal illness. Why?

Well of course, both factors (the suffering and the prognosis) may be present together, but to consider them separately, let us take two possible cases in the first, there is a terminal illness without unbearable suffering; in the other, it is vice versa.

In that first case, for whatever reason, the patient is not suffering unduly: either their illness is not such as to cause great pain or loss of dignity, or else maybe they are benefitting from excellent palliative care. This patient is not a good candidate for assisted dying; indeed, they are unlikely to request it.

In the other case, there is unbearable suffering without a terminal prognosis. This patient, despite receiving the best care, is still suffering unbearably, and will do so indefinitely. Such cases may be rare, but they must surely be first among those whose plight the legislation should address.

#### Who decides?

Jersey psychiatrist Dr Rachel Ruddy, contributing to debate in the run-up to the States Assembly vote of Nov 23rd 2021, asserted that 'unbearable suffering' cannot easily be defined, and that medical experts cannot be expected to diagnose it. She is quite right: this is not a decision for doctors to make. It is only ever the patient who truly knows their own pain (just as when you sit in your dentist's chair). Let the patient decide.

Of course, we still need the doctor's expert opinion in other respects—for a patient to be eligible, a doctor should certify that their condition is currently incurable, and that it has a severe impact upon their quality of life; but it is only the patient who can say whether that impact is unbearable.

CONCLUSION. The law to be drafted must include 'unbearable suffering' as a key criterion of eligibility for assisted dying, together with a clear statement that it is for the patient to determine this aspect of their case.

# END OF LIFE CHOICES POLICY STATEMENT 2 OF 5

## TOPIC: SIX MONTHS TO LIVE

To limit assisted dying to those patients with a six-month prognosis is known as the 'Oregon Model', after the American state where it was first introduced. We believe it to be unworkable, cruel and irrational.

Why unworkable? If the law grants assistance to die (or any other benefit) preferentially to those with only six months to live, then patients will put pressure on doctors to give that prognosis. Yet, famously, most doctors are unwilling to give any such figure, knowing how inaccurate it generally is.

Why cruel? Consider two possible cases, both involving similar suffering, the first of which has a six-month prognosis, the other not. Are we really going to say to that second patient, 'the one over there we can help, because she'll be dead within six months, but since you have to bear the same pain for longer, or indefinitely, we can't give you the same choice'? That is appalling.

The very same arguments would clearly rule out any suggested policy of nine months, or twelve, or of any fixed period.

The only assisted dying group which proposes that we adopt the Oregon model is *Dignity in Dying*. All other (otherwise similar) organisations, such as ourselves, *My Death, My Decision,* and *Humanists*, reject it, as does the UK *Assisted Dying Coalition,* to which we all belong (DiD excepted). Time after time, we hear individual members of DiD admit that they favour the Oregon model not from conviction but only as a tactic, believing it is all they can expect to get passed into law. At one time that may have seemed canny, but looking around the world, it now seems entirely outmoded.

We believe one should openly argue for what is right, tactics aside. Happily, we also think the November 2021 vote demonstrated that the vast majority of members of the States of Jersey are more open and liberal than DiD may fear them to be. The resolution then accepted by so many was not limited in that way: regrettably, it does include the words "*reasonably expected to die within six months*" but it does not give that as the only option. For the reasons given above, it would be far better now to remove that phrase.

CONCLUSION. The law to be drafted should not include any reference to six months, nor to any other specific period of time for which the patient is expected to survive.

# END OF LIFE CHOICES POLICY STATEMENT 3 OF 5

# TOPIC: LEGAL PRE-APPROVAL

The proposal passed by the States in November 2021 states in Paragraph (c) "that assisted dying should be subject to a pre-approval process which, subject to further consultation, may involve a decision made by a court or specialist tribunal".

We believe that this would be a grievous error, with the potential to nullify the whole benefit of the legislation.

#### Arguments for this view:-

#### 1. Delay when time is of the essence.

Data from other jurisdictions show that, even though they may have thought about it for years beforehand, most patients who do eventually request an assisted death will do so a relatively short while before they die, when their condition worsens. Most often, there simply will not be enough time then to take this through a law court—any such requirement would be obstructive, cruel and expensive.

#### 2. Sufficient expertise of practitioners.

If the legislation is well drafted, with its safeguards made clear, then doctors or nurses who are trained practitioners in this field will know exactly how to stay within the law, without first going to court—as they already do in broadly similar situations, such as non-resuscitation orders (DNR) and abortion.

#### 3. Normal operation of law.

What the law allows, it generally allows without constant appeal to the courts. If I have a driving license, I may drive on the roads, or if I have children of school age, I may enrol them in school, without first employing lawyers to establish my right to do so. Whatever the law permits, it permits, without a judge repeatedly declaring that this citizen or that may exercise their right.

#### 4. Motive for the pre-approval clause.

We fear that this pre-approval process may have been suggested to the citizens jury by those who wish to obstruct assisted dying as much as they can—or maybe just to make work for lawyers. It is difficult to see what other purpose it might serve which cannot be addressed in a better way.

CONCLUSION. The law to be drafted should not include any requirement for a legal pre-approval process.

# END OF LIFE CHOICES POLICY STATEMENT 4 OF 5

#### TOPIC: SAFEGUARDS DOCUMENT

The proposal passed by the States in November 2021 states that a patient's wish to end their life should be "voluntary, clear, settled and informed." We agree with this wholeheartedly, and suggest (below) a mechanism to ensure these safeguards.

A document is required—a form with several sections, each of which should be signed and dated both by the patient and by the relevant healthcare professional.

This cannot be achieved 'cold' but must arrive as follows: as soon as a patient requests assistance to die, they should be offered the support of one or more specially trained doctors or nurses, who will begin a series of conversations to help them through filling in the form.

The form will need to include the following sections, each preceded by its own 'lead-in' conversation. These conversations cannot be rushed: the process may take several days. We suggest that the form should contain the following sections:

1) To record that the patient has had all options explained as to further medical treatment; that it has been made clear whether their condition is considered incurable by current medical science.

2) To record that the patient has had all options explained as to further palliative care, and has understood this.

3) To record that (after 1 & 2) they still wish to request assistance to die.

4) To record that this is truly their own wish, and that they have not been persuaded to it by anyone else. (To establish this, the lead-in conversation should be conducted in a sensitive but thorough manner).

5) To record how long the patient has felt that, if their current predicament or something like it should arise, then they would wish for assistance to die. A few months might be considered a sufficient answer here.

6) To record how long the patient has felt that the severity of their plight is now such as to call urgently for assistance to die in the near future. A few days may be a sufficient answer here, dependent upon the rapidity of their decline.

7) To record that an experienced specialist considers that the patient's answers (above) fully demonstrate a 'voluntary, clear, settled and informed' wish for assistance to die.

The November 2021 States proposal also refers to a "mandatory period of reflection" but we believe this to be an unnecessary additional hurdle, given that we already have in operation a process of the kind outlined above.

# END OF LIFE CHOICES POLICY STATEMENT 5 OF 5

### TOPIC: WAYS AND MEANS

The safeguards document we have outlined (or something like it) can establish that an assisted death is appropriate and within the law. It should be sufficient in those cases where the assistance is to be rendered within a short time. However, it cannot remain in effect indefinitely. If there has been a certain lapse of time—say a week or more—then one may need from both doctor and patient a dated confirmatory signature to show that the procedure remains desired and appropriate.

Assistance to die should be given always and only under proper medical supervision. This is necessary in order to guarantee the safe completion of the procedure. The medication should remain under the control of the physician until the time when it is used. Thus a 100% success rate can be achieved—as is the case, for example, in Switzerland.

