

## Appendix B:

### Assisted Dying in Jersey Phase 2 Consultation Feedback:

#### Stakeholder individual written responses

A list of stakeholder individuals and their full written responses to the Assisted Dying consultation are presented below, where the stakeholder has given their permission for their full response to be attributed to them and included in this document.

1	<a href="#">Ryan Spielvogel, MD, MS</a>	Medical Director, Sutter Health End of Life Option Act Services
2	<a href="#">Christopher A. Riddle, PhD</a>	Professor and Chair of Philosophy - Utica University, NY USA
3	<a href="#">Professor Ben Smart</a>	Director, The Centre for Philosophy of Epidemiology, Medicine and Public Health - University of Johannesburg
4	<a href="#">Dr Isra Black</a>	Lecturer in Health Law, UCL Faculty of Laws, University College London
5	<a href="#">Dr Jaimee Mallion</a>	Division of Psychology, School of Applied Sciences, London South Bank University
6	<a href="#">Hon Kyam Maher MLC</a>	Attorney-General of South Australia
7	<a href="#">Dr Jennifer Klimiuk</a>	Consultant in Palliative medicine, Bolton Hospice
8	<a href="#">Dr Angharad Gray</a>	NHS Community Psychiatrist
9	<a href="#">Dr John Stewart Jones</a>	Retired Jersey GP
10	<a href="#">Thomas Thorp</a>	Consultant Geriatrician
11	<a href="#">James Downar, MDCM, MHSc, FRCPC</a>	Head and Professor, Division of Palliative Care, Department of Medicine, University of Ottawa
12	<a href="#">Professor David Albert Jones</a>	Director, Anscombe Bioethics Centre, Professor of Bioethics, St Mary's University, Twickenham
13	<a href="#">Professor Ben White &amp; Professor Lindy Willmott</a>	Professor of End-of-Life Law and Regulation and Professor of Law, Australian Centre for Health Law Research
14	<a href="#">Gay Lee</a>	Retired Palliative Care Nurse

## 1. Ryan Spielvogel, MD, MS

December 22, 2022

Dear Government of Jersey,

I write to you today to urge you and your colleagues to **pass legislation authorizing assisted death in Jersey**. As a practicing physician in California where assisted death is legal, I have seen up close the universally positive impact having assisted death as an option has had on my patients and my physician colleagues. Personally and professionally, my journey from open-minded ambivalence to avid support was gradual but always steadily unidirectional.

As I compose this letter, some specific formative experiences come to mind. The law authorizing assisted death (what has come to be called “medical aid in dying” in the United States) went into effect in June of 2016 in California. The following week, I received my first consult. For the first time in my career as a physician, I was about to help a man die. I remember sitting at my desk not knowing what to feel. But like many experiences before this, I decided the only way for me to sort out my feelings on the topic was to try it and reflect afterwards.

In the room, Percival\* sat across from me, waiting for me to speak. There was no formal training on how to do this yet and awkward moments passed. I somehow fumbled my way through our first visit, but he didn’t seem to mind. I was most struck by how clear he was in his reasoning and how firm he was in his resolve. Unlike most of my patients, Percival had no illusions about what lay ahead. His disease was consuming him—sapping his strength and robbing him of any pleasure in life. Moreover, there was no way for him to ever get that back. “I want to end it before I get so weak that I become a vegetable,” I remember him saying.

In the weeks that followed, Percival fulfilled the rest of the legal requirements. Throughout the process, I held it together better than I expected until the time came for him to leave my office for the last time. I shook his hand and opened my mouth, but the words failed me. “Good to see you,” didn’t feel right. “See you later” was an outright lie. I had never been faced with this before. I was knowingly sending a patient to his death. I settled on, “It’s been a pleasure.” He nodded his acknowledgement and left.

I prescribed him the aid-in-dying drug that day, and he took it the next. A few days later, I called his daughter to check in on how everything went. I’ll never forget what she said. “We got to have a memorial for Dad while he was still alive. Then he took the medication surrounded by friends and family. He went to sleep and passed away peacefully. It was beautiful.” My eyes welled up, not expecting how far the gift had expanded beyond the patient.

I thought long and hard about Percival and death in the weeks that followed. It was once said that nothing in life is certain except for death and taxes, yet most people seem surprised when death

comes knocking at the door. This unexpected quality that our culture has ascribed to death along with our erroneous assumption that we can somehow prevent it if we just try harder is what Dame Cicely Saunders—the mother of modern hospice—once referred to as our “death-denying society.”

But then here was Percival—a man who accepted the inevitability of his death and met it head on. He took control of his suffering and exercised his autonomy in a way that was heretofore unthinkable in California. As a result, his death was not at all traumatic for himself or his family—it was a celebration.

The power in his action was transformative. It was a statement that death does not need to be something that happens to you on its terms. It gave him the agency to write for himself that last sentence in his book of life. Through this, **I came to recognize assisted death for what it is—an invaluable form of restorative justice.**

In the years that have followed my experience with Percival, I have overseen many deaths from medical aid in dying—either directly or through the medical residents in the program where I am faculty. I am now the senior medical director for aid in dying services for my large healthcare institution that includes 5,000 physicians and 60,000 employees and covers the care of 3 million patients. I can say unequivocally that **having this option available has had an enormously positive effect on patients and physicians alike.**

The way our law has been written and implemented, safeguards exist on all sides. Only patients who can demonstrate their capacity to make sound medical decisions can access aid in dying. This helps prevent coercion, and in the 25 years that aid in dying has been legal in jurisdictions in the United States, **there has never been a single substantiated claim of coercion.** In our law, two physicians must independently assess a patient and determine that the patient is eligible (terminal prognosis plus mental capacity). This serves not only as a potential check-and-balance for such a consequential determination but also offers the primary physician a valuable second perspective on cases and the complexities therein.

And most importantly, participation is optional—for patients, physicians, and staff. **Physicians and staff who have objections to the practice of assisted death for any reason are allowed to opt out** of providing this service—without fear of censure, discipline, or retribution. For the physicians who do not want to participate, they simply don’t have to. However, I hear time and time again from the physicians who *do* participate how rewarding this work is. Far from being distressed, **participating physicians often describe offering this service to their patients as one of the most meaningful and fulfilling acts they can facilitate as a doctor.**

As the medical director, I personally train all physicians in our system on the process of assisted death when they are considering offering this service (usually in the context of a specific patient of theirs asking for it). Without exception, the physicians are anxious at the start—just like I was. After

their respective patients' deaths, I always check back in with the doctors and I hear things like "paradigm shift" or "this was an inspiration" or "it is a privilege that we can offer this to our patients." Those are direct quotations.

What about patients who object? Patients who have objections to the practice simply do not have to pursue the option—same as all options in life. However, for patients approaching the end who want to exercise their autonomy and gain some control over their own dying process, assisted death offers them empowerment at a time that many feel powerless and disenfranchised. As I noted in an editorial for our local medical society (Spielvogel, 2022), the option of assisted death allows patients like Percival to bypass much of the suffering they know is ahead and skip to a more humane ending consistent with their values. Patients choosing assisted death are *not* choosing between life and death. Their time is up either way; it's just a question of how much suffering they want to endure. In six years and the many cases in which I have participated, **I have yet to meet a patient who wants to die. They would gladly relinquish the opportunity for more suffering-free time with their loved ones, but that's a choice they don't have.**

There will always be physicians who oppose this practice. At issue is that bedrock of medicine: do no harm. But what constitutes harm? For the imminently dying patient who has no quality of life left and is ready to move on, continuing to live may constitute harm to them. Forcing our patients to endure suffering because it is the natural order of things is not new to our profession. James Young Simpson famously experienced a backlash when he first used chloroform for effective labor analgesia in the 1800s because suffering was felt to be a necessary part of a woman's delivery. Quite clearly, it has since become common practice to ease labor pain with various medications. The insistence that all must suffer their lot when their end is near is similarly antiquated.

Ana\* was a patient of mine a few years ago who was dying from metastatic colon cancer. Spinal metastases made every movement agony and took away her last pleasurable activity: going out and tending her garden. She sought my assistance to help her end her suffering, but her family stonewalled us at every turn. Due to their deeply held religious beliefs, they felt strongly that going through with this act would damn her immortal soul. So under false pretenses, the family sent her to a religiously-affiliated skilled nursing facility that would not allow her to ingest the aid in dying drug on the premises. Then they quickly sold her house so that she would have nowhere to go. Once she and I figured out what was going on, it was too late. Ana was beyond distraught at the duplicity, but she was at their mercy.

I spent a whole month exploring options for her while she wasted away in bed suffering exactly the kind of agonizing existence she wanted to avoid. I did eventually find a skilled nursing facility that was willing to take her on a charitable basis and allow her to ingest once she got there, but Ana died before the transfer could happen. Ana had made her choice and her family had denied her that.

Every time I see a patient for assisted death I think of Percival, Ana and others like them. Some make it out on their terms; some do not. I try to think about my own mortality, too. If I were facing a slow, steady decline and had intractable suffering resistant to other efforts to palliate, would I choose this option for myself? I honestly don't know, but the fact that I would have the choice makes all the difference.

Over and over again I see how having responsible and effective assisted death as an option in our society enriches it and improves the quality of life for those still here. It provides reassurance to those facing terminal illness—always giving them the final say. And it relieves the existential angst faced by many physicians as they watch their patients dwindle and suffer through the dying process. For the most part, when I now see my patients endure suffering at the end of life, I know it's their choice. Respecting our patients' choices is at the heart of being a good physician and is the highest achievement in fulfilling our oaths.

As such, I hope that you and your colleagues find it in your hearts to author and pass legislation that will bring this humane option to the citizens of Jersey. Thank you for your time and consideration. I am happy to answer any and all questions you might have and am available to provide oral evidence if needed.

Sincerely,

A handwritten signature in black ink, appearing to read 'R. Spielvogel', written in a cursive style.

Ryan Spielvogel, MD, MS  
Medical Director, Sutter Health End of Life Option Act Services  
California, USA

\*Names of patients have been altered for confidentiality

Reference:

Spielvogel, R. Apr 2022. Letting go: A physician's tale of medical aid in dying. *Sierra Sacramento Valley Medicine*.

## 2. Christopher A. Riddle, PhD

To Whom It May Concern:

My name is Christopher A. Riddle, PhD, and I am a Professor and Chair of Philosophy at Utica University in New York, USA. I have dedicated my life to promoting the rights of people with disabilities and have written books on disability and justice, as well as the promoting of human rights for people with disabilities. I very strongly support Assisted Dying and have published in some of the most prestigious academic venues detailing my defense of it. The following is an excerpt from a forthcoming publication detailing what can be learned from those jurisdictions that permit aid in dying. I argue that despite criticism from some disability rights organizations, their concerns are neither justified, nor representative of all people with disabilities. This book chapter will appear as:

Riddle, C. A. "Medical Aid in Dying: The Case of Disability." In *New Directions in the Ethics of Assisted Suicide and Euthanasia – 2<sup>nd</sup> Edition*, edited by Michael Cholbi and Jukka Varelius. New York: Springer, (forthcoming) 2023.

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Concerns about person affecting harm permeate almost all disability rights organizations' objections to aid in dying. The question at hand is the following: Is there any evidence in jurisdictions where aid in dying is legal that suggests harm befalls people with disabilities or other vulnerable populations to a greater extent than other states without legalized aid in dying? The short answer is that no harm appears to have befallen people with disabilities or others as a result of permitting aid in dying.

Consider first, jurisdictions outside of America prior to moving to American ones. There exist more complexities with systems in most European jurisdictions than American ones, but nonetheless, these complexities do not give way to abuse.

In the Netherlands, for example, there is no evidence that people with disabilities or other vulnerable groups are experiencing harm as a result of medical aid in dying. There is some well-documented concern over under-reporting within the Netherlands, but Govert den Hartogh (2012) attributes this under-reporting to what he calls "a relic of prelegalization practice" (366), and not as a result of the legalizing of euthanasia.

Opponents suggest that doctors and other medical professionals might be inclined to hasten the death experience against the wishes of a patient. Disability Rights Organizations suggest that this practice is more likely employed against people with disabilities who might be perceived to have a life not worth living. Disability Rights objectors cite concerns that the most likely manner in which lives might be ended without request would be for those outside of the terminal window to be killed (Hartogh 2012, 365). The concern emerges from the claim that with normalizing the taking of lives, compassion might be thought to extend outside of the legal restrictions placed on aid in dying practices. Medical professionals might view suffering to be so bad that they hasten the death

experience, even without death being immanent, as defined by the law. Perhaps obviously, given the ablest attitudes of many in society, disability rights organizations suggest this notion of suffering and a life not worth living might be more likely to be applied to people with disabilities. The concern here then, is that an under-reporting of the use of some drugs, such as morphine, might result in the use of it in large doses to kill those who have not expressed desire to die, and who have not navigated the legal process and the safeguards within. Opponents do not attribute malicious intent to medical professionals in all instances, but instead, can suggest such actions could emerge from a misbegotten effort to spare the disabled from lives perceived to be so dominated by suffering that they are not worth living.

That said, there appears to be no evidence of this in the Netherlands that cannot be explained by a more general underreporting of morphine use (Hartogh 2012, 366). In short, “no evidence for this causal nexus has ever been offered” (Hartogh 2012, 365). In other words, while under-reporting of terminal sedative drugs exists, although degreasing in frequency (OnwuteakaPhilipsen 2012, 127), there is no evidence to suggest that this under-reporting constitutes an instance of abuse against disabled people or other vulnerable populations (Battin et al. 2007, 597).

Similar conclusions can be drawn in Belgium. Indeed, little or no opposition exists to Belgian laws from Belgian disability rights organizations or people with disabilities. Concern about abuse is not present in Belgium and there appears to have been little or no opposition to the legalizing of euthanasia from disabled people (Fitzpatrick and Jones 2017, 147). There is no evidence to suggest abuse of any kind, and indeed, there remains to be no organized disabilityrights-based opposition to even a mere hypothetical risk of harm, let alone any attempt to suggest actual harm exists (Fitzpatrick and Jones 2017, 149).

In Canada, where aid in dying has been legal since 2016, and where 2 percent of all accounted deaths were attributed to the practice in 2019, there is no evidence of person affecting harm emerging from either abuse of the system, or the system itself (Martin 2021, 137). Indeed, recent data from Canada, the Netherlands, and Belgium are consistent with the claim that there is “no indication that individuals who *may* be vulnerable to undue influence are accessing assistance in dying” (Martin 2021, 142).

Within the United States, and Oregon in particular, the jurisdiction with the oldest assisted dying laws in America, there is no evidence of vulnerable populations of any kind experiencing person affecting harm. No Oregonians with disabilities have, since 1997, experienced person affecting harm from aid in dying. No people without a terminal diagnosis confirmed by two physicians have died in Oregon (Battin et al. 2007, 594). More pointedly, “no one received such assistance for disability alone” (Battin et al. 2007, 594). Robert Lindsay has concluded that a “decade after implementation of the ODWDA [Oregon Death with Dignity Act], the weight of evidence suggests that these predictions of dire consequences were incorrect” (Lindsay 2009, 19).

Indeed, a good deal of data points to rejecting many people who requested aid in dying, who were not deemed capable of consenting to such action. Almost 20 percent of requests for aid in dying came from patients deemed to be experiencing depression, and exactly none of them progressed to medical aid in dying (Battin et al. 2007, 596). More generally, no people availing themselves of aid in dying were concluded to have a mental illness influencing their decision (Battin et al. 2007, 596).<sup>1</sup>

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1 It is relevant to note that this study has received critical appraisal (Finlay and George 2011). That said, the critical remarks focused on the study’s perceived failure to identify all possible forms of

Indeed, not only has no disparate impact on those perceived to be vulnerable been detected, but there has been no slippery slope, and there has been, more generally, the effective prevention of abuse (Lindsay 2009, 22–23). Indeed, some strong opponents to medical aid in dying have publicly expressed that the concerns they previously stated have not materialized (Coombs Lee 2014, 97–98). In short, there is no evidence of abuse or coercion, and there is no evidence to suggest the misuse of the carefully crafted policies supporting aid in dying (Coombs Lee 2014, 99).

To support this point further, consider that 87.8 percent of individuals availing themselves of medical aid in dying were in a hospice setting (Al Rabadi et al. 2019, 5). If patients were typically placed in a hospice care setting prior to initiating medical aid in dying requests, there is an additional layer of protection to confirm terminal diagnosis, and to thus, avoid or mitigate the potential for the sort of abuse opponents suggest is present.<sup>2</sup> That said, data “supports the overall safety and reliability of the lethal medications used in MAID [medical aid in dying]” (Al Rabadi et al. 2019, 5).