The medication may well be a barbiturate such as nembutal, which is used for this purpose around the world, and which has the advantage that, since it has been employed in various medical contexts for many years, correct dosages are well understood—but there are other safe options.

The preferred procedure should be for the patient themself to ingest the medication, with the doctor in attendance. In those few cases, however, where the patient, though conscious and able to express their wishes, is physically incapacitated, it should be legal for the doctor to administer the procedure on the patient's behalf.

Location: experience in the field of palliative care confirms that patients can often be treated at home, and often prefer this. [Incidentally, we recommend the closest possible co-operation throughout between specialists in palliative care and those in assisted dying.]

Therefore, the location where the patient takes the lethal medication may be either a designated room in a hospital or hospice, or else in the patient's own home or other place of their own choosing. If the latter option is preferred by the patient, it should be permitted, though only where proper medical supervision is still available. It depends, therefore, upon the doctor being able to visit the patient in their chosen location at the appropriate time.
# Appendix 2.2 – Written submission from Channel Islands Humanists received 06.04.22

# GOVERNMENT OF JERSEY: ASSISTED DYING PUBLIC ENGAGEMENT

Response from Channel Island Humanists, April 2022



# 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 115 members of the All-Party Parliamentary Humanist Group, and by humanist members of the Jersey and Guernsey Assemblies.

We have long supported attempts to legalise assisted dying across the Channel Islands, to afford freedom of choice to those who have made a clear and free decision to end their lives and who are physically unable to do so themselves. In many cases, the person in question 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 we wish to see reform of the law that would be responsive to the needs of other people who are permanently and incurably suffering. In recent years we have intervened in all the UK court cases on assisted dying, and have supported all legislative attempts to legalise assisted dying for the terminally ill. We are a co-founder of the Assisted Dying Coalition, the UK, Ireland, and crown dependencies-wide coalition working for assisted dying. End of Life Choices Jersey is also a member of the coalition.

#### ASSISTED DYING IN JERSEY

In 2021, Jersey's Citizens' Jury on Assisted Dying overwhelmingly recommended the legalisation of a right to die. Humanists UK gave oral and written expert evidence to the panel. 78% of the panellists recommended that assisted dying should be permitted for adults in Jersey and 70% recommended that it should be available to adults of sound mind, who are either terminally ill or experiencing unbearable suffering, subject to robust safeguards.<sup>1</sup> In 2021, Jersey's States Assembly approved the principle of legalising assisted dying. A further debate on processes and safeguards is due to be held this year and a draft law to be discussed and voted on in 2023.<sup>2</sup>

#### THE CASE FOR CHANGE

- Research from the Assisted Dying Coalition has found that more than one person a week from the UK and crown dependencies is now forced to end their life abroad.<sup>3</sup>
  However, many others cannot afford the high costs of travelling abroad. The right to die should not be limited to those with means. Those who are able to travel abroad to die often do so before it would be necessary if they did not need to travel.
- The current law forces families to make an intolerable choice: either to let their loved ones suffer; or support them and risk criminal investigation.

#### GOVERNMENT OF JERSEY: ASSISTED DYING PUBLIC ENGAGEMENT



- A Medix survey has established that 45% of British doctors believe that some health professionals assist the death of patients.<sup>4</sup> A safer system of stringent safeguards is the best way to protect patients, as well as doctors and families, from being prosecuted for crimes of compassion.
- There is no credible evidence from jurisdictions that have legalised assisted dying that vulnerable people will be pressured to end their life. In fact, Professor Battin et al concluded in the most comprehensive study on this topic: 'Where assisted dying is already legal, there is no current evidence for the claim that legalised PAS [physician-assisted suicide] or euthanasia will have a disproportionate impact on patients in vulnerable groups.'<sup>5</sup>

# PUBLIC, MEDICAL, AND DISABILITY COMMUNITY OPINION

**90% of the public in Jersey favour assisted dying reform.** A poll of 2,801 adults in Jersey, Guernsey, and the Isle of Man found that at least eight in ten people favour assisted dying.<sup>6</sup>

In Britain, **88% of people with a disability favour assisted dying for both those who are terminally ill or incurably suffering**.<sup>7</sup> This is reflected by an independent study of 140 UK disability rights organisations that found that 97% do not oppose law reform.<sup>8</sup>

The majority of UK doctors and nurses support assisted dying reform.<sup>9</sup> For example, 55% of GPs agree or strongly agree that the law on assisted dying should change.<sup>10</sup> The British Medical Association, the Royal College of Physicians, the Royal Society of Medicine, the Royal College of Nursing, and the Royal College of Psychiatrists all also either support or have a neutral stance. The Royal College of Surgeons is currently reviewing its position. The Royal College of GPs remain opposed to a change in the law. The RCGP conducted a review in 2021, and found a majority wanting it to move from opposition to neutrality and support.

# INTERNATIONAL CONTEXT

**Over 200 million citizens worldwide now have access to assisted dying.**<sup>11</sup> There are predominately two models of assisted dying around the world. The first, found in **Austria, Canada, Belgium, Germany, Luxembourg, the Netherlands, Colombia, Switzerland, and Spain** provides

<sup>7</sup> Populus. Dignity in Dying Poll. 2015. <u>https://www.populus.co.uk/wp-content/uploads/2015/12/</u>

<sup>&</sup>lt;sup>4</sup> House of Lords. *Select Committee on Assisted Dying for the Terminally III Bill Volume I: Report* . 2005. <u>https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/86i.pdf</u>

<sup>&</sup>lt;sup>5</sup> Battin et al. 'Legal physician-assisted dying in Oregon and the Netherlands: evidence concerning the impact on patients in "vulnerable" groups'. *J Med Ethics* 2007. <u>https://www.ncbi.nlm.nih.gov/pubmed/17906058</u> <sup>6</sup> Island Global Research Ltd, Dignity in Dying Poll, 18 May 2021

https://www.islandglobalresearch.com/View?id=2232

DIGNITY-IN-DYING-Populus-poll-March-2015-data-tables-with-full-party-crossbreaks.compressed.pdf <sup>8</sup> G Box *et al*, 'Views of disability rights organisations on assisted dying legislation in England, Wales and Scotland: an analysis of position statements' *J Med Ethics* 2021 <u>https://pubmed.ncbi.nlm.nih.gov/33402428/</u> <sup>9</sup> British Medical Journal. 'Most UK doctors support assisted dying, a new poll shows'. 2019. <u>https://www.bmi.com/content/360/bmi.k301</u>

<sup>&</sup>lt;sup>10</sup> Dignity in Dying. 'Majority of doctors want medical bodies to have neutral stance on assisted dying'. 2019. www.dignityindying.org.uk/news/majority-of-doctors-want-medical-bodies-to-have-neutral-stance-on-ass isted-dying/

<sup>&</sup>lt;sup>11</sup> British Medical Journal, 'Assisted dying: a question of when, not if'. 9 September 2021 https://doi.org/10.1136/bmj.n2128



assisted dying for both the terminally ill and incurably suffering.<sup>12</sup> The second, found in 11 US jurisdictions, Columbia, New Zealand, and five Australian states, only provides assistance to those who are terminally ill (likely to die within six months or fewer).

# SCOPE AND SAFEGUARDS

We advocate for a compassionate assisted dying law for the terminally ill and intolerably suffering. We believe those who have made a clear decision, free from coercion, to end their lives should be able to do so. There is no moral case for limiting the law to the terminally ill.