But, in the absence of evidence of person affecting harm, is there still cause to be concerned about this possibility as a matter of principle? I suggest there is not.

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Arguments concerned about person affecting harm ought not to be regarded as justifying a prohibition on aid in dying for at least the following two reasons. First, disability rights organizations that suggest person affecting harm constitutes a sufficient threat to prohibit medical aid in dying are guilty of moral inconsistency. Second, these arguments also fail because of moral disproportionality.

Some forms of the argument suggest that there is an illusion of free choice when seeking medical aid in dying, and thus, people with disabilities will be harmed because they will be forced or coerced to avail themselves of it. The claim is that for some vulnerable populations, it is not a free choice, but instead, a forced one (Scoccia 2010, 481). It is suggested that when choices are made in the context of pervasive inequality, or under a structure of oppression, free choices cannot exist (Scoccia 2010, 481). Indeed, actions taken by people with disabilities to seek aid in dying might be thought to be suitably likened to those taken by others when under duress (Feinberg 1989, 98–219).

Additionally, not only is the concern that people with disabilities might avail themselves of aid in dying due to social pressures, but that they themselves might be viewed as preferential subjects or objects of euthanasia and be killed against their will (Somerville 2001, 263). In short people with disabilities might not only be pressured to invoke the legal process for aid in dying, but they might be killed, against their will, in spite of safeguards or laws designed to protect them. Some suggest the only method to ensure the prevention of person affecting harm as a result of aid in dying is its prohibition:

‘[S]afeguards cannot be established to prevent abuses resulting in the wrongful death of death of numerous disabled persons, old and young.’ Indeed, the only true safeguards against abuse ‘is that assisted suicide remain illegal and socially condemned for all citizens equally’ (Bickenbach 1998, 125).

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vulnerability, and thus, do not undermine the claims pertaining to any potential person affecting harm to people with disabilities.

<sup>2</sup> Indeed, palliative care, has appeared to have improved in jurisdictions permitting aid in dying (Lindsay 2009, 19).



Sumner (2018, 105) calls arguments of this variety, 'arguments from abuse', and suggests the common thread is a concern over safeguards being inadequately established, or monitored and enforced. Similarly, but more generally, I have previously called these arguments, 'avoidance of harm' arguments (Riddle 2019, 188–90).

I believe arguments of this kind suffer from a moral inconsistency that renders them ineffective. First, consider how many people die as a result of aid in dying. This number differs significantly depending upon jurisdiction, but ranges from .05 percent of deaths, to as high as 1.7 percent of total deaths (Emanuel et al. 2016, 85). By any measure, this number represents a very low percentage of total deaths. In other words, not many people are dying from aid in dying.

In contrast, consider those who have opted to refuse or remove life sustaining treatment. Approximately 85 percent of critical care physician respondents acknowledged that they had withdrawn or withheld life support in the preceding year (Way, Back, and Curtis 2002, 1342). An American study indicated that between 1992 and 1993, over 90 percent of deaths in intensive care units resulted from a decision to withdraw or withhold life support (Way, Back, and Curtis 2002, 1342). This is true in most countries, where most deaths in intensive care units occur as a result of a decision to stop or refuse life sustaining treatment (Way, Back, and Curtis 2002, 1342).

Importantly, all the reasons that can be invoked to support the refusal or removal of life sustaining treatment, can be applied, with equal force, to medical aid in dying. Because we value patient autonomy, and relief of suffering, we permit patients to make choices about the kind of care they receive, or do not receive, at the end of their life. These reasons are so powerful, that we permit people the autonomy to make them even when it will surely result in their death. Why then, are disability rights organizations not in favor of denying patients the right to remove or refuse treatment? I suggest that for their argument against aid in dying to be morally consistent, they must.

Surely the potential for abuse that can emerge with aid in dying is also present in current practices. People with disabilities or other vulnerable groups, such as the elderly, or even those living in poverty, might be thought to be pressured into hastening their death experience. They could just as likely be subjected to an unjust death from a medical professional exercising a wrongful notion of compassion to rid them of a life perceived to be so dominated by suffering or misery, that it is not worth living. In short, our current practices that permit people to make choices about care at the end of their life are not subject to the same scrutiny that medical aid in dying is, and many more people are forced to make choices pertaining to the refusal or removal of care, than those who will be eligible, or who will seek, aid in dying. If disability rights organizations were genuinely concerned about abuse of healthcare systems and person affecting harm against people with disabilities, they should be equally as concerned about granting *any* autonomous decision-making ability at the end of life, due to both its equal potential for abuse, and its more frequent use. They are silent on this matter however. To fail to apply their moral logic in this case constitutes a moral inconsistency that is both unjustifiable as a matter of principle, as well as inexplicable.

I argue that opposition of this kind is also morally disproportionate. By morally disproportionate, I mean to suggest something like the following: as a result of a moral wrong or harm, actions to be taken must be proportionate to that harm, and similar to analogous cases where moral wrong or harm has been done. In other words, despite the fact that no demonstrable harm emerges from permitting aid in dying, *if* it could, it would be insufficient to point to an instance or instances of harm, and suggest that on the basis of that harm, a proportionate response is its prohibition. Instead, one must demonstrate, again, counterfactually, that not only will harm emerge, but that it

is of a sufficient quality and quantity that it justifies an outright refusal to permit the action leading to that harm.

To be clear, such an argument has not been made with reference to aid in dying, nor can it be. To demonstrate this, consider other actions that have risks. All medicine carries risk. For example, it is thought to be the case that as high as 10 percent of patients admitted into a hospital setting will suffer an adverse reaction, or acquire a new ailment, often as a result of medical error, by virtue of being in the hospital (Riddle 2019, 190). This number is startling, and demonstrates the risk that we endure to receive medical treatment. No one suggests we ought to prohibit hospital visits as a result of medical error and the person affecting harm that emerges as a result of it. The reason this is not suggested is because it is not morally proportionate to do so. It is neither proportionate to risk aversion strategies employed in morally similar situations, nor would it be proportionate to the actual quality and quantity of harm or risk, more generally.

We can now circle back to a discussion of the refusal or removal of life sustaining care. I argue that this represents a much greater threat to people with disabilities and other vulnerable populations than aid in dying. That said, no one has argued for a denial of autonomy at the end of a patients' life in this regard. As a result of moral proportionality, disability rights organizations cannot argue for a moral prohibition on aid in dying. At most, opponents to aid in dying can argue for safeguards to be enacted, as we do with reference to hospital visits more generally, and to end of life decisions to refuse or remove life sustaining care. To suggest a prohibition on aid in dying is justifiable, is to make a morally disproportionate argument. In other words, opponents to aid in dying overstate the implication of their argument, and suggest a prohibition on the practice, when at best, their principled case can justify the enacting of safeguards, which have already been established, and proven to be reliable.

That said, not all harm that can emerge from legalized aid in dying is of this kind. There is also a concern that the mere permitting of assisted dying causing emotional, attitudinal, or existential harm, to vulnerable groups by suggesting their lives are not worth living. The prejudices that exist against people with disabilities are in fact, harmful and abundant (Morin et al. 2013). Disability rights organizations suggest that by legalizing aid in dying, people with disabilities will be further devalued and harmful stereotypes will be ignited, rather than extinguished. If people with disabilities are at present, devalued, which we have sound reason to believe is true, the concern is that legalizing medical aid in dying would be even more "detrimental to the way that [the disabled] are viewed by society as a whole" (Box and Chambaere 2021, 4).

Measuring social attitudes is difficult, especially when subjects are asked about attitudes or dispositions that they know they ought not to have, or that are not socially favorable, such as discriminatory or ableist ones (LaPiere 1934, 230). Indeed, it is often thought that actions are more representative of attitudes or dispositions (LaPiere 1934, 237). The adage, 'actions speak louder than words' is perhaps helpful to bear in mind here. If what we aim to discover is if people with disabilities are devalued to a greater extent in states that have legally permissible aid in dying, than examining how those states *treat* people with disabilities, and not just reported attitudes, is perhaps a good starting point. In other words, if disability rights organizations suggest that disabled people are devalued by legalized aid in dying, it should be the case that support services and spending on

people with disabilities is less in states with medical aid in dying than in those without. In fact, the opposite appears to be true.<sup>3</sup>

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Just as with person affecting harm, let us start by examining non-American jurisdictions first. Public expenditure on disability (PED) is a measure commonly used in Europe to assess welfare programs for people with disabilities across different, and seemingly incommensurable, social welfare models. European models of disability welfare are startlingly different in their approaches and application, but have a common solidarity and commitment to both social justice more generally, as well as the provision of resources to mitigate and eliminate social exclusion, more specifically (Boeri, Borsch-Supan, and Tabellini 2001; Hemerijck 2002). People with disabilities are thought to represent approximately 17 percent of the population of Europe for people between the ages of 16 and 64 (Navarro, Rodríguez, and Santamaría 2021, 1481). Given the significance of this number, PED is an especially important measure.

The typical manner in which PED is assessed is as a percentage of total social expenditures. Thus, the higher the percentage of total social expenditure absorbed by PED, the more resources allocated to people with disabilities, and in my estimation, the greater the social value placed upon disabled people. After all, if people with disabilities were devalued, presumably the policies within those States would reflect those values, and public expenditure would at least trend in a direction that reflected those social values. Conversely, if disabled people were thought to deserve provisions necessary through the law, public expenditure would also reflect this positive disposition (or at least not a negative one) towards the disabled.

The European Union (EU) average is 7.38 percent of total social expenditure on PED. Countries that are thought to correspond to the Nordic typology, perhaps unsurprisingly, do remarkably well in this regard. Denmark, Sweden, Holland, and Finland, are all significantly higher than the other EU countries (Navarro, Rodríguez, and Santamaría 2021, 1481). That said,

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it is at least possible that in light of a concern over abuse of aid in dying, states increase support services for people with disabilities. This has not been established however.

Belgium and the Netherlands have a PED as a total percentage of social expenditure much higher than average. Belgium's PED as a percentage of total social expenditure is just below 9 percent, and the Netherlands is just above 9 percent – significantly above the European Union average (Navarro, Rodríguez, and Santamaría 2021, 1481).

In short, if it were true that legalized aid in dying causes the further devaluing of disabled people, and if it were also true that this devaluing would manifest itself in harmful social policy and less expenditure on support for people with disabilities, then those countries that permit aid in dying should be spending less on the disabled. This is not the case.

Let us shift our focus now to American jurisdictions. In the United States, the most common measure utilized for our present purposes is disability-associated health expenditures

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<sup>3</sup> It is important to note that I am not suggesting a causal effect between aid and dying and support for people with disabilities. I am not suggesting that legalizing aid in dying increases support services for disabled people. That said,

(DAHE). In 2015, for example, DAHE were \$868 billion nationally (Khavjou et al. 2021, 441). This number accounted for 36 percent of total health care expenditure nationally, and it ranged from 29 percent to 41 percent across states (Khavjou et al. 2021, 441).

Oregon spent 40 percent of total health expenditures on DAHE (Khavjou et al. 2021, 444). This number is bested only by two other states. Washington, which has the second oldest aid in dying laws in the country, also has a DAHE that is above the national average (Khavjou et al. 2021, 444). Vermont, the next state to legalize medical aid in dying, is on par with the national average (Khavjou et al. 2021, 444). California, although aid in dying was legalized the same year as the data was gathered, has a DAHE two points above the national average. Indeed, no state that had legalized aid in dying had a DAHE as a percentage of total health expenditures less than the national average at the time the data was collected. More pointedly, the data in the United States suggests that states with legalized aid in dying have a DAHE as a percentage of their total expenditure of health services, that is equal, or greater than, the national average. States that permit aid in dying are not devaluing people with disabilities or under-funding support services to any greater extent than states that do not permit medical aid in dying. Just as in Belgium and the

Netherlands, there appears to be a correlation between those states with aid in dying, and a higher DAHE as a percentage of total health expenditure.

Indeed, between 2003 and 2015, DAHE per capita spending increased well above the national average in Oregon. While nationally, the increase represented a 28 percent change, in Oregon it was 64 percent (Khavjou et al. 2021, 448). In other words, Oregon appears to be increasing its DAHE as a percentage of total health expenditure at a rate much faster than other states. Presumably, if aid in dying caused the devaluing of disabled people, this would result in DAHE per capita spending decreasing, or at least increasing slower than national trends, and not much faster. Again, every state with legalized aid in dying at the time these data were collected is above the national average with respect to increased spending on DAHE between 2003 and 2015 (Khavjou et al. 2021, 448).

In short, there appears to be no factual evidence to support the claim that legalizing aid in dying causes the greater devaluing of people with disabilities. More pointedly, harm of this second kind does not emerge as a result of aid in dying. It is simply inaccurate to suggest it does.

However, do arguments pertaining to this kind of harm have any principled merit? I argue that they do not. I argue that respect for people with disabilities and their autonomy demands access to aid in dying, and not its denial or prevention.

Arguments of this kind share a common sentiment: permitting aid in dying devalues the lives of people with disabilities. A primary concern is that harmful stereotypes become further ingrained into society when we suggest some lives are not worth living (Gill 2010, 35). More strongly, opponents can suggest that even if medical aid in dying provided a benefit to everyone, including people with disabilities, and did not introduce person affecting harm into their lives, that it would still be impermissible because the very practice harms people with disabilities as a group, or class (Scoccia 2010, 480). An analogy can be drawn between arguments of this sort, and arguments against something like sex work, for example, that suggest even if it were not harmful to sex workers themselves, the very practice harms women, more generally (Scoccia 2010, 480). Arguments of this kind are such that even without harm actually befalling people with disabilities, there is a greater social harm being done in the perpetuating of harmful attitudes or demeaning stereotypes against the disabled. These arguments suggest that an already marginalized or oppressed group is only bound to have those harmful attitudes magnified if aid in dying is encouraged or allowed. Given that many of us tend to think we have even stronger obligations to avoid *further* harming already

disadvantaged populations, it only stands to reason, they might suggest, that the argumentative force behind a denial of access to aid in dying is even stronger when couched as being a matter of importance for disabled people.

Opponents to aid in dying suggest that it results in an affront to the dignity of disabled people that manifests itself through social policy and laws. As a result of this vulnerability, disability rights organizations argue that aid in dying ought not to be permissible.

To the contrary, I suggest that respect for people with disabilities demands the guaranteeing of autonomy and the recognition that people with disabilities, like people without disabilities, are best suited to make decisions about their own life and their own medical care. To suggest that people with disabilities ought to be denied the ability to control what happens with their own bodies at the end of their lives is an overly paternalistic attitude that cannot be justified, and that itself, does harm.

Indeed, respect for patient autonomy and compassion for patient suffering are claimed to provide powerful *pro tanto* reasons for permitting aid in dying (Sumner 2018, 103). The very manner in which these arguments are constructed demonstrates a lack of respect for the autonomy of people with disabilities. People with disabilities are individuals, and not an amorphous group of insignificant parts. Instead, rightly regarded, disabled people are capable of making important decisions on their own (Nelson 2003, 3).

I have previously argued that denying “people with disabilities the right to exercise autonomy over their own life and death says powerfully damaging things about the disabled, their abilities, and their need to be protected” (Riddle 2017, 487). The late Anita Silvers (1998) has forcefully stated that “characterizing people with disabilities as incompetent, easily coerced, and inclined to end their lives places them in the roles to which they have been confined by disability discrimination” (133). The attitude that people with disabilities need protecting from themselves is in itself, demeaning and patronizing.

Thus, if disability rights organizations want to promote the dignity and rights of people with disabilities, denying medical aid in dying is not the proper means of doing so. The patronizing and paternalistic attitudes displayed by opponents to aid in dying *cause* personhood affecting harm, rather than prevent it. By acknowledging that people with disabilities do not need protecting from themselves and that they are capable of making choices about their own care, even if pressured from ableist social attitudes, we can begin to undo the negative stereotypes that have followed disabled people even after the enacting of human rights provisions such as the Americans with Disabilities Act, or the UN Convention on the Rights of Persons with Disabilities. If true regard or care is to be given to endorsing actions that promote accurate, positive dispositions towards people with disabilities, disabled people need to stop being painted as helpless, pitiable individuals, requiring the care and protection of others. Such a disposition plays in to ableist preconceptions of disability and further entrenches attitudes of disability as a state of suboptimal or inferior functioning.

Importantly, the general practice of aid in dying, or the particular laws surrounding its implementation, make no judgments about what kinds of life are worth living. The only inherent values in the practice of medical aid in dying are ones concerning compassion for suffering, and perhaps most importantly, respect for autonomy. Neither the practice nor the laws force anyone to seek aid in dying and to suggest that people with disabilities are especially vulnerable to social nudging is to perpetuate the myth that people with disabilities cannot make decisions of their own and need to be protected from themselves. Similarly, these laws offer no guidance as to who ought to consider such a practice, aside from those with terminal conditions. Negative valuations about

people with disabilities are not perpetuated or brought to the forefront through legalized medical aid in dying. Denying its practice as a result of the perceived vulnerability of disabled people, however, does.

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### 3. Professor Ben Smart

1/9/2023

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#### **Approval Process for Assisted Dying in Jersey**

To whom it may concern

First, let me commend all those involved in putting together these progressive amendments to existing legislation.

I was born in Jersey and educated at Victoria College, before leaving the island in 2012 to begin my career in academia. My family remain on the island, which I frequently visit. I am now director of The Centre for Philosophy of Epidemiology, Medicine and Public Health at the University of Johannesburg, and a widely published philosopher of medicine and public health.

The new assisted dying legislation in Jersey was brought to my attention by a friend, and given my area of expertise, I decided to look over the proposal. Whilst many very positive steps are clearly being taken, I would like to bring the following to the committee's attention:

#### *Section 193. b. Differences between objectivity and subjectivity in decision making.*

In my opinion, the authors have misunderstood the distinction between objectivity and subjectivity in the proposal. First, they suggest that a doctor's opinion regarding the terminal nature of a disease (when backed up by a second opinion) is "objective". This is not the case. There is of course an objective matter of fact regarding when the patient will die, but the doctors' opinions remain just that: opinions (which are, by their nature, subjective). Whilst I would not contend the finding that, in these cases, no court or tribunal need be engaged in the decision-making process regarding assisted dying, the underlying logic cannot be that of "objectivity". It follows that the apparent lack of objectivity in the case of "unbearable suffering" cannot be a reason to demand a court process or tribunal.

Furthermore, whilst doctors sometimes make inaccurate predictions regarding the life expectancy of a patient, the patient is the only individual capable of determining whether their pain is "bearable". The document accurately states in 199 that "It is only the person affected who can determine if they can bear their suffering", but this is not a subjective matter, as the document suggests. The patient, and only the patient, *knows* if they can bear their suffering. Whether or not Marmite tastes good is a subjective matter. But I enjoy the taste, and that is an objective matter of fact. Similarly, whether 'X degree of pain' is bearable may be a subjective matter, but individual patients have an objective perspective on whether X degree of pain is bearable.

In short - all else being equal, the patient's word should be taken as seriously with respect to their own suffering, as the doctors' word is taken with respect to the nature and likely course of their disease.

#### *Bearable Suffering*

It's worth noting that one needs to interpret "bearable suffering" in a careful and appropriate way. Given that patients falling into this category survive despite their pain, "bearable" cannot be interpreted as "one is able to live with the pain" (since this is true for all these patients, by definition). The ethical underpinning of this legislation is



to empower patients with incurable painful conditions to escape lives not worth living. The patient, then, should be the sole determinant of this. No court or tribunal could ever be in as good a position as the patient to make this decision.

The States of Jersey must embrace a patient centred care approach to assisted dying, and empower patients with painful chronic conditions to make their own decisions. Putting this power in the hands of a court or tribunal will only exacerbate the pain and stress these patients endure towards the end of their lives.

Yours faithfully,

A handwritten signature in blue ink, appearing to read 'Benjamin Smart', with a stylized flourish at the end.

**Professor Benjamin Smart**

Director, The Centre for Philosophy of Epidemiology, Medicine and Public Health

#### 4. Dr Isra Black

UCL FACULTY OF LAWS



**Consultation response submitted by Dr Isra Black, UCL Laws on 6 January 2023  
Dept of Strategic Policy, Planning and Performance, Government of Jersey  
Assisted dying in Jersey public consultation**

The following is a response to the public consultation on assisted dying in Jersey. I am a Lecturer in Health Law at the UCL Faculty of Laws.<sup>4</sup> My area of research specialisation is in health law, in particular the law and philosophy of assisted death and end-of-life decision-making.<sup>5</sup> I was an expert witness for the Jersey Assisted Dying Citizens' Jury in 2021, presenting on legal eligibility criteria for assisted death.<sup>6</sup> I am responding in my capacity as an academic expert in this area.<sup>7</sup>

My response pertains to QQ4, 6, 13-14, 20-21 of the Consultation on eligibility criteria (neurodegenerative disease, age), minimum timeframes, and the Route 1 and Route 2 processes, respectively. I have provided additional comments on causation in eligibility criterion (e) (terminal illness/neurodegenerative disease) and the drafting of eligibility criteria (c) and (d) in relation to decision-making capacity and information.

With regard to QQ1-3 of the Consultation, I give permission for my comments to be quoted with attribution (Dr Isra Black, UCL Laws) (Q1). My considered view is that assisted dying should be lawful (QQ2-3).

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<sup>4</sup> <https://www.ucl.ac.uk/laws/>

<sup>5</sup> See Isra Black, 'Patients, physicians and law at the end of life in England and Wales' in Ruth E Board et al (eds), *End of Life Choices for Cancer Patients* (EBN Health 2020); Isra Black, 'A pro tanto moral case for assisted death' in Sue Westwood (ed), *Regulating the end of life: death rights* (1st edn, Routledge 2021); Penney J Lewis and Isra Black, 'The effectiveness of legal safeguards in jurisdictions that allow assisted dying', *Briefing Paper for the Commission on Assisted Dying* (Demos, 2012). For a complete list of publications, see <https://iris.ucl.ac.uk/iris/browse/profile?upi=IBLAC83>.

<sup>6</sup> See presentation [video](#) (YouTube) and [slides](#) (Govt of Jersey website).

<sup>7</sup> UCL has no institutional position on the morality of or the legalisation of assisted death.

## A. Executive summary

My consultation response contains 10 key recommendations, summarised here.

- 1. Neurogenerative disease:** The eligibility criteria on qualifying medical condition are ambiguous as to whether the newly inserted part of criterion (e) on neurodegenerative disease *exhausts* the circumstances in which a person with such a disease may access assisted death. The States Assembly should clarify its intention—in law ideally, but otherwise (or also) in guidance on the operation of the law.
- 2. Qualifying medical condition—causation:** The States Assembly should amend criterion (e) to require a causal link between a person’s terminal illness or neurodegenerative disease and their death or life expectancy.
- 3. Decision-making capacity and information:** Amending eligibility criteria (c) and (d) would capture the relation between information and decision-making capacity. This change would enable simplification of the legislative framework for assisted death to align better with the provisions of the Capacity and Self-Determination (Jersey) Law 2016.

**A.3.1.** The States Assembly should amend eligibility criteria (c) and (d) to bring the information and decision-making capacity requirements together.

**A.3.2.** The States Assembly should detail the information to be disclosed to individuals requesting assisted death in the section of the Jersey Assisted Dying Law on capacity.

**A.4. Age:** The States Assembly should legislate for access to assisted death for minors with decision-making capacity. If, pragmatically, it is necessary or desirable to wait to permit minor assisted death until the practice has become established for adults, the Assembly should legislate for minors now, but make commencement of the relevant part of the Jersey Assisted Dying Law subject to ministerial decision.

**A.5. Route 1 and Route 2:** The reasons offered for two distinct approval routes are not sufficient to justify different treatment of individuals with terminal illness or unbearable suffering, respectively. Routine tribunal involvement would likely narrow access to assisted death considerably.

**A.5.1.** The States Assembly should clarify whether individuals requesting assisted death under Route 1 will be eligible on diagnosis of terminal illness or neurodegenerative disease and fulfilment of the life expectancy criterion alone, or whether (as currently drafted) an unbearable suffering criterion also applies to Route 1 cases.

**A.5.2.** If an unbearable suffering criterion also applies to Route 1 cases, the States Assembly should not treat Route 1 and Route 2 cases differently, since under both Routes, unbearable suffering will play an important role in determining eligibility for assisted death. **A.5.3.** The States Assembly should provide that in all cases requests for assisted death are approved by the Coordinating and Independent Assessing Doctor alone—there should be no Tribunal involvement. There should be routine retrospective administrative review of each instance of assisted death.

**A.6. Minimum timeframe:** The 90-day minimum reflection period proposed for Route 2 cases may be unethical. Individuals experiencing unbearable suffering should not be made to wait longer to access assisted death than individuals with terminal illness or the amount of time necessary to complete the process prescribed by law. The States Assembly should align the minimum timeframes for Route 1 and Route 2 cases. If this is not possible because of routine Tribunal involvement in Route 2 cases, the States Assembly should consider whether a timeframe shorter than 90 days is achievable.

## B. Eligibility criteria—qualifying medical condition: neurodegenerative disease (Consultation Q4)

**B.1.** Consultation Q4 asks respondents: ‘Do you agree that the eligibility criteria should be changed to allow for those with a neurodegenerative disease to become eligible for assisted dying when they have a life expectancy of [f] 12 months or less?’

**B.2.** Under the proposed (revised) eligibility criteria in the Consultation Report, a person will be eligible for assisted death if criteria (a)-(d) are met, as well as one of the following medical and experiential criteria: (e)(i) terminal illness, expectation of unbearable and subjectively intolerable suffering, six months life expectancy; or (e)(ii) neurodegenerative disease, expectation of unbearable and subjectively intolerable suffering, 12 months life expectancy; or (f) incurable medical condition, current unbearable and subjectively intolerable suffering.

**B.3. Eligibility criteria (e) and (f) as current drafted are ambiguous as to whether the newly inserted part of criterion (e) on neurodegenerative diseases exhausts the circumstances in which a person with a neurodegenerative disease may access assisted death under proposed legal regime.** That is, it is unclear whether individuals with neurodegenerative diseases may only access assisted death under criterion (e)(ii) (terminal physical medical condition) or whether they may also access assisted death under criterion (f) (non-terminal unbearable suffering).

**B.4.** Consultation Q4 can be interpreted either exhaustively or non-exhaustively. A plausible interpretation of paragraph 23 of the Consultation Report is that individuals with a neurodegenerative disease that is *incurable* but *neither* terminal *nor* giving rise to a reasonable expectation of death within 6 or 12 months may nevertheless access assisted death on unbearable suffering grounds. That is, a person may meet the conditions of eligibility criterion (f) if they have a neurodegenerative disease that gives rise to unbearable and intolerable suffering that is *either* not terminal, *or* terminal although not yet within the scope of eligibility criterion (e)(ii).

**B.5. Recommendation:** The States Assembly should consider whether it intends criterion (e) as it applies to neurodegenerative disease to exhaust eligibility for assisted death for individuals with such conditions. The States Assembly should clarify its intention—in law ideally, but otherwise (or also) in guidance on the operation of the law.

## C. Eligibility criteria—qualifying medical condition: causation in criterion (e)

**C.1. Criterion (e) as drafted in the Consultation Report does not provide for a causal link between a person’s terminal illness or neurodegenerative disease and their death or life expectancy.** This is because of the use of the conjunction ‘and’, as opposed to more specific causal language. The current formulation would make it possible for a person with terminal illness or neurodegenerative disease with a longer life expectancy than that set out in criterion (e) to access assisted death, if a distinct condition were reasonably expected to result in their death within 6 or 12 months, respectively. An immediate example might be frailty.

**C.2.** Criterion (e) can be contrasted with, for example, s.1.01.(12) of the Oregon Death with Dignity Act, which defines terminal illness as:

an incurable and irreversible disease that has been medically confirmed and *will*, within reasonable medical judgment, *produce* death within six months.<sup>8</sup>

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<sup>8</sup> Oregon Revised Statutes 127.800 to 127.897 (emphasis added). See also Voluntary Assisted Dying Act 2017 (Victoria), s 9, which provides: '(d) the person must be diagnosed with a disease, illness or medical condition that—(i) is incurable; and (ii) is advanced, progressive and *will cause* death; and (iii) *is expected to cause* death within weeks or months, not exceeding 6 months...' (emphasis added).

**C.3. Recommendation:** The States Assembly should amend the language of criterion (e) to require a causal link between the medical condition that makes a person eligible for assisted death and their life expectancy. A suitable formulation might be:

(e) has been diagnosed with a terminal physical medical condition... ~~and where the person is reasonably expected to die within six months~~ [insert: and which is reasonably expected to cause the person's death within six months]

OR

has been diagnosed with a physical medical condition that is neurodegenerative... ~~and where the person is reasonably expected to die within twelve months~~ [insert: and which is reasonably expected to cause the person's death within twelve months]

#### **D. Eligibility criteria—criteria (c) and (d): decision-making capacity and information**

**D.1.** The Consultation Report proposes organising conditions that go to the quality of the individual's decision about assisted death across eligibility criteria (c) (voluntary, clear, settled, and informed) and (d) (decision-making capacity). **The distribution of these eligibility criteria across (c) and (d) fails to capture the relation between information and capacity.**

**D.2.** The requirement that a person have an informed wish to die is intimately connected to the requirement that they have decision-making capacity in respect of assisted death. This is clear from the nexus of the information contained in paragraphs 13-16 and paragraph 24 of Appendix 1 of the Consultation Report. **The reason to mandate provision of information**

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on assisted death is that this information forms the basis against which to assess a person's capacity to opt for assistance to die (over the alternatives).

**Recommendation:** The States Assembly should amend eligibility criteria (c) and (d) to bring the information and capacity requirements together. A suitable formulation might be:

- (c) has a voluntary, clear [insert: and] settled ~~and informed~~ wish to end their own life, and
- (d) has the capacity to make the [insert: an informed] decision to end their own life

**D.3.** Making this change would have the **additional benefit of enabling simplification of the legislative framework for assisted death to align it better with the provisions of the Capacity and Self-Determination (Jersey) Law 2016** (the 'Jersey Capacity Law 2016'), since the information required to be disclosed to individuals requesting assisted death may simply be specified as among the information relevant to the decision for the purposes of decision-making capacity. At present, the matters listed as relevant to capacity in paragraph 24 of Appendix 1 of the Consultation Report are coarse-grained and do not map precisely onto the provisions of the Jersey Capacity Law 2016—in particular, the crucial 'use' criterion, which goes to appreciation or applying the relevant information to oneself, has been omitted.<sup>9</sup>

**D.4. Recommendation:** The States Assembly should detail the information required to be disclosed to individuals requesting an assisted death in the section on decision-making capacity of the Assisted Dying Law. A suitable formulation might be:

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<sup>9</sup> Jersey Capacity Law 2016, s 5(1)(c).

- (1) Subject to subsection (2), ‘decision-making capacity’ has the same meaning as in the Capacity and Self-Determination (Jersey) Law 2016.
- (2) For the purposes of this Law, the information relevant to a person’s ability to make a decision about assisted dying includes information about the reasonably foreseeable consequences of deciding one way or another, or of failing to make the decision, and:  
[include material from paragraph 16 of Appendix 1 of the Consultation Report here]

## E. Eligibility criteria—age (consultation Q6)

**E.1.** Consultation Q6 asks respondents: ‘Do you agree that assisted dying should only be permitted for people aged 18 or over?’

**E.2.** **Minors should be permitted access to assisted death under the Jersey Assisted Dying Law. The principled rationale for denying minors with decision-making capacity the legal right to take their own medical decisions when such decisions are likely to be fatal—that it is important to ‘shield’ minors from the full brunt of (and responsibility for) autonomous action<sup>10</sup>—is attenuated in the context of assisted death.**

**E.3.** We shield minors—we may scrutinise and override their medical decisions (or, in this case, deny the opportunity for such decisions)—because our concern is for the long-term consequences of such decisions, or because we worry that the values minors use to take decisions are unstable. But in the case of minors with capacity who would be eligible for assisted death but for an age criterion:

- a) there may be less long term to speak of (in the case of terminal or life-limiting illness) compared to minors expected to live a full life;

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- b) the fatal consequences of assisted death may be less bad than the prolonged experience of unbearable suffering (until death or adulthood); and

- c) the individuals concerned may have developed, through the experience of serious medical conditions and treatment, a sophisticated, mature perspective.<sup>11</sup>

**E.4.** On pragmatic grounds, the States Assembly might wish to wait until assisted death settles in law and practice before (re)considering whether to permit access to competent minors. However, **legislating for minors’ access to assisted death at a later date is not without risks.** It leaves the Assembly vulnerable to the charge of ‘criterion expansion’, ‘mission creep’, ‘slippery slope’ etc. The optics around a future shift in position regarding minor assisted death may cause undue controversy and opposition, which in turn may threaten passage of the amendment notwithstanding that permissive legal change may be easily justified on principled grounds.