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. Assisted dying should not be considered an alternative to palliative care, but should be offered together, as in many other countries. We support the decisions made in the Citizen's Jury's Final Report and as such an assisted dying law in Jersey should include the following safeguards and criteria:

- The law should apply only to those over the age of 18
- There should be a conscientious objection clause for medical professionals
- Assisted dying should only be allowed at certain approved locations, such as at home, at the hospital or at a specialist facility
- There must be an official format of the request such as a written, witnessed request
- Withdrawal of a request for an assisted death is permitted at any time
- There should be a 'cooling-off period' to allow subjects to change their mind.

In addition to this, there should be regular general reporting on assisted dying in Jersey with no disclosure of individual identifying details.

For more details, information, and evidence, contact Humanists UK:

Richy Thompson Director of Public Affairs and Policy 0781 5589 636 020 7324 3072 richy@humanists.uk humanists.uk

<sup>&</sup>lt;sup>12</sup> Humanists UK, Assisted Dying Around the World, 2021: <u>https://humanists.uk/wp-content/uploads/</u> <u>Humanists-UK-Mapping-Assisted-Dying-Laws-Around-The-World.pdf</u>



# ANNEX: FAQs ON ASSISTED DYING

#### Q: What do disability and medical charities think?

A: Most disability and medical charities are neutral on assisted dying. But most people with conditions such as motor neurone disease and most disabled people support a change in the law, as do most doctors as evidenced by the recent British Medical Association poll on assisted dying.

#### Q: What if people change their minds?

A: Adequate safeguards should be put in place to make sure that any decisions people make are clear and settled wishes, arrived at free from coercion. In Switzerland, this means having a psychological assessment, and also a waiting period to make sure a person's wishes don't change.

#### Q. What if there is a cure in the future?

A: People can make their own decision as to the likelihood of this happening weighed against their current suffering.

#### Q: Isn't it enough that people can go to Switzerland?

A: That prolongs the suffering of people who have already made the decision but where it takes time to arrange it; paradoxically, it means that some people end up going sooner than they otherwise might, before they become too sick to fly. Further, it is only available to those that can afford it. It also means that people are denied the option to die at home or in familiar circumstances.

#### Q: Assisted Dying is rarely prosecuted, isn't that enough?

A: Where people are helping others to die they are doing this without safeguards and at the risk of a criminal charge. This is not enough. And if it's happening already, why not legislate and regulate the situation?

#### Q: Why are Channel Islands Humanists focusing on this?

A: Humanists defend the right of everyone to live by their own personal values, and the freedom to make decisions about their own life as long as this does not result in harm to others. Assisted dying clearly affords people freedom of choice, dignity, and autonomy. This is a common view amongst humanists.

#### Q: In country X, assisted dying has led to involuntary deaths.

A: In places where assisted dying is legal, the evidence is overwhelmingly of success – people accessing assisted dying free from coercion. The result is a reduction in suffering.

#### Q: Isn't palliative care enough? Shouldn't we work to make people happier, not to end it?

A: Improving palliative care is vital. But good palliative care and legal assisted dying are not mutually exclusive. Instead the best care that can be given is for people to be given the best palliative care available, and then be able to have the right to die should they find that that's not good enough.

#### Q: Will doctors find it hard to assist a death?

A: 55% of UK GPs agree or strongly agree that the law on assisted dying should change. Doctors will be following the wishes of their patients and using their medical skills to ensure that the procedure is dignified and humane. It is likely that any legislative scheme would create a new group of medical professionals who would carry out assisted dying and provide for healthcare workers to conscientiously object from taking part.

# Jersey Assisted Dying Consultation

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')<sup>1</sup>. Following this decision, the States Assembly seeks the opinions, hopes and concerns around an assisted dying proposal. The following is our submission to the 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.

# **Executive Summary**

This document outlines Living and Dying Well's response to Jersey's public consultation on assisted dying. Addressing each aspect of the issue as outlined on the Citizen's assembly website, this paper highlights the serious dangers of any assisted dying law. From vague eligibility criteria to unspecified roles of doctors, psychiatrists and legal professionals, an assisted dying proposal has too many flaws to be workable. Moreover, the lack of good recording, monitoring, training and key safeguards as evidenced in other jurisdictions with an assisted dying law do not give confidence that any such system in Jersey would protect the best interests of vulnerable people and society at large. Finally, this document highlights the incompatibility of an assisted dying law with a comprehensive system of palliative care. Drawing on extensive data from other jurisdictions, this response is a critical analysis of why assisted dying legislation in Jersey would be gravely inappropriate.

<sup>&</sup>lt;sup>1</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

#### The Law

The law in Jersey should accurately and conscientiously reflect the perceptions which, as a society, we have of suicide - that, while those who attempt to take their own lives must not be stigmatised or punished, suicide itself should not be encouraged or assisted. We call on governments to support suicide prevention strategies. Those contemplating taking their own life must be treated with great empathy and the causes of their profound distress must be urgently addressed.

Contrary to the claim made in the proposal document, if suicide is not an offence, it <u>does not</u> follow that there is "no offence of aiding, abetting, counselling or procuring suicide"<sup>2</sup>. There is a fundamental legal and ethical difference: since the abolition of capital punishment, outside war no citizen is permitted by law to assist or cause the death of another.

If the aim of the 'assisted dying' proposal is to eliminate "unbearable suffering"<sup>3</sup>, there is an onus on the government to ensure adequate service provision to ameliorate distress. For example, relief of distress in those with serious progressive illness could be more effectively achieved through the improvement of palliative and end of life care services, with equitable access early in the course of a person's illness. This would enable and encourage doctors, and Jersey at large, to provide excellent care for patients until the moment of death, with support for families facing bereavement, rather than ending life weeks, months or even years prematurely.

Laws send social messages. The introduction of an assisted dying law suggests that if a patient is terminally ill then seeking lethal drugs is something that he or she should consider and that it may even be a moral duty. Yet most terminally ill people want to live and hope that society wants them to live as well as possible as their lives draw to a close. They can be frightened about how their illness will develop or worried about the burdens it is imposing on those around them. They may be frightened of what lies ahead, often needlessly, unaware of what can and should be done to support them. For many people the lack of publicity around good deaths, and the negative messaging used by those campaigning for assisted suicide and euthanasia, has the potential to cause harm, adding anxiety towards the end of life and increasing suffering.

The proposals state that "in its broadest sense, 'vulnerable' or the potential to be vulnerable would appropriately describe any individual seeking an assisted death"<sup>4</sup>. However, vulnerability extends to those who are not seeking an assisted death but may feel pressured to do so because of a law that presents assisted death as a desirable alternative to good care.

<sup>&</sup>lt;sup>2</sup> Page 5, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>3</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>4</sup> Page 21, <u>Report and proposition on Assisted Dying on States Assembly website</u>

#### **Nature of the Request**

#### "voluntary, clear, settled and informed wish to end their own life"5

**Voluntary** - "The doctor(s) (or panel/tribunal) must be absolutely confident that an individual is making the request for assisted dying of their own volition, with no persuasion or coercion by family members or any other person, whether for self-motivated or altruistic purposes."<sup>6</sup>

It is not clear in the proposals who will be responsible for detecting any coercive pressure underlying a person's decision to seek lethal drugs. If it is to be clinicians, it is unclear how they will be able to detect what occurs behind the closed doors of a person's home as clinicians often have little knowledge of the patient and their circumstances beyond the short clinical consultation. If it is to be a panel/tribunal, as suggested in the proposals, it is unclear how the panel would be constituted and what evidence would be required to satisfy itself with legal certainty that such pressures do not exist. There are no required minimum steps outlined, such as an objective assessment of financial and other pressures, that must be taken to exclude coercion.

Undue influence in the form of elder abuse and coercive control are widespread and often go undetected. Financial abuse is one of the most prevalent forms of elder abuse. According to 2007 statistics from the Prevalence Survey Report by King's College, London and the National Centre for Social Research on behalf of Comic Relief and the Department of Health, approximately 57,000 people aged 66 and over experience financial abuse every year, making it the second most prevalent type of mistreatment (after neglect) in the UK<sup>7</sup>. Physicians are particularly badly placed to detect coercion, unless the person informs them directly, and even flagrant abuse can go undetected by healthcare staff. Data from Oregon reveals that the duration of some of the physician-patient relationships in Oregon is "0 weeks" prior to the assisted suicide request<sup>8</sup>. This can be a consequence of 'doctor-shopping' for assisted suicide drugs, resulting in coercion or abuse remaining undetectable, yet notably in Oregon, recorded cases of elder abuse have risen year on year<sup>910</sup>.

Oregon data has also shown increasing numbers of people citing concern over the cost or burden of care for them and their families.

<sup>&</sup>lt;sup>5</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>6</sup> Page 14, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>7</sup> <u>Centre for Policy on Ageing, 2008, The Financial Abuse of Older People: A review from the literature carried out by the Centre for Policy on Ageing on behalf of Help the Aged</u>

<sup>&</sup>lt;sup>8</sup> Oregon Health Authority, Death with Dignity Act Report 2020

<sup>&</sup>lt;sup>9</sup> Oregon Public Broadcasting, 23 Oct 2015 Error! Hyperlink reference not valid.

<sup>&</sup>lt;sup>10</sup> The Statesman Journal, 30 Oct 2014





The normalisation of assisted suicide and euthanasia in a society suggests that the 'right to die' can itself become a subtle coercive influence on people. In the Netherlands, there are reports of such normalisation leading to the premature ending of life<sup>11</sup>. In a small population like Jersey, it is likely that such societal coercion would have a greater impact and could occur rapidly.

# Clear - "usually a written, witnessed request"12

The proposals say that "usually", in other jurisdictions, a request for an assisted death is written and witnessed. It is, however, unclear what the process would be in Jersey, what the "request" should include and who would be required to sign such a declaration. Any request that is made must be subject to strict safeguards and criteria to ensure clarity. An unwritten request is unverifiable and at greater risk of coercion and misinterpretation, being wholly dependent for veracity on those witnessing the request.

Any declaration should be witnessed by solicitors, to avoid undue influence from family members or relatives, and should be presented to the court for judicial review. Written assurances should be required from clinicians, lawyers and psychiatrists to confirm the clarity of a request and that the person

<sup>&</sup>lt;sup>11</sup> <u>Anscombe Bioethics Centre, 2021, Euthanasia case studies from Belgium: Concerns about legislation and hope for palliative care</u>Error! Hyperlink reference not valid.

<sup>&</sup>lt;sup>12</sup> Page 9, <u>Report and proposition on Assisted Dying on States Assembly website</u>

had mental capacity for that decision at the time of the request. Provisions must be put in place for those who cannot for whatever reason sign a written statement, to demonstrate to a judge that theirs is a valid, informed request, free from coercion.

# **Settled** - "Those reviewing a request for assisted dying must be assured that the request is something the person is certain about and that it is a settled, non-fluctuating, decision."<sup>13</sup>

It is not clear how long a person must have a non-fluctuating wish to die in order for it to qualify as 'settled'. The proposals suggest that a mandatory period of reflection will provide for greater certainty as to whether a person's request for assisted dying is persistent and non-fluctuating, however research shows that a wish to die may fluctuate over years, rather than weeks (the reflection period in Oregon is only two weeks).

A recent study has shown that 72% of older people who first reported a wish to die did not report a wish to die when reassessed 2 years later, and in cases where a wish to die does not persist, loneliness and depressive symptoms improve longitudinally<sup>14</sup>.

**Informed** - "A person requesting assisted dying must be made aware of what the process entails. This typically includes ensuring that a person is fully informed of all available alternatives to relieve their suffering."<sup>15</sup>

In evidence to the House of Lords Select Committee on Assisted Dying for the Terminally III Bill in 2004, witnesses testified that the experience of pain control is radically different from the promise of pain control and that patients seeking assistance to die without having experienced good symptom control cannot be deemed fully informed. Therefore, an applicant for 'assisted dying' must receive specialist palliative care input to ensure the patient's request reflects a fully informed decision, before the request for lethal drugs can be confirmed.

It is also essential that a person is informed of what is known and unknown about the process of assisting suicide and euthanasia, particularly the lethal drugs used, potential complications, actions that would not be taken in the event that complications such as vomiting, choking or fitting occur, and the possible length of time taken to die

#### Wish to end their own life

A 'wish' is a complex concept to define and does not necessarily mean that a person intends to act on their wishes. A wish to die may mean different things to different individuals. It can potentially be due to

<sup>&</sup>lt;sup>13</sup> Page 15, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>14</sup> The 'Wish to Die' in later life: prevalence, longitudinal course and mortality. Data from TILDA, Age and Ageing, Vol 50 (July 2021), pp. 1321-28

<sup>&</sup>lt;sup>15</sup> Page 14, <u>Report and proposition on Assisted Dying on States Assembly website</u>

several interlinking factors, including physical symptoms, psychological distress, existential suffering or social deprivation<sup>16 17</sup>. Or it may signal acceptance of the inevitability of imminent death.

The statement 'I wish I was dead' and a true wish to die are often very different. The former usually indicates complex underlying questions, ranging from an expression of seeking assurance that the person is still of value and has a role in life through to profound remorse or exhaustion. There has been powerful research that shows that the way a person is cared for can enhance their sense of dignity and personal value, while it can be undermined by the attitude of others, both those in direct contact with the person and from attitudes in wider society<sup>18</sup>.

#### "capacity to make the decision to end their own life"19

Mental capacity is decision and time-specific. Mental capacity is easily impaired by depression, illness and medication<sup>20</sup>. The more serious the decision, the greater the capacity required, e.g. people can chose what to eat or wear but may be unable to take even moderate decisions, let alone major ones. And there can be no more grave and irrevocable decision than ending one's life.

Assessments of capacity are difficult, and the majority of clinicians are inadequately skilled at detecting some types of impaired capacity. Specialist psychiatric examinations should be a mandatory requirement in assessing any person for lethal drugs for an 'assisted death'.

In the recently proposed Private Member's Bill in Westminster, the assessment of mental capacity would have been left to the assessing doctors with referral for psychiatric examination limited to cases where doubts as to mental capacity exist, as in Oregon. However, Oregon's experience has shown that referrals of applicants for physician-assisted suicide for psychiatric examination are in practice rare and becoming rarer, despite estimates that 1 in 6 patients who receive lethal drugs meet the criteria for a diagnosis of clinical depression<sup>21</sup>. In 2021, only two patients who received a lethal prescription were referred for psychological evaluation<sup>22</sup>.

<sup>&</sup>lt;sup>16</sup> The 'Wish to Die' in later life: prevalence, longitudinal course and mortality. Data from TILDA, *Age and Ageing*, <u>Vol 50 (July 2021)</u>, pp. 1321-285

<sup>&</sup>lt;sup>17</sup> Balaguer et al, 2016, An international consensus definition of the wish to hasten death and its related factors.

 <sup>&</sup>lt;sup>18</sup> The Importance of Patient Dignity in Care at the End of Life, Ulster Medical Journal, Vol 85 (Jan 2016), pp. 45-8.
<sup>19</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>20</sup> <u>Concepts of mental capacity for patients requesting assisted suicide: a qualitative analysis of expert evidence</u> presented to the Commission on Assisted Dying, *BMC Medical Ethics*, Vol 15 (April 2014), pp. 15-32.