**E.5. Recommendation:** **The States Assembly should legislate for access to assisted death for competent minors. If, on pragmatic grounds, it is necessary or desirable to wait to permit minor assisted death until the practice has become established for adults, the Assembly should legislate for minors now, but make commencement of the relevant part of the Law subject to ministerial decision.**

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<sup>10</sup> Anthony Skelton, Lisa Forsberg and Isra Black, ‘Overriding Adolescent Refusals of Treatment’ (2021) 20(3) *Journal of Ethics and Social Philosophy* 221-247.

<sup>11</sup> Priscilla Alderson, ‘Competent children? Minors’ consent to health care treatment and research’ (2007) 65(11) *Social Science & Medicine* 2272-2283.



## F. Route 1 and Route 2 processes (consultation QQ20-21)

**F.1.** Consultation Q20 asks respondents, ‘Do you agree with the two different approval routes [Routes 1 and Routes 2] as proposed?’

**F.2.** The key difference between Routes 1 and 2 is that for Route 1, a person’s request for assisted death may be approved by the Coordinating and Independent Assessment Doctor, whereas for Route 2, approval of a person’s request for assisted death by the two doctors is a necessary, but not a sufficient condition for lawful assisted death, since—in addition—a Tribunal must review and confirm the medical approval.

**F.3. The reasons offered for two distinct approval routes are not sufficient to justify different treatment of individuals requesting assisted death on grounds of terminal illness or unbearable suffering, respectively.**

**F.4.** In respect of parallels with current medical practice/decision-making (paragraphs 194-196 of the Consultation Report), **doctors are required (by law and professional guidance) to respect valid patient decisions to refuse life-prolonging medical treatment or food and fluids** as a means to exert a degree of control over the time and manner of death.<sup>12</sup> **This is the position regardless of the patient is in an end-of-life situation.** For example, Tony Nicklinson, who suffered from ‘locked-in’ syndrome, refused food and fluids prior to his death from pneumonia—no question of overriding his refusal arose.<sup>13</sup> In the face of a refusal of treatment (for whatever reason), doctors will often provide—and indeed may be required by the law of negligence,<sup>14</sup> as well as professional guidance,<sup>15</sup> to provide—supportive care/symptom control while the patient is dying. Moreover, **the life-shortening effect of best practice care at**

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**the end-of-life is yet to be demonstrated,**<sup>16</sup> although we might argue that the offer of symptom control is sometimes a factor that causally influences a person’s willingness to pursue refusal of treatment or food and fluids in the first place.<sup>17</sup> Therefore, **the conclusion in paragraph 196 of the Consultation Report that grounds the distinction between Routes 1 and 2 in ‘existing medical practice and decision-making processes’ and ‘the shift from shortening a person’s life by days or months, to altering the trajectory of someone’s life and possibly bringing their death forward by many months or potentially years’ respectively is not well-founded.**

**F.5.** On objectivity and subjectivity, paragraphs 197-201 Consultation Report justify Tribunal scrutiny of unbearable suffering cases on the grounds that Route 1 assessment of life expectancy can be said to be objective (‘based on medical knowledge’), whereas Route 2 assessments of unbearable suffering are subjective (‘only the person affected... can determine if they can bear their suffering’). However, this argument raises the question of what in fact are the substantive criteria for access to assisted death under Route 1. That is, **the objectivity justification for Route 1 suggests that a person with a terminal illness or neurodegenerative disease will**

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<sup>12</sup> See Isra Black, ‘Refusing Life-Prolonging Medical Treatment and the ECHR’ (2018) 38(2) Oxford Journal of Legal Studies 299-327, General Medical Council, *Treatment and care towards the end of life: good practice in decision making* (2022) <https://www.gmc-uk.org/ethical-guidance/ethical-guidance-for-doctors/treatment-and-care-towards-the-end-of-life> accessed 22/01/02. See eg *King’s College Hospital NHS Foundation Trust v C* [2015] EW COP 80.

<sup>13</sup> Sarah Boseley, ‘Tony Nicklinson dies after losing “right to die” legal battle’ *The Guardian* (22 August 2012) <https://www.theguardian.com/uk/2012/aug/22/tony-nicklinson-dies-right-to-die> accessed 23/01/02.

<sup>14</sup> See eg *R (Oao Burke) v General Medical Council* [2005] EWCA Civ 1003.

<sup>15</sup> See General Medical Council, *Treatment and care towards the end of life: good practice in decision making* (n 9).

<sup>16</sup> See eg Nigel Sykes and Andrew Thorns, ‘The use of opioids and sedatives at the end of life’ (2003) 4(5) *Lancet Oncology* 312; Nigel P Sykes, ‘Morphine kills the pain, not the patient’ (2007) 369(9570) *Lancet* 1325.

<sup>17</sup> In these latter cases, doctors may be described as participants in a course of conduct that shortens life.

become eligible for assisted death merely on meeting the relevant life expectancy ground (as well as the age, residence, and decisional criteria). But what is currently written into the eligibility criterion (e) is that the terminal illness or neurodegenerative disease is ‘expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable’.

**F.6. If Route 1 also requires an assessment of unbearable suffering (as currently drafted),<sup>18</sup> then subjectivity is an issue for this route too, as well as for Route 2.** Moreover, in the case of Route 1, the doctors’ judgement about a person’s unbearable suffering may permissibly be speculative, as opposed to Route 2, which require that a person currently experience unbearable suffering. Thus, contrary to the process framework proposed, there may be more reason for a tribunal to scrutinise terminal illness cases than unbearable suffering cases.

**F.7. Recommendation:** The States Assembly should clarify whether individuals requesting assisted death under Route 1 will be eligible on diagnosis of terminal illness or neurodegenerative disease and fulfilment of the life expectancy criterion alone, or whether (as currently drafted) an unbearable suffering criterion also applies to Route 1 cases.

**F.8. Recommendation:** If a suffering criterion also applies to Route 1 cases, the States Assembly should not treat Route 1 and Route 2 cases differently, since a judgement of unbearable suffering will play an important role in determining eligibility for assisted death under both routes.

**F.9.** If the same approval process were to apply to Route 1 and Route 2 cases, the options would be (as noted in Consultation Q20) a) to have all approvals made by the Coordinated and Independent Assessing Doctor alone, or b) to have additional Tribunal review for all approvals. As paragraph 189 of the Consultation Report evinces, **routine tribunal involvement gives rise to concerns about undue burdening of individuals requesting assisted death and their**

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**loved ones, increased duration of the approval process, and increased (and unnecessary) cost.** These concerns are plausible; their cumulative effect would likely narrow access to assisted death considerably.

**F.10. Recommendation:** The States Assembly should provide that in all cases requests for assisted death are approved by the Coordinating and Independent Assessing Doctor alone—there should be no Tribunal involvement. There should be routine retrospective administrative review of each instance of assisted death.

## **G. Minimum timeframe (consultation QQ13-14)**

**G.1.** A further important difference between Route 1 and Route 2 cases is that the minimum timeframe for Route 1 (terminal illness or neurodegenerative disease) is 14 days, whereas the minimum timeframe for Route 2 (unbearable suffering) is 90 days—Consultation QQ13-14 ask respondents for their views on these reflection periods.

**G.2. The 90-day minimum reflection period proposed for Route 2 cases may be unethical. If a person is assessed to be suffering unbearably in a way that cannot be alleviated in a way that they deem tolerable, there is a strong case that they should not be**

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<sup>18</sup> Compare s.2.01.(1) of the Oregon Death With Dignity Act (ORS 127.805), which allows for prescription of legal medication on the basis of diagnosis (and life-expectancy) alone: ‘Who may initiate a written request for medication (1) An adult who is capable, is a resident of Oregon, and has been determined by the attending physician and consulting physician to be suffering from a terminal disease, and who has voluntarily expressed his or her wish to die, may make a written request for medication for the purpose of ending his or her life in a humane and dignified manner in accordance with ORS 127.800 to 127.897’.



**made to wait longer than individuals with terminal illness or the amount of time necessary to complete the process prescribed by law.**

G.3. If a tribunal is routinely involved in Route 2 approvals, it may be the case that a 14-day timeframe is unachievable and thus a longer period will need to be specified, in order to set appropriate expectations.

**G.4. Recommendation:** The States Assembly should align the minimum timeframes for Route 1 and Route 2 cases. If this is not possible because of routine Tribunal involvement in Route 2 cases, the States Assembly should consider whether a timeframe shorter than 90 days is achievable.

I would be pleased to speak further about my response and am available to assist at [isra.black@ucl.ac.uk](mailto:isra.black@ucl.ac.uk).

**\*\*\* ENDS \*\*\***

## 5. Dr Jaimee Mallion

“The problem was dying badly, and the answer was dying well”

### Assisted Dying: A policy briefing

*This briefing summarises research about assisted dying, conducted by Dr Jaimee Mallion and Lauren Murphy, between January and May 2022. Interviews were conducted with eighteen people who had experience of terminal illness, were family members of those who had experienced a ‘bad death’ or had travelled abroad for an assisted death<sup>19</sup>.*

According to new data by the Office for National Statistics<sup>20</sup>, people in the UK with severe and potentially terminal illnesses are more than twice as likely to take their own lives than the general population. Currently, one person every eight days travels to Switzerland from the UK to end their life.<sup>21</sup> This is, unfortunately, unsurprising given that each year over 50,000 end-of-life patients will die experiencing some level of pain, whilst an estimated 6,000 patients will experience no relief from pain *at all* during their last three months of life<sup>22</sup>. Despite this, assisted dying is currently prohibited in the UK, and those who assist a loved one to die are at risk of prosecution.

This policy briefing identifies and summarises relevant literature, expanding on this with the addition of findings from a qualitative research project (conducted by the authors), concluding that a law change in favour of assisted dying should be supported, on the basis that it **enables terminally ill individuals to attain their basic human needs of autonomy, competence, and relatedness, and experience a good quality death.**

These conclusions are supported by three key research findings:

- 1) Assisted dying gives quality to the end-of-life
- 2) Assisted dying allows people to secure their basic human needs
- 3) Assisted dying does *not* result from the sense of being a burden

This briefing is based on research currently in preparation for publication, which was conducted at London South Bank University, in collaboration with Dignity in Dying.

#### 1. Assisted dying gives quality to the end of life

Regardless of whether there was universal access to the highest quality palliative care, approximately 6,400 people annually would still suffer intractable pain during the last three months of life<sup>23</sup>. As Jackson and colleagues<sup>24</sup> explain, not only does the experience of pain result in direct suffering, but it also prevents individuals completing tasks important to them at the end-of-life (e.g., grieving for the loss of their own life, organising legal affairs, and saying goodbye to loved ones).

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<sup>19</sup> Some participants have requested to remain anonymous, to adhere to their wishes their names have been changed.

<sup>20</sup> Office for National Statistics. (2022). *Suicides among people diagnosed with severe health conditions, England: 2017 to 2020*. <https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/suicidesamongpeoplewithseverehealthconditionengland/2017to2020>

<sup>21</sup> Dignity in Dying. (2017). *The true cost: How the UK outsources death to Dignitas*. [https://cdn.dignityindying.org.uk/wp-content/uploads/DID\\_True\\_Cost\\_report\\_FINAL\\_WEB.pdf](https://cdn.dignityindying.org.uk/wp-content/uploads/DID_True_Cost_report_FINAL_WEB.pdf)

<sup>22</sup> Zamora, B., Cookson, G., & Garau, M. (2019). Unrelieved pain in palliative care in England. Office of Health Economics. <https://www.ohe.org/publications/unrelieved-pain-palliative-care-england>

<sup>23</sup> Dignity in Dying. (2017). *Last Resort: The hidden truth about how dying people take their own lives in the UK*. <https://www.dignityindying.org.uk/wp-content/uploads/Last-Resort-Dignity-in-Dying-Oct-2021.pdf>

<sup>24</sup> Jackson, V. A., & Leiter, R. E. (2021). Ethical considerations in effective pain management at the end of life. *UpToDate*. <https://www.uptodate.com/contents/ethical-considerations-in-effective-pain-management-at-the-end-of-life>

The ability to access assisted dying would add to the individual's quality of life by alleviating total pain (i.e., physical, psychological, social, and spiritual pain) and suffering, preventing a sense of hopelessness, and enabling people to retain a sense of self<sup>25</sup>. Consistent with this, participants we interviewed saw assisted dying as a "basic humanity" that "could actually improve current palliative care services" (Emma, experienced bad deaths of family members). The desire to end intractable pain and suffering was cited as the most important reason for seeking an assisted death, as Hilary explains:

"If palliative care can't help me, then I want to know that I can say, 'I've had enough of this intolerable pain or this enormous discomfort.'" (Hilary, mum experienced a bad death).

It was highlighted that having the option of an assisted death added quality at the end of life, with assisted dying seen as "reassuring" and a "safety-net" (Norma, who has terminal cancer). Assisted dying enables individuals to enjoy the remainder of their lives to the full, knowing that if the pain was unbearable there were still options available.

"I can sit back and say, 'I can really enjoy my life, what's left of it now', and I don't have to worry about it anymore, because assisted dying is just ... it's a nice, gentle, dignified, hopeful way to go." (Alex, who has terminal cancer).

The option of an assisted death reduces concerns about the future, helping individuals to live in the present. Participants explain that this can help them to come to terms with dying:

"I think not everyone that wants an assisted death will actually act it out in the end, but it may help them on the journey of dealing with their terminal illness." (Louise, whose father-in-law experienced a bad death from MND).

By enabling assisted dying, this could improve the end-of-life experience, particularly for those experiencing intractable suffering.

Under no circumstances did participants believe that assisted dying would replace palliative care, but assisted dying was perceived as an additional tool that could *improve* current practices.

## 2. Assisted dying allows people to secure their basic human needs

As demonstrated above, assisted dying is primarily motivated by the desire to alleviate pain and suffering<sup>25</sup>. To develop a deeper understanding, the current research explored additional factors which can lead some individuals to seek an assisted death.

According to Self-Determination Theory<sup>26</sup>, there are three basic human needs: *competence* (mastery over activities), *autonomy* (sense of control and independence), and *relatedness* (feeling securely connected to others). Fulfilling all needs is fundamental for psychological well-being.

When an individual is terminally ill, it becomes challenging to achieve these. Take *competence*, as illnesses progress and pain and/or physical functioning worsens, individuals become less able to maintain activities they previously mastered (e.g., work/hobbies<sup>27</sup>). Factors such as accessibility, pain, and embarrassment (e.g., fungating cancers) can reduce one's ability to spend time with others,

<sup>25</sup> Hendry, M., Pasterfield, D., Lewis, R., Carter, B., Hodgson, D., & Wilkinson, C. (2013). Why do we want the right to die? A systematic review of the international literature on the views of patients, carers and the public on assisted dying. *Palliative medicine*, 27(1), 13-26. <https://doi.org/10.1177/0269216312463623>

<sup>26</sup> Ryan, R. M., & Deci, E. L. (2000). Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. *American Psychologist*, 55(1), 68-78. <https://doi.org/10.1037/0003-066X.55.1.68>

<sup>27</sup> Marie Curie. (2022a). *Work and terminal illness*. <https://www.mariecurie.org.uk/help/support/ Diagnosed/practical-emotional-support/about-work>

negatively impacting on the basic human need of *relatedness*<sup>28</sup>. Finally, a loss of independence, choice, and dignity, prevents a sense of *autonomy*<sup>29</sup>.

When we consider assisted dying, we often assume that it is the product of loss: a loss of function, loss of ability, loss of independence. However, our research has demonstrated that assisted dying can also **give**; give a sense of competence, relatedness, and autonomy. Critically, *these basic human needs are valued as much during the dying process as they are in life.*

Consistent with past research<sup>9</sup>, our participants want to have control over their life and the right to choose how they experience death: giving a sense of *autonomy*.

“I’m not scared of death. What I’m scared of is not being able to control it and not being able to do it in the way that I want to do it” (Sarah, who has experienced life-limiting conditions).

Participants highlighted that being able to make end-of-life decisions allows them to gain a sense of mastery over the dying process: fulfilling the basic human need of *competence*. Regarding *relatedness*, participants discussed how having an assisted death allows them to have their family with them during death, in a way which is peaceful and minimally distressing to all involved.

“What a nice thing to do, to choose your time, have your family round... had a big meal, they’ve all said their goodbyes, you have a wee drink, and you go to sleep, how fabulous is that?” (Norma, who has terminal cancer).

By enabling assisted dying, this could allow the attainment of basic human needs, leading to improved psychological well-being at the end-of-life.

### 3. Assisted dying does not result from the sense of being a burden

Opponents often argue that vulnerable individuals are at risk of feeling pressurised into seeking an assisted death, because of being an emotional, physical, or financial burden on family/friends/wider society<sup>30</sup>. Past research has indicated that experiencing feelings of being a burden are common among individuals with terminal illness<sup>31</sup>. However, a recent systematic mixed studies review, found this to be among the least important and least frequently cited reasons for seeking an assisted death. Instead, unbearable suffering, pain, loss of dignity and autonomy, and hopelessness were the most important reasons<sup>32</sup>. This suggests that whilst feelings of burdensomeness are common in the terminally ill, it is not a strong motivating factor for seeking an assisted death.

This was supported by our current research, with findings indicating that whilst some (not all) participants ‘felt like a burden’, they highlighted that burdensomeness was driven by societal expectations, rather than because of personal or familial reactions to caregiving. Indeed, family members of those who had an assisted death abroad indicated that they did not perceive them to be a burden:

<sup>28</sup> Marie Curie. (2022b). “You’re the first person who’s sat on that sofa in 12 months: Experience of loneliness among people at the end of life and their carers in Northern Ireland. <https://www.mariecurie.org.uk/globalassets/media/documents/policy/policy-publications/2022/experiences-of-loneliness-among-people-at-the-end-of-life-and-their-carers-in-northern-ireland.pdf>

<sup>29</sup> Colburn, B. (2020). Autonomy, voluntariness and assisted dying. *Journal of Medical Ethics*, 46(5), 316-319. <https://doi.org/10.1136/medethics-2019-105720>

<sup>30</sup> Not Dead Yet UK. (2022). *Why are you concerned about assisted suicide becoming legal?* <http://notdeadyetuk.org/faqs/>

<sup>31</sup> McPherson, C. J., Wilson, K. G., & Murray, M. A. (2007). Feeling like a burden to others: a systematic review focusing on the end of life. *Palliative medicine*, 21(2), 115-128.

<sup>32</sup> Roest, B., Trappenburg, M., & Leget, C. (2019). The involvement of family in the Dutch practice of euthanasia and physician assisted suicide: a systematic mixed studies review. *BMC Medical Ethics*, 20(1), 1-21. <https://doi.org/10.1186/s12910-019-0361-2>

“Society says they’re going to be a burden so then the person thinks they’re a burden... I didn’t think she was a burden” (Tom, whose mum travelled to Dignitas for an assisted death).

Importantly, feeling like a burden on others was not cited as a reason for wanting or pursuing an assisted death. Instead, participants perceived *continued living* to be a burden for themselves:

“‘I’m not tired of life; I’m tired of living with MND.’ And that was the burden: it was his burden. He wasn’t a burden on anybody else: it was a burden to him – life was a burden to him” (Lesley, whose brother travelled to Dignitas for an assisted death).

As Lesley went on to highlight, the NHS<sup>33</sup> commitment to patient-centred care should be considered when discussing the ethical considerations regarding burdensomeness:

“‘Patient-centred’ and ‘burdensome’, in my opinion, don’t go together because it’s you that wants it and you’re driving the process, it doesn’t matter what anybody else says... it’s what you want that drives everything” (Lesley).

Participants did indicate support for safeguards surrounding assisted dying, emphasising that having transparent procedures in place surrounding assisted dying could *protect* vulnerable people from the current informal, unregulated, and unreported processes that take place at the end of life (e.g., withholding/withdrawing life-sustaining treatment and palliative sedation) or from terminally ill individuals having to resort to attempting suicide using dangerous, painful, and often unsuccessful means.

## Conclusion

This briefing has summarised the relevant literature, incorporating findings from a new qualitative study exploring attitudes toward assisted dying in the UK. As highlighted above, assisted dying can: give quality to the end-of-life, relieve intractable pain and suffering, add to palliative care practices, and enable people to achieve the basic human needs of competence, relatedness, and autonomy throughout the dying process. The findings of this research support the need for a change in the assisted dying law in the UK.

In the words of Lesley: **“The problem was dying badly, and the answer was dying well”**.

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<sup>33</sup> NHS England. (2022). *Involving people in their own care*. <https://www.england.nhs.uk/ourwork/patient-participation/>

## 6. Hon Kyam Maher MLC

### Kyam Maher MLC – Submission of Evidence to the UK Parliament’s Health and Social Care Select Committee on Voluntary Assisted Dying

*My name is Kyam Maher and I am a member of the Legislative Council in the Parliament of South Australia. While I am currently the Attorney-General, Minister for Aboriginal Affairs and Minister for Industrial Relations and Public Sector in the Malinauskas Labor Government, my involvement in South Australia’s voluntary assisted dying legislation was as a Private Member of our Parliament in 2020 and 2021. In December 2020, I introduced the legislation and worked closely with medical and legal experts to lead debates in Parliament until the passing of the bill in 2021.*

*I was invited by Ms Sarah Wootton, Chief Executive of Dignity in Dying UK, to make a submission of evidence to the Health and Social Care Select Committee in light of this experience.*

#### **2. What can be learnt from the evidence in countries where assisted dying is legal?**

In May 2021, the Voluntary Assisted Dying Act<sup>34</sup> passed South Australian Parliament after 16 previous attempts spanning 27 years. On 31<sup>st</sup> January 2023, that legislation will begin operation and eligible South Australians will be able to have the choice of dying with dignity. Voluntary assisted dying (VAD) is now legal in every state in Australia.

Victoria was the first state in Australia to pass VAD laws in 2017<sup>35</sup>, commencing in 2019. Since implementation, that VAD Scheme has facilitated over 600 Victorians having a dignified death.<sup>36</sup>

#### Palliative effect of peace of mind

In their most recent publication, the Victorian VAD Review Board<sup>37</sup> have reported that as of 30 June 2022, over 900 permits had been issued under the Victorian VAD Scheme and of those, only 604 permit holders ultimately died from taking the prescribed lethal substance.<sup>38</sup>

Feedback from Victorian applicants and their relatives have reported on the palliative effect of knowing that they have access to the VAD substance if they choose to use it.<sup>39</sup> Families and loved ones are often comforted by witnessing the applicant’s wishes being fulfilled and their autonomy respected, regardless of whether the applicant uses the lethal substance.<sup>40</sup>

In Victoria, 81 percent of applicants were accessing palliative care at the time of requesting VAD.<sup>41</sup>

#### Palliative Care

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<sup>34</sup> [Voluntary Assisted Dying Act 2021 | South Australian Legislation](#)

<sup>35</sup> [Voluntary Assisted Dying Act 2017 \(legislation.vic.gov.au\)](#)

<sup>36</sup> [Voluntary Assisted Dying Review Board Report of Operations July 2021-June 22\\_FINAL.pdf \(safecare.vic.gov.au\)](#) p 5.

<sup>37</sup> [Voluntary Assisted Dying Review Board | Safer Care Victoria](#)

<sup>38</sup> Ibid 3, p 22.

<sup>39</sup> Ibid 4, p 1.

<sup>40</sup> Ibid, p 1.

<sup>41</sup> Ibid, p 16.

In Belgium and the Netherlands, research suggests the introduction of VAD has not stunted the development of palliative care, and that government funding grew at a consistent rate with countries such as the UK that have not legalised VAD.<sup>42</sup> The same year that VAD was implemented in Victoria, the Victorian State Government announced more than \$62 million in additional funding to palliative care services.<sup>43</sup>

### Incurable disease, illness or medical condition

One of the eligibility criteria for accessing VAD is that the person must have been diagnosed with an incurable disease, illness or medical condition. The Victorian Ministerial Advisory Panel on Voluntary Assisted Dying (Panel) considered 'incurable' to mean the person is suffering from a condition that is causing enduring and unbearable suffering that cannot be cured, and cannot be relieved in a manner *the person deems tolerable*.<sup>44</sup> Therefore, the Panel considers that denying a person access to VAD because they have refused medical treatment options that are available but are not acceptable to them would be inconsistent with the right to refuse life-sustaining medical treatment and may infringe other human rights and amount to discrimination.<sup>45</sup>

### Safeguards

Between 1 July 2021 and 30 June 2022, the Victorian VAD Review Board found four cases to be non-compliant with the VAD Act.<sup>46</sup> Three of those were due to a delay in returning the lethal substance to the Statewide Pharmacy. The law requires the contact person to return any outstanding substance within 15 days of the death of an applicant. These delays were for various reasons, but all were found to be absent of concerning behaviour and the Review Board recommended that contact persons are made better aware of this requirement when they are appointed. The other case of non-compliance was where someone signed an application document on behalf of an applicant and was also a witness to the document, which is prohibited by the Act. After investigating the case, the Review Board considered this was an oversight and the case was considered clinically appropriate.<sup>47</sup>

The Victorian VAD model now implemented from the Panel Recommendations is even more rigorous than any existing process in Victoria for medical treatment, and provides greater opportunity to identify instances of elder abuse.<sup>48</sup>

In the South Australian legislation, there are 71 safeguards before a person can administer the lethal substance, which is 3 more than the highly rigorous Victorian legislation.<sup>49</sup>

### Language

Another point I wish to make is the importance of language and not referring to VAD as suicide or assisted killing. The Panel recognises that language in the VAD space is often used to imply judgements about something through its description and can be associated with unnecessary stigma.<sup>50</sup> The South Australian VAD Act clarifies that a person who performs an act or omission in

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<sup>42</sup> 'State of palliative care development in European countries with and without legally regulated physician-assisted dying', *Health Care* 2014 (Ministerial Advisory Panel on Voluntary Assisted Dying Final Report p. 39).

<sup>43</sup> [Additional palliative care funding for Victoria announced | Aged Care Guide](#)

<sup>44</sup> Victorian Ministerial Advisory Panel on Voluntary Assisted Dying, Final Report 2017, p 66.

<sup>45</sup> Ibid p 67.

<sup>46</sup> Ibid 4, 25.

<sup>47</sup> Ibid.

<sup>48</sup> Ibid 11, p 88.

<sup>49</sup> Ibid 1.

<sup>50</sup> Ibid 11, pp 7-8.

relation to the voluntary assisted dying of a person in accordance with this Act will be taken not, by that act or omission alone, to have aided, abetted, counselled or procured the suicide of the other person.

#### Suicide in the alternative

As reported in the Parliament of South Australia's Joint Committee on End of Life Choices, the State Coroner David Whittle advised that people who are chronically or terminally ill and experiencing an 'irreversible decline in physical health' have elected to commit suicide rather than endure what palliative care has to offer.<sup>51</sup> The Coroner had identified a number of deaths by suicide, seemingly in response to people suffering 'a deteriorating quality of life' from a disease likely to result in death. South Australia's Assistant Commissioner of Police, Scott Duval, reported that from 1 January until 22 November 2019, ten people had taken their lives as a result of terminal illness, equating to approximately 11 per cent of all suicides during that period. The age of those persons ranged from 63 to 88 years, and most deaths in such circumstances are undignified, violent, and sometimes botched.<sup>52</sup>

Under South Australia's *Criminal Law Consolidation Act 1935*, it is not an offence to commit or attempt to commit suicide.<sup>53</sup> It is however an offence to assist someone in their suicide or suicide attempt. Consequently, the 'vast majority' of suicides in South Australia are committed when the person is alone and 'without their family to comfort them'. This usually leads to the deceased not being found for some time, and often being discovered by a family member.

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<sup>51</sup> Report of the Joint Committee on End of Life Choices, Parliament of South Australia, Second Session, Fifty-Fourth Parliament 2020, p 18.

<sup>52</sup> *Ibid*, p 19.

<sup>53</sup> [Criminal Law Consolidation Act 1935 | South Australian Legislation](#)



## 7. Dr Jennifer Klimiuk

I am a Consultant in Palliative Medicine working at a hospice in the UK.

Assisted dying drastically undermines the practice and principles of Palliative Care and is a threat to the safety of vulnerable patients; it also threatens the relationship of trust and care that exists between patients and healthcare professionals whose duty is to 'do no harm'.

There have been many concerning reports from countries that have already legalised assisted dying which detail harrowing tales of pressure on vulnerable patients to end their lives to prevent them being a 'burden' on their families and society. The Oregon Health Authority's **annual report from 2020** (Public Health Division, Center for Health Statistics, 2021) **showed that [53% of people opting for assisted suicide mentioned the fear of being a burden on family, friends or caregivers as a factor in their decision.](#)** There have also been reports of slackening of what were originally 'rigid' laws to allow other groups to be euthanised- even though some were not terminally ill. Some places have now introduced assisted dying for children. In the Netherlands despite tight laws initially when assisted dying was introduced in 2001, this has now extended to other groups including those with dementia and no capacity to consent to this decision. A review of trends in the Netherlands (Chambaere et al., 2015) showed that in 2013 more **than 25% of physician-assisted deaths were categorised as "Hastening of death without an explicit request from the patient."** This most commonly involved elderly patients over 80 years old, those in a coma and those with dementia.

Access to good Palliative care services is extraordinarily fragmented across the UK which means some people have access to Gold standard levels of care, others do not. A recent report by Pask S et al. (2022) shows the level of inequity across the UK for out of hours palliative care provision. This is one of many reports with similar themes. It would be extremely detrimental to palliative care services to introduce assisted dying as this would detract from the need to improve care across the board for all patients. It would also be dangerous for patients as it would be seen as an 'easy alternative' for those who don't have access to the level of care and support they need. Access needs to be equitable which

requires better support and funding from government, and I believe that this would negate some of the current arguments for assisted dying.

In society we must protect and cherish our most vulnerable by providing the best quality palliative care to those who need it. With assisted dying, the focus will be on enabling people to 'end suffering' rather than providing the appropriate resources for the majority who wish to live the best life they can until natural death. In my experience and in discussion with colleagues- the number of patients who ever seriously request the option of assisted dying is in a tiny minority, the majority of patients want to live as well as they can until their natural death. Seeking to change a law which protects the majority, to serve the interests of a minority is irrational, dangerous and undemocratic. It places the most vulnerable at risk. If society shifts to providing death on demand then the focus on providing excellent palliative and supportive care will be severely undermined, important resources will be diverted and the ability to provide good quality care will be even harder. Vulnerable patients are likely to feel pressured into ending their lives to prevent burden to their loved ones and eventually, we are likely to see the 'slippery slope' with slackening of once rigid rules to allow more patients the 'right to die'. We must learn from the mistakes of others before we follow this course from which there will be no going back.

I urge the government to oppose introducing assisted dying. It does not protect wider society but only serves the needs of a select few and it seriously threatens the most vulnerable, whom it is our duty to protect.

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<https://www.oregon.gov/oha/PH/PROVIDERPARTNERRESOURCES/EVALUATIONRESEARCH/DEATHWITHDIGNITYACT/Documents/year23.pdf>.

## 8. Dr Angharad Gray

Dear Sir / Madam,

I write to express my profound sadness and deep concern about the decision made by Jersey's State Assembly to agree 'in principle' that assisted suicide and euthanasia should be permitted.

It was really concerning to look at the public consultation documents online, the wording of which seemed to indicate that the decision has already been made and definite timeline set, rather than the State

Assembly remaining open and responsive with a willingness to consider the rational and legitimate voices of those who clearly still remain against this proposed killing of the vulnerable; in the context of such

repeated and relentless calls from certain advocates who refuse to accept that this matter has been thoroughly debated and voted against in the British isles over time including during the past decade or so.

May I please raise your awareness of the following points for your consideration:

1. Changing the law in this way inevitably casts judgement on the value of human life and how vulnerable people would perceive themselves and how they would be perceived by others.
2. I work as an NHS community psychiatrist and I find it abhorrent that Canada, on introducing its euthanasia law in 2016 has already widened its scope to include those with mental illness, and that they have discarded the requirement for death to be 'reasonably foreseeable'. As someone who works hard to prevent suicide, the work of psychiatrists colleagues would be foreseeably undermined in Jersey.
3. The law in Belgium moved from killing adults in 2002 to killing children in 2014 under their euthanasia laws. It is such a 'slippery slope'.
4. I believe that the availability of good quality palliative care is very important and that our resources ought to be channelled in that positive and life-valuing direction. All major royal colleges of doctors caring for terminally ill patients on the mainland are publically against these proposals. They include the Association of Palliative Medicine of Great Britain, the British Geriatric Society, the Royal College of GP's.
5. Assisted suicide deaths have been reported at times to be very drawn out, and to have been distressing with much suffering - they are not to be regarded as a guaranteed quick and easy, gentle 'fix'.
6. Coercion, exploitation and abuse of the ill, vulnerable and elderly will be exacerbated, allowing opportunities for beneficiaries of wills, inheritance etc or pressurised families in need of help, to take advantage of their own relatives. People's sense of burdensomeness to their loved ones and wider society will be greatly worsened. In their most desperate of mindsets, patients who consider assisted dying to be a solution (or the path that they feel driven towards) will not be given sufficient time to change their minds. Many many many people contemplate suicide however do not end up taking their own lives.
7. The World Medical Association states that doctors should not be required to participate in assisted suicide or euthanasia deaths, and 'nor should any physician be obliged to make referral

decisions to this end'. I'm afraid the assertion documented on the Jersey public consultation website that doctors do not have to be 'directly' involved really does not go far enough. Unprotected conscientious healthcare workers will leave their professions as a result and these highly principled people are too valuable a resource for the NHS and society to lose.