<sup>&</sup>lt;sup>21</sup> Prevalence of depression and anxiety in patients requesting physicians' aid in dying: cross sectional survey, <u>British Medical Journal, August 2008</u>2

<sup>&</sup>lt;sup>22</sup>Oregon Death with Dignity Act, 2021 Data Summary Error! Hyperlink reference not valid.

# Eligibility

#### "terminal illness, which is expected to result in unbearable suffering that cannot be alleviated"23

The proposals state that "The requirement for the expectation of 'unbearable suffering', combined with 'death within six months', provides for where a person is terminally ill, will die in a short time frame and will, during the course of that time, experience unbearable suffering which cannot be alleviated"<sup>24</sup>.

It is claimed that the risk that someone who chooses an assisted death solely on the basis that they are expected to die within six months may actually have lived for more than six months "would be counterbalanced, albeit not completely eradicated in Jersey, by the proposed additional requirement of the expectation of unbearable suffering, in addition to the six-month timeframe"<sup>25</sup>. How is it possible to determine whether suffering can or cannot be alleviated if a decision for an assisted death is taken on the basis that future suffering might arise and be unbearable?

The proposals suggest that a criterion for eligibility for an assisted death is a terminal illness "expected to result in unbearable suffering". The expectation of suffering, however, is as unpredictable as the time prognosis of a terminal illness. If the notion of "unbearable suffering is self-determined by an individual", 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 experience of a given condition. Two patients with the same condition might quantify their suffering differently. 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. It is inappropriate to not require that attempts to relieve the unbearable nature of suffering have been exhausted, by requiring a redoubling of efforts of medical intervention aimed at alleviating symptoms and other aspects of distress.

#### "or, has an incurable physical condition, resulting in unbearable suffering"26

The proposals suggest that assisted dying should not be made available for those suffering as a result of a mental condition or psychiatric illness<sup>27</sup>. However, 41% of the Jury thought eligibility criteria for health should include psychological suffering. Given the inherent connection between physical and mental health, psychological suffering cannot be differentiated from physical suffering. Dame Cicely Saunders coined the term 'Total Pain' to explain that pain is a physical experience greatly compounded and magnified by emotional, social and spiritual distress.

As mentioned above, if unbearable suffering is self-determined by an individual, this would open the door for anyone with an incurable or terminal illness to request an assisted death on the grounds that

<sup>&</sup>lt;sup>23</sup> Page 2, Report and proposition on Assisted Dying on States Assembly website

<sup>&</sup>lt;sup>24</sup> Page 16, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>25</sup> Page 17, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>26</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>27</sup> Page 18, <u>Report and proposition on Assisted Dying on States Assembly website</u>

there is an expectation that they would suffer mentally with that condition to a degree so unbearable that they felt they could not continue to live.

Determining the presence of a psychological condition that may prevent a clear, informed and settled wish to die is an immensely important safeguard and the concerns around this issue have been laid out above.

#### "reasonably expected to die within six months"28

A prognosis of six months life expectancy is notoriously inaccurate and a probabilistic art. 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<sup>29</sup>. The House of Lords Select Committee on the Assisted Dying for the Terminally III 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<sup>30</sup>
- "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<sup>31</sup>

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 actually is. A guestimate of prognosis is not a safeguard, there is no test for prognosis that can be verified.

#### **Residency Status**

The question of residency status will need to be addressed to avoid Jersey becoming a commercial or not-for-profit assisted suicide destination, similar to the way that Dignitas in Switzerland has become.

### **Advanced Decisions**

It is appropriate that, despite a narrow majority of those in favour of permitting advanced decisions to trigger the administration of lethal drugs, the Jury has "considered that further consultation and research should be undertaken prior to lodging any associated legislation"<sup>32</sup>. Advanced decisions require stringent safeguards to ensure the presence of a settled and persistent request. Even with safeguards, however, there are significant problems. Even when people have stipulated an advance decision to refuse treatment, not infrequently they change their mind in the face of deteriorating health and seek

<sup>&</sup>lt;sup>28</sup> Page 2, Report and proposition on Assisted Dying on States Assembly website

<sup>&</sup>lt;sup>29</sup>More Care, Less Pathway: A Review of the Liverpool Care Pathway, 2013

<sup>&</sup>lt;sup>30</sup> House of Lords Report 86-II (Session 2004-05), Page 555.

<sup>&</sup>lt;sup>31</sup> House of Lords Report 86-I (Session 2004-05), Paragraph 118.

<sup>&</sup>lt;sup>32</sup> Page 15, <u>Report and proposition on Assisted Dying on States Assembly website</u>

life prolonging treatment. In the case of a person losing capacity to reaffirm a request for lethal drugs, or that of a person whose personal and/or medical circumstances have changed in the course of an illness which affect their ability to make an informed decision, it is incredibly difficult to confidently assert the clarity of a request and be sure of an ongoing wish to die.

# **Role of Doctors**

It is important to consider how doctors view this responsibility. A 2020 survey of BMA members, which includes members from Jersey, showed that the majority of those licensed to practice and closest to terminally ill and dying patients – those in palliative care, geriatric medicine, oncology, and GPs – do not support legalisation<sup>33</sup>. Additionally, a majority of BMA members holding a license to practice, said they would not participate in such practices<sup>34</sup>.

Research reveals that the primary motivation for clinicians refusing to participate in assisted suicide is not religious or moral beliefs, but the burden of having to determine patient eligibility and fear of psychological and emotional repercussion<sup>35</sup>. Medical practitioners themselves are aware of the ambiguity of the presented eligibility criteria and are hesitant to take on such responsibility. Balancing rights and enforcing them is the proper province of the courts, not of the consulting room.

Doctors have a duty of care towards their patients, and the compassion that characterises good medical practice in this country is the very reason that doctors should not be involved in the process of assisted dying. It is the responsibility of doctors to act in the best interest of patients, and to do what is possible to alleviate pain and give good care to the dying. Their compassion and empathy with the patient makes them unable to take a dispassionate decision over the legal certainty required to deliberately be involved in foreshortening life.

Doctors are used to the responsibility of decisions that may life-changing, but the legal requirement to default to life saving when in doubt is an important safeguard for patients against the doctor who is burnt out, has a utilitarian motivation or may even wish to cover up diagnostic or therapeutic errors.

Patients trust their doctors because they have to – they know they are in need of help and rely on the clinical and scientific knowledge of the doctor to provide them with such help. Involving doctors in the process would alter the patient-doctor relationship, as every patient with a terminal illness would have to be told by their doctor that an assisted suicide is an available option, as seen in Canada. Patients cannot know if their doctors are solely motivated to provide good care, leaving patients at the mercy of unconscious bias in the doctor. Although one hopes there will not be another Dr Shipman, it is important to recognise that such necrophilic tendencies would be harder to detect.

<sup>&</sup>lt;sup>33</sup> BMA Survey on Physician Assisted Dying: Research Report (Oct 2020)

<sup>&</sup>lt;sup>34</sup> BMA Survey on Physician Assisted Dying: Research Report (Oct 2020)

<sup>&</sup>lt;sup>35</sup> <u>A qualitative study of physicians' conscientious objections to medical aid in dying</u>, *Palliative Medicine*, Vol 33 (July 2019)

# Safeguards

# **Pre-approval Process**

It is proposed that assisted dying should be permitted in Jersey subject to a pre-approval process. This pre-approval process may, subject to further consultation, involve a decision made by a court or specialist tribunal.