With many thanks for your kind attention and consideration.

Yours sincerely,

Dr Angharad Gray.  
NHS Community Psychiatrist.

## 9. Dr John Stewart-Jones

To Whom it May Concern.

I am writing as a retired General Medical Practitioner having been a GP in the island of Jersey for 35 years and a qualified doctor for 41 years. The proposed law on Assisted Dying will have a profound and increasingly harmful effect upon the lives of our people for decades to come. The Assisted Dying law was voted for 'in principle' in November 2021 by the States of Jersey, subject to there being sufficient 'safeguards' in place before such a law is introduced.

THERE ARE NO SUFFICIENT SAFEGUARDS FOR euthanasia or assisted suicide. The proposed law will affect vulnerable people who in over 50% of cases will feel a burden to others. What is put forward as a 'right to die' will in a significant number of vulnerable people result in them believing that they have a 'duty to die' due to being a burden on carers and relatives..

Vulnerable people due to age, disability or illness will be especially at risk of harm. A letter was written to the Guernsey Post in 2018 by Helen Arkwright, who was a care manager with vulnerable people for 20 years. The letter was entitled 'Legalising Euthanasia, would put sick & elderly at great risk.' Her letter to the Guernsey Post makes this very clear that this can be the only conclusion.

*'I hope that the readers of this letter end the above as sickening and chilling as I found it to write. If the law is changed in the Bailiwick of Guernsey to allow the killing of the sick and disabled – and I won't dress it up with any euphemism, please realise that there will be no protection or safeguards in law against what I have described above and never can be.'*

<https://guernseypress.com/news/voices/readers-letters/2018/01/19/legalising-euthanasia-would-put-sick-and-elderly-at-great-risk/>

(Extracted text document as Word Doc attached to this email.)

Elder Abuse is hidden and very common, particularly financial abuse. The proposed so called 'safeguards' will not protect the elderly from coercion and manipulation by unscrupulous relatives who for selfish motives will manipulate the vulnerable person for financial and even their own convenience. An example of which is a son returned home from abroad to Australia due to his mother's diagnosis of a terminal illness and persuaded her to proceed with VAD as a matter of convenience so he would not have to wait the months ahead or revisit. The partner of the mother was angry and disturbed as he missed out in what would have been months of time during her final illness.

***Hourglass a UK Charity states: 'One in six older people are victims of abuse. That's over 16% of our mothers, fathers, uncles, aunts, grannies, grandads, friends and neighbours. Around one million people over the age of 65 are victims of abuse each year in the UK.'***

<https://wearehourglass.org/who-we-are>

In Jersey in 2021 about a sixth (18%) were 65 years or older, which equates to about 18,000 people. Calculation of the UK equivalence of Elder Abuse would mean that there could be as many as 3,000 who suffer and a significant majority of these it will be financial abuse. Even a small proportion of this number would mean that several elderly people would be exposed to coercion and manipulation to early death by Assisted Suicide.

<https://www.gov.je/Government/JerseyInFigures/Population/Pages/PopulationStatistics.aspx>

Route 1 (Terminal illness with 'unbearable suffering') and Route 2 (Chronic Illness with 'unbearable suffering') are being proposed in the Public Consultation document. The inclusion of Route 2 is alarming as it opens up assisted suicide for many chronic health conditions.

The Jersey proposals state that Assisted Suicide and Euthanasia would be implemented for 'unbearable suffering'. In 'Route 1 – terminal illness' and 'Route 2 – unbearable suffering'. This raises the question – can suffering be reliably estimated and understood? It is very subjective and there are no known methods or tools for measuring or estimating suffering by healthcare professionals.

Route 2 is for suffering an incurable physical condition, causing unbearable suffering. This opens the door very wide to many long-term medical conditions such as diabetes, depression, COPD, chronic pain, incontinence, and mobility problems.

Eventually legal challenge on equality of availability could result in the inclusion of conditions such as memory loss, personality disorders, treatment-resistant schizophrenia, PTSD (Post Traumatic Stress Disorder), and Anorexia Nervosa. Oregon's 2021 report includes Anorexia in the broad list of medical reasons for Assisted Suicide.

Although the present proposals exclude mental health disorders, this will not be the case in practice as these co-exist with physical illnesses. A person with severe Anorexia Nervosa will eventually have physical symptoms due to their condition and could request assisted dying on that basis.

Any person with anorexia over 18 years of age would qualify under the proposed 'safeguards' by being an adult, having capacity, being terminal if they failed to take enough nutrition, suffering unbearably and, since it is no longer seen as a solely psychological illness, would fit the requirement for it to be a physical illness. A person's estimate of their own suffering is strongly affected by a wide range of treatable issues including psychosocial support, loneliness, and depression. Physical illness and depression commonly co-exist.

After my expressing these concerns publicly, I was contacted by someone who has suffered with Anorexia Nervosa who thanked me for bringing this to people's attention. The person had suffered for many years with anorexia and when alone and struggling, wondered whether they may have taken the option of assisted suicide if there had been such a law. The concluding comment was that there must be a better way than this, and that it is upsetting and frightening to think that many people may take this route.

In Belgium, 82.8% of causes for "unbearable suffering" are of a psychological nature, such as dependence on care, loss of autonomy, loneliness, despair, feelings of unworthiness, desolation, diminished social contacts. In every jurisdiction where there are laws governing 'assisted dying' safeguards have been gradually stretched and lost.

There is increasing evidence of the harmful effects of the Medical Assistance in Dying (MAiD) in Canada that were not available at the time of the Citizens Jury met nearly 2 years ago. Due to poverty, disability, and other social reasons there are people in Canada who have accessed MAiD. The press / media are becoming aware of these emerging facts, with increasing numbers reporting great concern about these developments. An example is the article in the Guardian by Sonia Sodha who though in principle would be in favour of Assisted Dying has indicated that she is not so in view of the risks to vulnerable people. (A Word Doc is attached for ease of reading.)

[https://www.theguardian.com/commentisfree/2023/jan/01/assisted-dying-seems-humane-but-can-we-protect-the-vulnerable-from-the-malign?CMP=Share\\_iOSApp\\_Other](https://www.theguardian.com/commentisfree/2023/jan/01/assisted-dying-seems-humane-but-can-we-protect-the-vulnerable-from-the-malign?CMP=Share_iOSApp_Other)

There is 'safeguarding' that extends to those involved in the caring and associated ancillary professions. The effect on a broad number of people who would not want to be involved in any way because of conscience issues is not addressed by a simple 'opt-in' or 'opt-out' decision. The issue of conscientious objection is a complex one, and although there would be some protection for the medical staff of doctors or nurses this would not extend to others if they were required by their employers to be involved in some part of the process. Doctors would be required to make 'effective or effectual referral' which although not legally required in the Jersey proposal, could result in the doctor being reported to the GMC, as causing distress to the patient for not being willing to refer on grounds of conscience or what they believe to be in the patient's best interest. It has been suggested that they could hand on a printed leaflet, which some may do but others would not.

Conscience issues alongside the desire to do no harm, is very strongly held by some people. There will be doctors or nurses who would consider leaving the Island rather than being forced into referral of patients for assisted dying. There will those who will not wish to be involved, who would otherwise have returned to the Island as a medical professional and would choose not to do so. There is a shortage of medical professionals in Jersey, and this would adversely affect recruitment.

There is a harmful effect on the medical staff themselves, who have been involved in administering 'assisted dying', which results in about 20% of them suffering from Post-Traumatic Stress Disorder.



As a GP in Jersey for decades I have been very privileged to be involved in the end-of-life care of many patients and what has been described by those who are pro-PAS-E with statements such as people 'rolling around in agony', is not recognisable to me over my 36 years as GP. There will be difficult cases, and I accept that there is not a 100% guarantee in persons having what could be described as a 'good death'. However, my experience with palliative care involvement and their expert input, has resulted in a peaceful end for patients.

It may be that the persons present describing the distress are projecting their own emotions and feelings by what is described as transference, as they do not understand that process of dying. An example is when a patient having what is called Cheyne-Stokes breathing in their final breaths. This could be mistakenly perceived as suffering. Therefore, there needs to be support and explanation by professionals 24/7 during the final days of a person's life, in order to help the relatives by way of explanation and assurance about what is happening.

It appears that this is borne out by a quote in the Irish Times Newspaper 10 Nov 2020:

*'Dr Twomey said that, while he couldn't speak for everyone, based on the experiences of the members of the Irish Palliative Medicine Consultants' Association (IPMCA) who have cared for thousands of highly complex palliative care patients with severe symptoms over many decades, it was "an extremely rare event" that extreme pain and distress could not be managed.'* (End of quote)

There needs to be an in-depth assessment of the provision of Palliative Care in Jersey, with support provided through government, which would give Jersey an opportunity to become world class in the provision of Palliative Care rather than opting for a law that results in the killing of patients.

There is so much more that I could write regarding the lack of adequate safeguards. I am also attaching a PDF Document of a leaflet that I put together for print in August 2021, 'Assisted Suicide – A Minefield of Harm'. This was written before it became public that the proposed law included Euthanasia as well as Assisted Suicide, so my reference in the article is only to the latter. Most of what I have written still applies to both.

Dr John Stewart-Jones

(Retired Jersey GP)

## 10. Thomas Thorp

Dear Sir,

I wish to contribute to the proposals to introduce euthanasia and assisted dying to Jersey.

I work as a consultant geriatrician. I believe euthanasia/assisted dying should not be available, for a number of reasons. These stem from my belief as a Christian that it is morally wrong, from my concern that it would do far more harm to those who wouldn't currently choose death, and would fundamentally erode the fabric of our society.

1. It is morally wrong. Life is a gift from God and is therefore not ours to take.
2. It is ethically wrong. The role of doctors is to treat illness and relieve suffering, not to kill their patients. It would be bizarre (and somewhat disturbing) to see 2 almost identical patients with pneumonia on a ward round, and to be discussing life-sustaining treatment (antibiotics, etc) with one and a lethal injection with the other, without prejudice, as if the decision was morally neutral.
3. It is unnecessary. Most suffering can be relieved with good palliative care and family/community support. In my experience sustained desire to die is very rare (I can only think of 4-5 patients in a 17 year career thus far). Therefore any change to the law is to accommodate a very small section of society (but at the potential expense of a much larger section of society when we consider potential risks/collateral effects).
4. It is uncontrollable. Many patients will feel pressure to die because they feel to be a burden on others, or because the option is presented to them as reasonable, when they actually wish to go on living. Killing patients is (practically) easier than treating them - thus euthanasia will be a cheap/easy 'healthcare option' for a pressured healthcare system to use. There are no safeguards that will prevent euthanasia becoming freely open to anyone who requests regardless of their diagnosis, prognosis, or any process of exploring alternatives - it will become an easy choice for anyone. The proposed safeguards regarding prognosis, diagnosis and autonomous desire for death are all vague, with arguments that suggest they are discriminatory. For example why should someone with a prognosis of less than 6 months be eligible, but not someone with a prognosis of 9 months (and we as healthcare professionals are not very good at distinguishing between the two)? Why should those with a terminal condition be eligible, but those with a chronic, but not necessarily terminal, condition be ineligible? How long does the desire for euthanasia have to be present (and how can this be assessed as being capacitous and unaffected by external factors)? I believe it is inevitable that, should an assisted dying law be passed, its 'safeguards' would be eroded to the point where death would become a choice for anyone at any point in their lives, regardless of circumstances.
5. It will fundamentally change the doctor-patient relationship, and not just in the area of dying. When assessing my patients there will be an unspoken (until it is spoken) fear that a patient might ask me to arrange for their death (something I would not be willing to do, but would be obligated both morally and legally to explore further with them), or that the patient may worry that there is an expectation from their healthcare provide or society in general to present the option of death along with treatment and palliation. Not only would this make my clinical practice practically very challenging, but also potentially deeply divisive and distressing (for all concerned).
6. I believe a change in the law would lead to a significant undermining of the fabric of our society, one in which the vulnerable are seen (and treated) as less worthy of care and compassion. We will begin to see ourselves as valuable only if we are able to contribute and are living fulfilled lives. Those who do not are given the option of being killed. This will I believe fundamentally degrade that which hold us together as society.

Yours sincerely,

## 11. James Downar MDCM, MHSc, FRCPC

### **Written Submission to the Government of Jersey, UK**

James Downar, MDCM, MHSc (Bioethics), FRCPC Head and Professor, Division of Palliative Care  
University of Ottawa, Ottawa, Canada.

To Whom It May Concern,

I am writing this submission to your Assembly to aid in your consultations regarding Assisted Dying.

As a **Canadian Palliative Care Physician and Researcher**, I will not be affected by any change in the UK's laws, and I have no wish to push my own view of Assisted Dying (or Medical Assistance in Dying- MAiD, as we call it) on UK citizens. However, as the prospect of legislation in the UK comes nearer, I am concerned that Britons and Canadians alike have been subjected to a number of **misleading or false public claims** about what is happening in my country. My only purpose in making this submission is to set the record straight about **who is actually receiving Assisted Death in Canada**, and what this says about the drivers of Assisted Death. I respect those who disagree with MAiD on a principled basis, as a number of my friends do, but this does not entitle anyone to make false claims.

#### **Disclaimers**

- I do not represent any organization or agency.
- I am an employee of a faith-based institution, so will not address issues where I have a conflict of interest.
- I have previously spoken in favour of the legalization of MAiD, but I have never promoted MAiD. I hope for a future where Canadians have access to MAiD, but choose not to use it because we are able to address the suffering that drives it.

#### **Key Points – Focused on the state of Palliative Care in Canada**

**1. Many Canadians have poor access to Palliative Care, as do many in the UK, but funding/support for clinical palliative care has increased dramatically in much of the country since MAiD became legal, including:**

- A large growth in funding and salaried positions for Palliative Care physicians. For example, in the past 4 years, the division I lead in Ottawa has almost doubled in size (~40 physicians).
- \$3 billion invested in home care in 2016, much of which went to palliative care services.
- Millions of dollars invested in research at the federal and provincial levels, providing funding for the Pan-Canadian Palliative Care Research Collaborative in Ottawa, and the Palliative Care Institute in Alberta, and announcing dedicated research funding for palliative therapies including psilocybin.
- There has been a large growth in the number of funded community hospice beds in Canada in particular over the past 5 years, mirroring the rapid growth seen in the Benelux countries following MAiD legalization there.<sup>1</sup> Some palliative care services have been transiently reduced as a result of staffing challenges during the pandemic, which has caused similar problems around the world. This is unrelated to MAiD and is already recovering.

**2. There is no data suggesting that the practice of MAiD in Canada is driven to any degree by poor access to Palliative Care, socioeconomic deprivation or isolation.** On the contrary, multiple reports have shown that MAiD is extremely rare in “vulnerable” demographics, indicating that vulnerability is not a driver of MAiD. We do expect people requesting MAiD from every demographic, as suffering is not limited to the privileged. But if vulnerability was driving MAiD requests, MAiD would be more common in structurally vulnerable groups; in reality, MAiD is substantially less common in these groups.

- The second annual report on MAiD in Canada (covering 2020)<sup>2</sup> indicated that even during the pandemic, only 126 of 7394 people (1.7%) who received MAiD were unable to access palliative care services that they needed. Similarly, only 3.8% of those receiving MAiD were unable to access disability services that were needed.
- This claim is not based on “self-reported data”, as is sometimes reported. In Ontario, the Coroner’s office reviews every MAiD case and their own assessments of Palliative Care involvement concur with the findings of the Health Canada report<sup>3</sup>.
- Canadians who receive MAiD are much wealthier, more likely to be married and less likely to be widowed, and far less likely to be institutionalized<sup>3</sup> than those who do not receive MAiD.
- In Ontario, the poorest fifth of the population are 40% less likely to receive MAiD than the richest fifth<sup>4</sup>, even though the prevalence of chronic illness is much higher.
- Bottom line, **there are people who struggle to access palliative care<sup>5,6</sup> and disability services in Canada, but they’re rarely if ever receiving MAiD.** We need to improve access to palliative care and disability services, not because it will have any effect on MAiD, but to meet the needs of the 97% of Canadians who do not request MAiD.