To ensure objectivity and minimise bias in the process, all stages should be recorded and help in strict confidence to allow an anonymised s=audit of the process on an annual basis.

It is essential that any proposal for an assisted dying law should include a rigorous pre-approval process. Such a process should include - but not be limited to - a mental capacity assessment of an applicant, a psychiatric evaluation, inquiries into the presence of coercion, the presence of personal financial pressures, bullying or abuse, the history of that person's care, the medical history of an applicant - including previous mental health conditions – verification of the diagnosis and likely course of the illness, and an analysis of any care plans made by the person.

Whilst the doctors and relevant health professionals should make an assessment of the clinical elements of a person's eligibility, the declaration should be submitted, along with all relevant evidence, to the Court whose responsibility it should be to judge eligibility. Doctors do not know the personal or social factors in an individual's life beyond what is recorded in the clinical record. It is the role of the Court alone to balance the rights of some against the protection of others, not of individual doctors. The small community of Jersey, with a population of under 110,000, makes it particularly difficult for doctors to have a dispassionate view of those patients who are also friends or acquaintances.

The proposals state that a potential disadvantage of a pre-approval process could include "an increased time between a request for assisted dying and approval, which may be problematic for those close to death"<sup>36</sup>. It states that this could be mitigated against in the set up and design of processes, by allowing for example those who are expected to die soon to have their request reviewed in a shorter time frame.

However, if the person is going to die within a short time, the relevant approval processes and concomitant safeguards should not be weakened or side-tracked. Indeed, the integrity of the process surrounding the absolute majority of cases where suffering can be alleviated should not be undermined by the minority of cases where pain is harder to manage. "Close to death" remains an ambiguous assessment and should not precipitate the breakdown of necessarily rigorous checks and processes, especially if that person is thought to be about to die naturally anyway. If death is imminent, then it is more appropriate to undertake all measures for the person's comfort than to require their suffering to be such that they are eligible to be given lethal drugs; the Canadian experience suggests that pain and

<sup>&</sup>lt;sup>36</sup> Page 22, <u>Report and proposition on Assisted Dying on States Assembly website</u>

symptom control have worsened as a result of clinicians being fearful that with good symptom control the person then becomes ineligible for assisted suicide or euthanasia.

# **Administration of Lethal Drugs**

The proposals have not considered what lethal drugs will be used or the potential complications of these drugs. In other jurisdictions, the lethal drugs used have never been subject to proper scientific scrutiny. Previously, massive 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, but which result in longer median times to death<sup>37</sup>.

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<sup>38</sup>. This rate suggests a different picture to the 'idealised death' portrayed by those campaigning for such legislation.

It is also not clear how the healthcare professional is supposed to respond in the event that complications arise. For example, if a person is vomiting would they be expected to clear their airways (which would be a resuscitative procedure)? There will be an emotional conflict for the healthcare professional as their normal 'first aid' response would not be appropriate when the desired outcome is death, rather than to restore a person to living well.

# **Conscientious Objection**

The proposals state that "the law should provide for a conscientious objection clause so that any nurse, medical practitioner or other professional is not under a legal duty to participate in assisted dying"<sup>39</sup>.

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. In relation to abortion, the General Medical Council requires a clinician with conscientious objection to signpost the person to an alternative provider.<sup>40</sup>. It will be important to clarify the medical duty if a person feels the request for lethal drugs is unwarranted and what their legal obligation will be to provide evidence to the court or assessment tribunal.

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

<sup>&</sup>lt;sup>37</sup>Oregon Death with Dignity Act, 2021 Data Summary Error! Hyperlink reference not valid.

<sup>&</sup>lt;sup>38</sup>Oregon Death with Dignity Act, 2021 Data Summary Error! Hyperlink reference not valid.

<sup>&</sup>lt;sup>39</sup> Page 2, <u>Report and proposition on Assisted Dying on States Assembly website</u>

<sup>&</sup>lt;sup>40</sup> General Medical Council: Personal beliefs and medical practice

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.

Additionally, the law should state clearly that no recognised health body or organisation which operates in the field of health or social care should take into account 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.

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 judges and legal professionals, not just medical 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.

# **Cooling-off Period**

It is proposed that assisted dying should be subject to a mandatory period of reflection (a "cooling-off period"), but it does not clarify the length of this period. In draft Private Member's Bills presented to Westminster and the Scottish Parliament, the proposed requirement of a 14-day reflection period following approval of assisted suicide does not seem enough to permit sober reflection or to exclude coercive pressures. The short cooling off period fails to recognise the fluctuating nature of a wish for death over weeks and 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 even though they are ill.

# Withdrawal of Request

An applicant should be offered explicit opportunities regularly throughout the process of an application to withdraw his or her request.

# Non-abandonment of patients

There are real and deep-seated conflicts for clinicians who have worked to improve quality of life of their patients in the face of terminal illness, to then abandon those efforts to ensure the patient is eligible for the requested assisted dying lethal drugs.

The patient's application to the court or tribunal should be followed by a court appointed person (e.g. thanatologist) who is responsible for the provision of the fixed dose lethal drugs and for overseeing their ingestion. There are no clinical skills required in the 'prescribing' of such drugs as they are at a fixed toxic

dose, well above the threshold that would be clinically indicated. The supplier could be through a courtappointed specific pharmacy.

The person delivering the drugs should be required to stay with the person to ensure they are either ingested or, if the patient changes their mind and decides not to pursue death at that time, the drugs must be taken away to ensure they cannot be diverted into the community.

The thanatologist should have specific training in confirming prior to ingestion that the desire for death remains the person's considered, voluntary, and informed wish, should complete a pre-ingestion registration form, document any complications that occur, and must submit this for public record and data collation.

In the event that the decision is that the drugs should be injected (euthanasia), then the court appointed person should be someone also trained in venous access, such as a person who has undergone phlebotomist training.

The clinical team, particularly doctors and nurses, who have been involved in the patient's care would then be free to have no active part in precipitating the death. They would also be free to accompany the patient throughout and could stay with the patient and family if they wished to do so, thereby allowing involvement to be determined by patient and family, not by the administrative requirements of bringing about death by lethal drugs.

# Monitoring

Irrespective of who is licensed to provide lethal drugs to patients, it would be of paramount importance that sufficient data is collected and critically analysed. In jurisdictions where assisted suicide and/or euthanasia are legal, effective and reliable data collection has proved largely unattainable because the data collection relies on post-event reporting by the doctor. There are inherent dangers in this, because doctors very rarely report where they fail to adhere. The experience in Belgium estimates that at least 40% of euthanasia cases go unreported for a variety of reasons, including the workload of filling in a form<sup>41</sup>. Additionally, instances in which clinicians have refused any prior requests due to prognosis, capacity, or the presence of coercion go undocumented.

Without any record of how the assessment was conducted or triangulation by requiring reports from others involved, independent audit is impossible. A feasible solution may be to record consultations using body-worn video cameras, such as those used routinely by paramedics and in emergency departments, which would protect the patient from potential criminal malpractice and also protect the doctor from accusations of being too ready to end life.

The basic characteristics of the patients and their terminal condition which qualifies them for the prescription of lethal drugs, the number of requests, number of signed declarations, who was consulted

<sup>&</sup>lt;sup>41</sup> <u>Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases, *British Medical Journal*, July 2010</u>

in the approval process, whether they have received palliative care and for how long, the patients' end of life concerns, details of the prescribing physician and their medical specialty, which drugs are prescribed to bring about death, the time from ingestion to unconsciousness and death and the presence of complications must all be included in the data collected.

The proposal anticipates that the Jersey Care Commission will be responsible for regulatory oversight of any on-island assisted dying service and that new regulations will need to be brought forward under the Regulation of Care (Jersey) Law 2014.

In order to detect any criminal activity, monitoring needs 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. Data must be held securely for a minimum of 25 years. It is a grave concern that in Oregon the data is disposed of after a year making most forms of such coercion unidentifiable<sup>42</sup>. In the Netherlands, reporting through the Dutch independent review committees provides post-event reporting information for analysis and review, reliant on the doctor reporting actions, but does not provide any qualitative assurance over the consultation in which the decision to end life was taken.

# Training

The proposals suggest that training may be required in the practice of assisted dying. Costs relating to the education, training and commissioning of specialist healthcare practitioners to participate in assisted dying would be a necessary result from these proposals. Training, though, would not be the only required cost to make any legislation workable. The workforce costs involved will be significant, particularly as the accompanying court-appointed professionals may wait several hours until the patient dies. If the decision is to leave this healthcare professionals, they would need to be replaced in the clinical team to avoid jeopardising other patients. Taking into account the number of doctors who would abstain from participating in assisted dying - which, according to the 2020 BMA survey, would be 45% - alongside the current pressures on the health system because of the pandemic, the level of resource and extra funding this proposed bill would require if enacted could be substantial<sup>43</sup>.

# **Palliative Care**

In a statement on their website, Jersey Hospice Care supports the long-held position of the European Association of Palliative Care which declares that the provision of euthanasia and assisted dying shall not be included in the practice of palliative care. Rather, *"the focus of Jersey Hospice Care now and tomorrow shall always be about the living and living well and when the time comes to die well, pain free and with dignity. All patients and those important to them should be made aware of the options for palliative care and should be offered an assessment of their individual needs to make sure that appropriate palliative care is being provided." Such a statement from a key service provider on the island highlights the incompatibility of palliative care services with assisted dying legislation, as practitioners* 

<sup>&</sup>lt;sup>42</sup>Oregon's Death With Dignity Act FAQs

<sup>&</sup>lt;sup>43</sup> BMA Survey on Physician Assisted Dying: Research Report (Oct 2020)

want to provide comprehensive and compassionate care and support to dying people, to help them live well.

The proposal anticipates that the resources currently allocated to palliative care, or associated services, would not be redirected to assisted dying services but that the States Assembly would make additional financial provision for an assisted dying service. However, evidence shows that palliative care investment does not accompany assisted dying legislation. An analysis of specialised palliative care services in 51 European countries over the last 14 years reveals that the average growth in palliative care services in countries with 'assisted dying' has been slower than countries without such legislation<sup>44</sup>. Notably, Belgium and the Netherlands appear to have experienced no growth in palliative care services since 2012<sup>45</sup>.

Unlike the UK where a third of hospice services are publicly funded, in Jersey, all services at Hospice are funded by community fundraising, charity shops, donations and investments<sup>46</sup>. Jersey Hospice Care, the island's leader for all healthcare professionals in the development of specialist palliative care provision and education, receives some public funding to support healthcare providers across the community and in the hospital in the delivery of palliative care, but this accounts for only 8% of their expenditure. Palliative care services should be publicly funded and universally available in Jersey before any consideration of publicly funding an assisted dying provision.

The proposals state that research on assisted dying in Canada, the U.S. and some European countries indicates that "74%–88% of people who opt for assisted dying also receive hospice or palliative care services". In Canada, it is claimed that 82.8% of MAID recipients received palliative care, however, this data is based on self-reports by MAiD providers themselves and lacked any meaningful information on the quality or quantity of palliative care and who it was provided by<sup>47</sup>. On closer inspection of the data, 91 patients had no access to palliative care at all and 854 received palliative care only after they were experiencing a depth of suffering and despair that led them to request an end to their life. Canadian Palliative Care Doctor, Romayne Gallagher, writes that this is "an unacceptable number of people" and "should be considered a failure of our system"<sup>48</sup>. Another recent Canadian paper found palliative care involvement in patients requesting MAiD to be inadequate, revealing that in one region 72.6% of patients had no community palliative care physician and 40.5% had no palliative care involvement prior to requesting MAiD<sup>49</sup>.

<sup>&</sup>lt;sup>44</sup> <u>Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years, *Palliative Medicine*, Vol 34 (Sep 2020), pp. 1044-56</u>

<sup>&</sup>lt;sup>45</sup> <u>Trends analysis of specialized palliative care services in 51 countries of the WHO European region in the last 14 years, *Palliative Medicine*, Vol 34 (Sep 2020), pp. 1044-56</u>

<sup>&</sup>lt;sup>46</sup> Jersey Hospice Care website

<sup>&</sup>lt;sup>47</sup> Second Annual Report on Medical Assistance in Dying in Canada 2020

<sup>&</sup>lt;sup>48</sup> Lack of palliative care is a failure in too many MAiD requests, *Policy Options Politiques*, October 19, 2020.

<sup>&</sup>lt;sup>49</sup> Involvement of palliative care in patients requesting medical assistance in dying, *Canadian Family Physician*, Vol <u>66 (Nov 2020)</u>

The proposals say that *"in Canada \$6 billion was allocated to home and palliative care in the 2017 federal budget, the year after the introduction of assisted dying legislation. \$6 billion represents a significant increase on previous years"*. However, Canada also recently published a report that cited potential savings of up to £80 million on the annual public healthcare bill<sup>50</sup>. Proponents of a change in the law make conflicting claims regarding funding, claiming that palliative care investment is complementary to assisted dying, yet applaud the potential savings.

Further, in Canada, we have heard anecdotal evidence that specialist palliative care professionals are leaving services because they do not want to be involved in any aspect of assisted suicide and euthanasia. Workforce shortages further push up costs through a requirement for locum provision in services whilst losing clinical expertise.

If the proposal is serious about making access to palliative care a co-equal partner to an assisted dying 'service' in Jersey, and proponents believe in simultaneously increasing the quality of good palliative care, then such legislation should not commence until specialist palliative care services are core funded in all areas, fully integrated with all general medical and surgical services, as well as across the community and care homes on the island.

# **Other concerns**

# **Resources**

Evidence from overseas suggests that assisted suicides increase exponentially where legislation is in place<sup>51</sup>. This inevitably increases costs on processing and managing assisting suicide and euthanasia, if the quality of scrutiny over requests is maintained. If there is no investment in scrutiny then the standards fall and criteria put in as 'safeguards' are more easily abused.

The funding that is most necessary currently is funding to improve specialist palliative care services to support patients approaching the end of life. The health service is on its knees as a result of COVID-19 and does not have the capacity to stretch its workforce into a practice that has too many flaws to be workable. Diverting funding away from the critical care needs of patients at the end of life undermines the fundamental ethic at the nation's core which has always sought to protect the value of life.

# **Equalities**

The introduction of assisted dying has been shown to undermine the legislative framework that protects the equal rights of all people. The principle of a 'right to life' (Article 2) builds on the premise that all life is valuable and must be protected, but in the face of such legislation the duty of society to uphold Article 2 will no longer apply to all persons. the underlying assumption behind such legislation is that some lives

<sup>&</sup>lt;sup>50</sup> <u>Cost Estimate for Bill C-7 "Medical Assistance in Dying", Office of the Parliamentary Budget Officer, October</u> 2020

<sup>&</sup>lt;sup>51</sup> Euthanasia, Assisted Suicide, and Suicide Rates in Europe, Journal of Ethics in Mental Health, Vol 11 (2022)

are not worth striving to improve and can fuel ageist and ableist agendas through subconscious suggestions.