**3. The interaction between MAiD and Palliative Care doesn’t need to be a conflict.** MAiD is a point of friction in our community- many prominent palliative care providers are opposed to MAiD. **But in much of the country a respectful coexistence has evolved, as it has in most of Europe.** Palliative care and MAiD have been integrated in many palliative care units and hospices in Canada, and ~20% of Canadian MAiD procedures now take place in a palliative care facility<sup>2</sup>. They are not fully integrated everywhere, but it is incorrect to say that they are incompatible.

- One key concept is that although Palliative Care can be effective for providing comfort, no field of medicine can claim to fix every problem it sees. Even in the best Palliative Care Units in the world, suffering can be substantial and symptoms increase as patients approach death<sup>7</sup>. This does not mean that anyone should request MAiD, but it explains why so many MAiD recipient chose to end their lives despite having good access to PC.
- Palliative Care is generally more effective for addressing quality of life and physical symptoms, and less effective (or even ineffective) for treating **psychological or existential distress**<sup>8</sup>. Our Health Canada reports have clearly shown that this latter type of distress is the main driver of MAiD requests<sup>2</sup>.
- **Existential Distress** is not simply a concern about “being a burden” on others, but rather a sense of distress about their inability to do things that they enjoy, the things that define us as people. Existential distress is not caused by a lack of social or emotional support- these individuals often have very good emotional support available, and people to help with their physical needs. The distress is caused by the fact that they need those supports in the first place. We currently have no proven, scalable, effective treatments for relieving existential distress. **We should not trivialize existential suffering** by claiming that it doesn’t exist, or that it is an irrational fear, or that we can easily treat it.
- **Admitting that there are limits to what Palliative Care can achieve is not a sign of failure, but a call for more innovation and research into treating all types of suffering.** The benefits

of such research would be felt far beyond any impact on MAiD statistics, because suffering is much more common than MAiD among the dying.

- Ultimately, **the purpose of Palliative Care is not to prevent MAiD, and MAiD should not be considered a failure of Palliative Care or of the healthcare system.** Legalization of MAiD in Canada has allowed for more open, honest communication about end-of-life options. There are many people who have obtained better palliative care as a result of an honest conversation about MAiD.

**4. MAiD does not siphon resources from Palliative Care, or pull Palliative Care providers away from patients who are more appropriate.** The vast majority of MAiD requests in Canada arise in patients who are already followed by Palliative Care providers at the time of the request (75-80%)<sup>3</sup>, and most were followed by Palliative Care for months before they received MAiD. For the remainder- they are almost always people with end-stage or terminal illnesses, who have intolerable suffering. These are absolutely appropriate referrals for Palliative services, and should not be seen as a burden or a distraction from the mission of Palliative Care. If we make them feel more comfortable even for a short time, and they still request MAiD, then that was definitely not a waste of our time or resources. To address some common misconceptions:

- **MAiD providers do not receive resources that were intended for PC.** MAiD providers use palliative care fee codes in Ontario to be paid, but this doesn't reduce payments to Palliative Care providers in any way.
- Some MAiD assessments are performed by salaried Palliative Care providers, but they will usually do MAiD assessments for their own patients (which is a minimal additional workload for a provider who already knows the patient), or provisions during their non-clinical time. **It would be false to state that MAiD is pulling providers away from their PC duties.**
- **There is no "right" to MAiD in Canada** any more than there is a right to any healthcare service, including Palliative Care. This comment is usually raised during a discussion of access. Access to Palliative Care is a substantial issue for many Canadians, but Canadian data clearly show that the people who struggle to access palliative care and disability services in Canada don't seem to access MAiD either.

**5. There are many misconceptions about "Track 2" cases,** or MAiD for people who meet eligibility criteria but do not have a reasonably foreseeable death. To be sure, there are people with chronic, advanced conditions who want to receive MAiD and meet eligibility criteria. On the other hand, there are also people who are not eligible but are requesting MAiD as a signal for help obtaining social supports. These cases cause distress among caregivers and are challenging to address, as it may not be apparent how much of the suffering would truly be reversible given improved supports.

Some key points here are:

- **Nobody is eligible for MAiD based on social deprivation;** the eligibility criteria (e.g. serious and incurable condition, advanced state of irreversible decline in capability) are only met by a small proportion of the population and many "track 2" requests are found to be ineligible. There may be eligible individuals living in poverty who request MAiD, but financial distress would be only one of a long list of causes of suffering. These cases, and suffering in general, can be highly complicated. It should never be described in the unidimensional, black-and-white way that it has been presented in some media stories.
- **"Track 2" cases are a very small proportion of all MAiD cases, and extremely rare overall-** 219 according to Health Canada's report for 2021 (2% of all MAiD cases). For comparison, ~150-200 Canadians are struck by lightning every year<sup>9</sup>.

- Track 2 is definitely not an easy option to avoid more difficult questions about how we support the disabled and the vulnerable. Clinicians are generally hesitant to take these cases on because of the emotional burden and workload involved, which is why they are so rare.
- We should definitely increase supports that address key social determinants of health, particularly for the vulnerable. We should do this not because of the effect on MAiD requests, but because it is the right thing to do as a society. The impacts of social deprivation on health are well-established in Canada, as they are in the UK:
  - More than 4000 people die by suicide in Canada every year (20x the total number of track 2 cases) and much of this is driven by social deprivation.
  - Income inequality is associated with as many as 40,000 deaths per year in Canada (200x the total number of track 2 cases)<sup>10</sup>.
- **The legalization of MAiD did not create a link between social deprivation and death. This link was already there and very impactful.** Trying to blame MAiD legislation for mortality among the poor is a cynical and inappropriate distraction from the real issues that drive this problem. Anyone concerned with supporting the vulnerable should focus on things that we know will help improve the lives and survival of the vulnerable, such as better pharmaceutical coverage, increased social assistance, affordable housing, etc.

**6. Media reports of “abuses” should be treated with skepticism.** As the UK and other jurisdictions have moved closer to legalizing MAiD, there has been intense speculation about what is happening in Canada. Broadly speaking these stories fit into one of several categories:

- Claims that people have received MAiD despite being ineligible or incapable of making decisions. These claims are usually made by family members who were estranged, or who are morally opposed to MAiD. In Canada, eligibility is assessed by at least two assessors in every case, and each case is reviewed by a coroner or delegate to confirm eligibility. Some cases reported in the media were even reviewed by the police or the medical regulator. **Despite such scrutiny, I am not aware of any case where these claims were substantiated.**
- Claims that people are seeking MAiD due to trivial medical conditions. These claims often derive from the fact that people are asked to indicate a single diagnosis or problem prompting a MAiD request. This may be appropriate for some conditions (e.g. lung cancer) but not for others (e.g. multimorbid frailty- which can be debilitating but is not caused by a single diagnosis). In one well-known case (“AB”), a person requested MAiD due to severe osteoarthritis that had required multiple operations and left her completely bedbound, unable to sit upright, and in nearly constant pain, with no further treatment options<sup>11</sup>. This case was reported by some in the media as “simply arthritis”. Of course, not everyone in AB’s condition would request MAiD, but **it is wrong to trivialize or misrepresent the suffering of others.**
- Claims that hospital staff members are pressuring patients to receive MAiD. This claim stems from a story of a patient in London, Ontario, who was in a dispute with their hospital about the home care that would be provided on discharge. He recorded one of his interactions with an ethicist, and then sent the recording to a reporter who published a story entitled *“Chronically ill man releases audio of hospital staff offering assisted death”*<sup>12</sup>. In fact, the recording indicated the opposite- that **the ethicist was quite clearly discouraging him from pursuing MAiD but this was not picked up by the media outlets:**
  - “Oh, no, no, no,” the man is heard saying. “...Don’t get me wrong. I’m saying I don’t want you to be in here and wanting to take your life.”

Needless to say, privacy rules prevent many MAiD assessors and providers from coming forward to discuss these cases and provide the missing information. In such a context, it is easy for misinformation to persist and get amplified by those with an agenda.

**7. Changes in MAiD eligibility criteria in Canada do not represent a “Slippery Slope”.** Canada’s Supreme Court was very clear and unanimous in the initial *Carter* ruling about who should be eligible to request and receive MAiD. Following this ruling, **Canada’s Parliament initially attempted to restrict eligibility more than the court intended**, passing a MAiD Bill (C14) in 2016 that specifically excluded:

- ...those with a reasonably foreseeable death- this part of the law was struck down by a Quebec Superior Court decision (*Truchon*), which simply reflected the original *Carter* decision.
- ...those with mental illness as an incurable condition- this part of the law was removed by a subsequent Bill (C7) passed in 2021, which takes effect in March 2023.

Of course, every country that has legalized MAiD has chosen a slightly different set of eligibility criteria. But in Canada, the criteria set out in the *Carter* decision have never been changed, and the Quebec superior court has simply upheld the precedent set in the *Carter* decision. This is evidence of a Constitutional Democracy, not a slippery slope.

#### **My Brief CV (Relevant to Palliative Care)**

- Professor and Head, Division of Palliative Care, University of Ottawa
- Clinical Research Chair (Tier 2), Palliative and End of Life Care, University of Ottawa ○ Founder, co-chair of the Pan-Canadian Palliative Care Research Collaborative ○ Authored or co-authored >115 scientific publications
  - International guidelines on end-of-life care in the ICU
  - Communication and decision-making for people with serious illness ○ \$24 million in peer-reviewed grant funding
- Lead, Hospital-Based Models of Care (Adult) working group in the Ontario Palliative Care Network (part of Ontario Health).
- Former Member, Palliative Medicine Subspecialty Working Group at the Royal College of Physicians and Surgeons of Canada (established the standards of subspecialty training in Palliative Care in Canada).
- Former Chair, Postgraduate education committee of the Canadian Society of Palliative Care Physicians and the Education Committee of the Ontario Palliative Care Network.
- Founder, former director of the first accredited subspecialty palliative care residency training program in Canada at the University of Toronto (2016).

#### **Specific Relevance to MAiD**

- Former Co-Chair of Physician Advisory Committee, Dying with Dignity Canada
- Expert witness for prosecution in *Truchon* case, also called as a witness in *Lamb*
- Developed Canadian Medical Association educational material to train MAiD assessors and providers in Canada, also used in educational material in Australia
- Advised on legislation developed in Australia and New Zealand
- Lead study on demographics of MAiD recipients in Ontario, and compared them to people who died without receiving MAiD. MAiD recipients are much wealthier, more likely to be

married and less likely to be widowed, and far less likely to be institutionalized than those who do not receive MAID (referenced above).

## References.

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## 12. Professor David Albert Jones

### **Assisted dying in Jersey consultation Submission by Professor David Albert Jones**

This is not an institutional submission but a personal submission reflecting on my role as one of three content advisers on the Citizens' Jury on Assisted Dying.

It ends with a recommendation in relation to conscientious objection.

I was invited to be a part of the Citizens' Jury process after it had begun in order to bring balance to the content advisory group. I was glad to be approached and think that it was good that the content advisory group had three members with a variety of views. I think that the content provided to the Jury was wide-ranging and reasonably balanced with views from different jurisdictions and views from both 'sides' of the debate and from some who are ambivalent on this topic. I thought that those parts of the process of which I was aware were conducted in a conscientious way by all involved.

Looking at the outcomes of the Jury and the way that the outcomes have been used, however, and considering certain aspects of which I was not aware initially or about which I was misinformed, I am very critical of this process as a way to determine the shape of the criminal law. From my experience I would certainly advise other jurisdictions against adopting a similar approach.

This reaction is not simply disappointment about the fact that the Jersey States Assembly has decided to adopt legislation that I believe would be dangerous. Other jurisdictions have adopted similar laws through a variety of processes: through Private Members' Bills, through Bills supported by one or more political party, through court cases, or through a referendum. These processes carry more or less democratic legitimacy and so it is possible to say, for example, that a referendum is appropriate for 'yes/no' constitutional questions but not for matters of criminal law. In contrast for Parliament to consider the matter for itself, debate and then vote on a Bill is the appropriate way to pass legislation on the criminal law (which one can agree on even if one might disagree with the content of the law).

In my view it is Parliament, and in the case of Jersey, the States Assembly, which has democratic legitimacy. Reflecting on my experience, my fundamental concern about Citizens' Juries (sometimes termed Citizens' Assemblies) is that these make decisions which properly belong to the elected legislature. They undermine the role of representative Houses which is to take responsibility for the law, weighing up the evidence for itself, not 'outsourcing' policy decisions to a group that is neither expert nor elected (and hence is not democratically accountable).

### **Neither unbiased nor a 'jury'**

The first feature of the Jury of which I was unaware until after the process was complete was the way that the Jury had been selected so that most of the members had already made up their minds on the subject. Most either 'strongly agreed' or 'strongly disagreed', and an overwhelming majority (83%) were in favour of a change in the law ([Citizens' Jury Report p.10](#)) at the outset. This approach was taken so that the jury reflected public opinion on 'assisted dying' as assessed by previous surveys. At the end of the process most people held the opinions they went in with, the final tally being 78% in favour ([Citizens' Jury Report p.26](#)). This represents a net shift of one person away from changing the law but otherwise the great majority continuing with their views. Such a result is unsurprising but hardly significant.

It should be noticed how different this is from a 'jury' in a criminal or civil case. In relation to jury selection, having strong prior views about the specific case would be a reason to exclude some from the jury. Juries are supposed to be unbiased. Also, a jury is asked to determine matters of fact, whether a person performed the acts of which they are accused, whether a person did so knowingly and with criminal intent. The jury is not asked to determine matters of law or ethics. They function as a check within the system, a lay voice to help assure that innocent people are not found guilty through prejudice. They are also asked, at least in the first instance, for a unanimous verdict such that each juror must be convinced beyond a reasonable doubt. In contrast the 'Citizens' Jury' were a group who were selected to have strong prior views and were selected so that a majority were in favour of a change in the law. Furthermore, there was no test of the level of doubt nor a default in case of remaining doubt. Finally they were being asked to decide on matters of law, not only matters of fact. In summary this was not in any sense a 'jury' process, being neither unbiased nor limited to assessment of the facts beyond reasonable doubt.

### **A 'Citizens' Jury' as qualitative research**

When I entered this process I was informed that the aim was to get a richer understanding of the opinions of ordinary members of the public, and that the focus would be on the reasons people had for their views and how these reasons changed or were informed by the process, by the evidence they saw and by their facilitated discussions. I was assured that the process was not simply about the decisions of the majority but the rationale for those decisions and that the report would also include exploration of the reasons for the views held by the minority.

As explained, this process seemed to be analogous to a piece of qualitative research on the model of the social sciences. Qualitative research is distinct from quantitative research (which looks at numbers of people who think this or that, assessed through representative surveys). Qualitative research does not look at numbers or proportions but provides a deeper understanding of why people hold those thoughts and beliefs. A 'focus group' is a well established means of conducting qualitative research (often alongside individual semi-structured interviews). Politicians use (qualitative) focus groups as well as (quantitative) opinion polls to help them understand public opinion. The Citizens' Jury is like a sustained focus group with the addition of providing expert input on the topic of discussion.

I do not think in a Parliamentary democracy elected representatives should always do what is most popular. They should weigh up decisions on the basis of the common good. For example, they should pay more attention to the views of those who will be affected by the law, and by expert opinion in relation to likely consequences, as well as legal and human rights concerns, and the experience of professionals, more than simply the views of the majority. This is why democratic decisions should not be made only by a series of referendums. On the other hand, elected politicians are accountable to the electorate and they should be aware of public opinion and of the reasons why the public hold those views.

### **Votes of the Jury as determining the law**

As explained to me, this was about understanding what the public thinks and why, and this could be a worthwhile exercise to inform a decision. However, after the Jury delivered its findings, consideration of the outcomes focused not on their reasoning but, almost exclusively, on the final votes of this group. The report included discussion of reasons for the decisions and reasons for the views of those in the minority, but rather than discuss these reasons, and whether they were valid or not, the conclusions of the Jury were taken as determinative. This indeed is suggested by the term

'Jury'. A jury in civil or criminal law does not share its deliberations, indeed it is prohibited from doing so. The only thing that matters is the verdict.

I think even had it been called a 'Citizens' Assembly' there would have been the same danger of ignoring the potential insights into the rationale of public opinion (which is what this process can legitimately provide) and focusing entirely on the votes (which from the perspective of qualitative research are meaningless). Having set up the process, members of the Jersey States Assembly felt bound to accept the majority votes of the 'jury' as far as possible. This is very clear in the discussions over the proposals for the shape of the law which followed the Jury votes on all matters except the extension of euthanasia to minors, and even here allowed that the age limit could be revisited by future regulations (See [Consultation Report](#) p. 13, p. 16).