Such attitudes make certain populations, such as the elderly and disabled people, particularly vulnerable to coercion within society. Instances of elder abuse are known to be widespread and often go undetected. In Oregon, elder abuse grew by 13% in just one year<sup>52</sup> and in 2020 53% of those who died through taking lethal drugs described feeling a burden on their friends<sup>53</sup>, family and caregivers as an end of life concern. A request for lethal drugs may appear voluntary but, in reality, can result from various coercive pressures including the cost or burden of care, influence from family members, and psychological or emotional distress.

In jurisdictions where assisted dying is legal, reports acknowledge the existence of abuse<sup>54</sup> and explicitly describe higher proportions of vulnerable individuals being offered an assisted death. Case reports of assisted deaths in intellectually disabled people are a particular concern<sup>55</sup>. Further, because all reporting mechanisms rely on the prescribing doctor to self-report, it is inevitable that instances of discrimination and unconscious bias are largely undetected.

Concern has been voiced that vulnerable populations, such as those with complex needs, progressive disability and those who are socially marginalised, will also come under threat of subtle coercion through unconscious bias in health and legal professionals. Although early reports from Oregon indicated that more socio-economically deprived had lower uptake rates of assisted suicide, the profile of those taking lethal drugs is changing.

The current law exists to protect the vulnerable. Before changing the law to assist suicide, the protections for people at a vulnerable time should be strengthened, such as when emotionally or physically traumatised, or when mental capacity is impaired for whatever reason.

# **Sustainability**

The strongest, healthiest and most just societies are the ones which look after all in the population. Rather than creating a death-focused system which becomes the obvious route for those suffering mentally or physically or who are frightened of the possibility of suffering at the end of life, there is a need for an improved and integrated health and social care system to support the health and social needs of the population. It is notable that the vast majority of advocates for assisted dying are fit and well, some are clearly frightened of death. By contrast, the majority of those who are ill have renewed wish to live, as mentioned above. Diverting effort away from the improvement of the quality of life and care of all dying persons towards efforts to provide an assisted suicide/euthanasia service fundamentally

<sup>&</sup>lt;sup>52</sup> Oregon Department of Human Services

<sup>53</sup> Oregon Death with Dignity Act, 2021 Data Summary

<sup>&</sup>lt;sup>54</sup> <u>Suicide assisted by right-to-die associations: a population based cohort study, International Journal of</u> <u>Epidemiology, Vol 43 (April 2014)</u>

<sup>&</sup>lt;sup>55</sup> <u>"Because of His Intellectual Disability, He Couldn't Cope."</u> Is Euthanasia the Answer?, *Journal of Policy and* <u>Practice in Intellectual Disabilities, Vol 16 (June 2019)</u>

undermines the values of a society that stands in solidarity with its most vulnerable members. It appears an outdated way for a society to respond to the needs of its citizens. Ending life as a mechanism to end a person's suffering ignores the possibility of major improvement in their quality of life if the right expertise is available, just a judicial executions ignored the possibility of wrongful convictions.

An assessment of the possible financial implications is dealt with more comprehensively above, but it should be noted that the solution to the problem of economic unsustainability does not lie with legalising assisted dying. Yet the cost efficacy of specialist palliative care is proven as it relieves costs from the acute sector as well as improving quality of life for patients, Experience from overseas demonstrates that palliative care investment does not improve where assisted suicide is legal.

We are unaware of any long-term study of the impact of assisted suicide or euthanasia on the long-term health and wellbeing of the bereaved.

With regards to participative systems of governance, these proposals offer scant detail as to the provision of regulations, monitoring and scrutiny commitments, reporting obligations or indeed as to what happens in disputed cases. As it appears, the courts may not be involved, neither is a social work assessment. It is unclear how any form of abuse or coercion, from family or any other personal contact would be identified. The proposals laid out here for Jersey do not represent or promote a participative system of governance, but one that will open a door to manipulation, coercion and injustice.

It is not clear that any strong scientific evidence, apart from patchy opinion polls, has formed the basis of the policy outlined in the proposals. Regarding the lethal drugs involved in the assisted dying process, there is little factual evidence as to their safety or mode of action.

Since the European Commission restricted the sale of barbiturates to the US due to their use in judicial executions, the majority of assisted suicides in Oregon are brought about using experimental combinations referred to as "DDMA" and "DDMP"<sup>56</sup>. The extent to which previous and current assisted dying drugs are safe and effective is unknown, as there have been no controlled trials or observational studies. Experimental drug combinations, like "DDMA" and "DDMP" have not undergone standard drug evaluations<sup>57</sup>.

Patients who ingest lethal drugs can experience distressing complications. In Oregon in the last two years of the 31% of assisted suicides with available data, there is a complication rate of 8.2%<sup>58</sup>. Time from drug ingestion to death has taken up to 47 hours in 2019, up to 8 hours in 2020, but there is a report of death taking 108 hours after ingestion<sup>59</sup>. Patients in the United States have been asked to ingest the contents of 90-100 barbiturate pills<sup>60</sup>. The result is a mixture so bitter and potent that many

<sup>&</sup>lt;sup>56</sup> Oregon Death with Dignity Act, 2021 Data Summary

<sup>&</sup>lt;sup>57</sup> Oregon Death with Dignity Act, 2021 Data Summary

<sup>&</sup>lt;sup>58</sup> Oregon Death with Dignity Act, 2021 Data Summary

<sup>&</sup>lt;sup>59</sup> Oregon Death with Dignity Act, 2021 Data Summary

<sup>&</sup>lt;sup>60</sup> My aunt's struggle with assisted suicide: There was death, but not enough dignity, Los Angeles Times, August 14, 2016.

patients struggle to ingest the liquid and can experience choking, coughing and vomiting. In Canada's oral MAiD drug protocol, another drug regimen recommended is a mixture of phenobarbital, chloral hydrate and morphine<sup>61</sup>. Chloral hydrate is known to be caustic to oral and gastric mucosa and can cause painful burning in the throat and stomach<sup>62</sup>. In the context of judicial execution, it has been suggested that intravenous barbiturate overdose combined with a curare-like paralysing agent as used in many euthanasia's may result in distressing and painful deaths, even though they appear peaceful because the person cannot move a muscle. In a study of over 200 autopsies of executed prisoners, of those killed with a lethal dose of pentobarbital 84% showed signs of flash pulmonary oedema (their lungs were filled with fluid and weighed several times the weight of normal lungs)<sup>63</sup>.

It is not clear that the proposals laid out would lead to a bill which would protect the interests of society as a whole, nor that it would guarantee the idealised deaths that proponents suggest.

# 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 and surgical – which could benefit them. Advanced pain management techniques such as nerve blocks are also 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 UK already has a workforce that 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.

What the concerns laid out in this consultation response indicate is that any 'in principle' notion of assisted dying cannot progress without workable safeguards and a detailed process to ensure the practicability of an assisted dying law. It is our concern that no sufficient level of safeguarding can be achieved to make an assisted dying law workable, and that the 'in principle' assisted dying proposition has been based on inadequate consideration of the factual evidence that points to the inherent dangers of the proposal, which is both redundant and dangerous.

#### April 2021

<sup>&</sup>lt;sup>61</sup> The Oral MAiD Option in Canada Part 1: Medication Protocols Review and Recommendation, April 2018

<sup>&</sup>lt;sup>62</sup> Choral Hydrate, Compound Summary (Chloral hydrate | C2H3Cl3O2 - PubChem (nih.gov))

<sup>&</sup>lt;sup>63</sup> Gasping For Air: Autopsies Reveal Troubling Effects Of Lethal Injection, NPR, September 2020.