The resultant outline proposals represent a far more extreme law than those recently considered by Westminster or Holyrood. Rather than restricting 'assisted dying' to people who are otherwise dying (as the name might suggest) people would have their lives ended on the basis of having chronic physical illness or long term disability. Furthermore, rather than restrict this to self-administration (physician-assisted suicide) it includes administration by a doctor or nurse practitioner (euthanasia). This puts the power in the hands of the doctor and the evidence from other countries is that this leads to much higher rates of death and to doctors sometimes ending life without request.

In short, as a result of a biased Jury and a process that focused on the outcome, not as a deeper understanding of public opinion, but as 'votes' which were then taken to be determinative (where feasible), this process has resulted in very dangerous proposed legislation. *What the States' Assembly should do at this point is recognise these flaws in the process and revisit the issue, considering the evidence for themselves.* There should then be a repeat of the vote on the principle of the legislation and, if this is carried, the States Assembly should take responsibility for the shape of the legislation. This should not unthinkingly echo the results of the votes of the 'Citizens' Jury'.

If, as seems likely, the process is not revisited but continues and the present timetable for this legislation is followed, then the minimum that Members of the States Assembly must do is to seek to mitigate the harm in the Bill wherever possible. One area that is crucial for the safeguarding of medical and social care professionals, and the prevention of abuses under the law, is adequate protection for conscientious objection. Regrettably on this, as on other matters, the current proposals are deeply flawed.

### **Conscientious objection**

If this legislation is passed it will do so despite very little support from health and social care professionals on the island of Jersey. It may well be that, as in other jurisdictions, a large proportion of assisted deaths under this law will be performed by a small group of healthcare professionals who are strong advocates of the practice. This is because, as research shows, even where there is support in principle for euthanasia/assisted suicide among healthcare professionals, the figure drops significantly when those same professionals are asked if they would take part in the process. Within a jurisdiction of the size of Jersey it would soon be apparent who would provide 'assisted dying'.

In this context, there is a clear danger that healthcare professionals who remain opposed to these practices, and who are concerned for the safety of their patients, will be coerced into involvement in euthanasia or assisted suicide.

The consultation document does not regard self-administered assisted dying as 'assisted suicide' (e.g

See [Consultation Report](#) p. 11). However, it should be noted that very many people consider self-administered assisted dying to be a form of suicide, especially when the person is not otherwise dying. Not only is this the legal framework of most countries but even in the Netherlands,

Luxembourg and Switzerland where the practice is legal, it is termed 'assisted suicide'. The law in the

Netherlands is called the **Termination of Life on Request and Assisted Suicide (Review Procedures) 2002**, the law in Luxembourg is called the **Law on Euthanasia and Assisted suicide 2009**. The most recent official report in Switzerland is entitled **Assisted suicide and suicide in Switzerland 2014**. This is also the language of organisations such as EXIT and Dignitas that provide assisted suicide in

Switzerland. The recent briefing paper produced by the United Kingdom Parliamentary Office of Science and Technology acknowledged that terminology was disputed but after wide consultation by those on both sides of the debate defined assisted dying as follows:

'Assisted dying' refers here to the involvement of healthcare professionals in the provision of lethal drugs intended to end a patient's life at their voluntary request, subject to eligibility criteria and safeguards. It includes healthcare professionals prescribing lethal drugs for the patient to self-administer (**'physician-assisted suicide'**) and healthcare professionals administering lethal drugs (**'euthanasia'**).

As this language is very widely used then many healthcare professionals, and indeed many people, will regard the facilitating of 'assisted dying' as contradicting their commitment to suicide prevention. Again, the World Medical Association, which represents 116 medical associations worldwide including the British Medical Association, has strongly urged that:

***No physician should be forced to participate in euthanasia or assisted suicide, nor should any physician be obliged to make referral decisions to this end.***

By international standards, it is unethical and coercive to require healthcare professionals to refer patients, not least those who may not be dying, or who may still be coming to terms with a terminal diagnosis, for procedures that will end their lives.

The protection of freedom of conscience is a fundamental principle of human rights and this includes the freedom not to have to participate in the state sanctioned termination of human life. It should be noted that professionals are not only motivated by protecting themselves but they are motivated by a wish not to facilitate actions that will harm their patients.

A key question in relation to a conscience clause is what constitutes 'participation'. In the United Kingdom the Supreme Court ruled that the conscience clause in the Abortion Act 1967 should be interpreted narrowly. It is important to emphasise, however, that this was not a judgement about what ought to be included in a conscience clause but was about how to interpret the conscience clause in the Act. In the absence of clarity within the statute about what was included within participation that law should, in the view of the Supreme Court, be interpreted narrowly. This is not an argument for narrowing the scope of the statutory definition, it is an argument in favour of clarifying the scope of the law whether broad or narrow.

### **What forms of 'indirect' participation should be protected?**

The consultation report suggests that, in order to give some limit to conscientious objection, the protection of law should be limited to acts such as writing prescriptions for lethal drugs or giving the lethal injection and should not apply to 'indirect' involvement. The consultation report provides no definition of direct or indirect participation but provides examples that are highly contentious. For

example, there is no ability to refuse to deliver 'medical supplies' to be used for the purpose of 'the delivery of an assisted death'. Thus the law would coerce people into delivering lethal drugs knowing these were to be used to assist suicide. However, delivering lethal drugs for the purpose of facilitating suicide is archetypal of assisting suicide. If these drugs were knowingly delivered by a pharmacy to a company that wanted to make them freely available on the internet (outside the law), then this act of delivering the drugs would clearly constitute participation in assisted suicide.

What then should be the definition of participation in a conscience clause? From a human rights perspective the scope of what is 'conscientious' is itself a matter of conscience. Some people might consider delivering suicide pills to be acceptable but would not be willing to give a lethal injection, others might consider, in conscience, that delivering suicide pills constitutes participation. If the right to conscientious objection constrains what counts as participation this implies that some people should be coerced into doing what goes against their conscience where they consider it participation but the law does not. This willingness to coerce healthcare professionals to do what they would consider as participating in assisting suicide or in euthanasia is justified on the basis that it is necessary for pragmatic reasons in order to provide 'assisted dying'. No evidence is given that these interventions could not be provided without permitting coercion of health and social care professionals.

If there is a wish to provide objective limits to the protection of conscience the categories of 'direct' and 'indirect' participation will not suffice. In the case of assisted suicide all assistance is indirect in that death is the direct result of the act of the patient. On the other hand, there are forms of complicity with the law that is clearly much less direct. If the 'assisted dying service' has a budget then those who contribute to this via taxation are participating indirectly in assisted suicide or euthanasia, but this does not seem to justify withholding of taxation for this reason.

What then could function as a rule that would give clarity to the law and would respect the human rights of health and social care professionals and would give clear and reasonable limits as to what constitutes participation? One obvious source of such a rule is the Criminal Offences (Jersey) Law 2009 which makes it an offence to 'aid, abet, counsel, procure, conspire, attempt or incite' the commission of a statutory offence. These forms of participation are crimes if the action is a crime. In the same way, actions that would constitute 'aiding, abetting, counselling, procuring, conspiring, attempting or inciting' assisted suicide or euthanasia are forms of participation in those actions, and so should be subject to the same protection in relation to conscience. Is it 'aiding or abetting' to deliver lethal drugs that will be used in a crime? It might not constitute aiding and abetting for a postal service to deliver these items along with other lawful deliveries, especially if they appeared to be legitimate prescriptions. On the other hand, for someone to deliver the drugs by hand knowing what they were and what they were to be used for would constitute aiding and abetting. In a similar way, a nurse or pharmacist who knows that drugs are to be used to assist suicide should not be coerced into delivering these drugs.

In relation to what happens in a care home or a private facility again the question would be: what duty and thus what right do those running the home have to prevent illegal activity on its property (such as taking recreational drugs)? A care home is someone's home and residents have rights to privacy, and such rights also apply in relation to access to healthcare; but as there is no duty to facilitate illegal activity, so there should not be a duty to facilitate activities that contradicts the ethos of the institution. To be clear, it is not that assisted dying is treated as though it were illegal, but for the purpose of the right of protection of conscience (individual or institutional) the definition of 'participation' should extend to actions that would constitute 'aiding or abetting' if 'assisted dying' were illegal. The law on aiding and abetting provides a reasonable guide to what indirect

actions are complicit in the primary action. Such a definition would give the law clarity without making it unduly coercive.

13. Professor Ben White & Professor Lindy Willmott

10 January 2023

## Submission to Government of Jersey Consultation on Assisted Dying 2023

Thank you for the opportunity to make a submission in relation to the Government of Jersey's consultation exercise into assisted dying. We make this submission as Australian academics who have been conducting research into assisted dying and end-of-life law, policy and practice for over 20 years (including in relation to assisted dying systems internationally).

Because some aspects of Jersey's proposed assisted dying legislation reflect Australian models, we wished to share evidence about the Australian experience of assisted dying. We also make some observations about particular questions posed in the consultation paper, and about law reform generally, based on our research into the law-making process in the end-of-life area.

We would be pleased to provide any further information if that would be of assistance.

Yours sincerely



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**Submission to Government of Jersey Consultation on**

# Assisted Dying 2023

**Professors Ben White and Lindy Willmott, Australian Centre for Health Law Research, Queensland University of Technology, Australia**

## Background and expertise

We are health law academics whose principal area of research expertise is end-of-life law, particularly assisted dying. We have each been researching in the end-of-life area for over 20 years. We have published over 150 publications on end-of-life decision-making and received over \$45 million (Australian dollars) for our end-of-life research and training programs.

Our research on assisted dying includes a body of work on comparative and legal analysis of the various international assisted dying regimes. This includes developing a Model Voluntary Assisted Dying Bill which has been cited widely and also adopted as the basis for law reform in one Australian reform report.

Our current work includes a four-year project 'Optimal Regulation of Voluntary Assisted Dying' which includes research into assisted dying systems in Australia, Canada and Belgium: <https://research.qut.edu.au/voluntary-assisted-dying><https://research.qut.edu.au/voluntary-assisted-dying-regulation/regulation/>. This project will make recommendations about how best to safely regulate assisted dying.

We were also commissioned by the state governments of Victoria, Western Australia and Queensland to design and deliver the legislatively-mandated training for practitioners wishing to provide assisted dying. Lindy is a member of the oversight body for assisted dying in Queensland, the Voluntary Assisted Dying Review Board, and Ben is a member of the relevant review tribunal, the Queensland Civil and Administrative Tribunal.

In terms of law reform, we have been consulted and participated in the various assisted dying law reform exercises in Australia and overseas. We also edited the book 'International Perspectives on End-of-Life Law Reform' (2021, Cambridge University Press). This is a collection of ten case studies from six jurisdictions (the United Kingdom, the United States, Canada, Australia, Belgium and the Netherlands) analysing different aspects of end-of-life law reform.

More background information is available here:

<https://www.qut.edu.au/about/our-people/academic-profiles/bp.white>

<https://www.qut.edu.au/about/our-people/academic-profiles/l.willmott>

## The Australian experience of assisted dying

We note that some aspects of Jersey's proposed assisted dying law reflect Australian models and accordingly, we share evidence about the Australian experience of assisted dying.

### Sources of evidence

We base our comments below on two main types of evidence. The first is the reports of the oversight bodies in the Australian states of Victoria and Western Australia. These are the two systems that have been in operation the longest – Victoria for over three years and Western Australia for more than one year. The other state systems are newer and so the oversight bodies have not yet reported.

The second type of evidence is the research that we have undertaken about the law, policy and practice of assisted dying systems in Australia. This includes articles:

- Analysing the assisted dying models from a legal and regulatory perspective
- Analysing the policies produced by government and non-government bodies about assisted dying
- Reporting on the development and utilisation of the legislatively-mandated assisted dying training
- Reporting on empirical research about how the assisted dying models are operating in practice.

In relation to empirical research, we have conducted over 100 qualitative interviews with patients, families, doctors and regulators in the Australian states of Victoria and Western Australia to understand how these assisted dying models are working in practice. Some of this research has been published, some is under review, and some is currently being analysed. Because some of this research is not yet in the public domain, it is discussed in general terms. We would be happy to provide more information about specific findings if that would be of assistance, including providing in confidence access to unpublished or under review work.

### A policy briefing (August 2021)

To inform parliamentary debates in Australia, we produced a policy briefing which summarised the key findings from our research about assisted dying over a period of almost two decades. The briefing is reproduced in full below and may also be accessed at the following link: <https://research.qut.edu.au/voluntary-assisted-dyinghttps://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources/regulation/other-resources/>. Also available at that website is the research that underpins this policy briefing (see the PDFs extracted into five volumes).





# Voluntary assisted dying research: a policy briefing

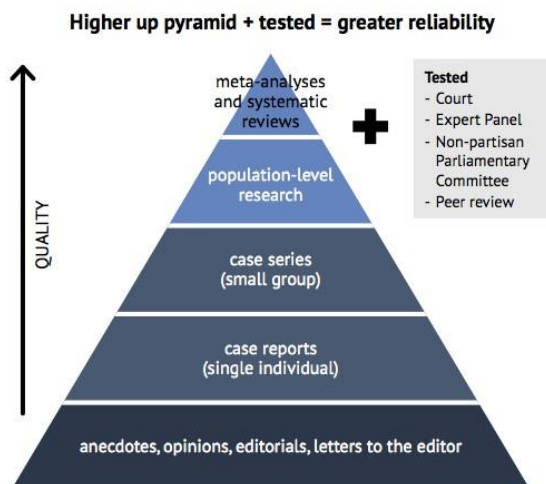
This briefing summarises research about voluntary assisted dying (VAD) conducted by Professors Ben White and Lindy Willmott (with colleagues).

## 1 Australia should have VAD laws: they are ethical and VAD can be safely regulated

- » There is a strong ethical case for allowing a limited cohort of patients, who are already dying, to choose VAD.
- » Reliable evidence about VAD systems internationally and now in Australia shows that VAD can be safely regulated.
- » Politically, legalising VAD has been challenging. Only narrow and conservative VAD models have passed in Australia.

## 2 VAD laws must be evidence-based and consistent with intended policy goals

- » Law reform must be based on reliable evidence (see the “reliability pyramid”).
- » VAD laws must be designed to meet their intended policy goals.



## 3 There is now a broad “Australian VAD model” but each jurisdiction should pass a law most appropriate for its circumstances

- » Although based on the same model, Victoria, Western Australia, Tasmania and South Australia have all taken slightly different approaches to regulating VAD.
- » Jurisdictions should learn from how existing laws work in practice and design a law that is most appropriate for its circumstances (e.g. unique geography and population distribution).

## 4 Designing VAD laws requires seeing how the entire legal framework operates

- » Evaluating a VAD law must be based on how it will work as a whole, and not by considering individual provisions in isolation.
- » For example, numerous eligibility criteria for accessing VAD work together in these laws. Concern about one criterion when considered in isolation may resolve if all criteria are considered as a whole.
- » The process of designing VAD laws should include testing how eligibility criteria affect who can access VAD and for what medical conditions.

## 5 “Piling on” ad hoc safeguards to already sound VAD laws does not make laws safer and can make them worse

- » Ad hoc safeguards have been added during parliamentary processes to already sound proposals for VAD laws.
- » This led to inconsistency and incoherence in those laws without improving patient or community safety.

**6 VAD systems must be workable so eligible patients can access VAD**

- » The complex Victorian VAD law and system make patient access to VAD challenging.
- » Key problems include:
  - doctors are not allowed to raise the topic of VAD with patients
  - the need to obtain a government permit to access VAD, and
  - the complexity of the administrative process when applying for VAD.

**7 The Commonwealth Criminal Code must be changed: it is an unjust barrier for patients seeking VAD and their doctors**

- » The Code makes illegal using a “carriage service” (e.g. email, telephone, fax, telehealth) in relation to “suicide”. This creates risk for doctors and others who are otherwise acting legally under State VAD systems.
- » This means some steps in the VAD process must be done face-to-face. This is causing hardship and delay for patients and doctors.
- » For constitutional law reasons, States cannot resolve this issue.
- » The Commonwealth Government should amend this law so it will not apply to lawful VAD systems.

**8 Institutions should not have power to prevent their patients or permanent residents from accessing VAD**

- » There is some limited evidence that institutions are blocking access to VAD in Victoria. Some institutions in other States have also indicated they will block access.
- » Legislation should permit an institution to not participate but must ensure eligible patients and permanent residents can still access VAD.

**9 Effective implementation of VAD is challenging but very important**

- » How a VAD system operates depends not only on the law, but also system design, including factors such as IT, navigation and support services.
- » Sufficient time and resources are needed to effectively implement VAD laws. And once implemented, VAD systems should be kept under constant review.
- » VAD laws are complex so implementation should aim to make the patient, family and doctor experience as smooth and simple as possible.
- » Effective training for practitioners involved in VAD (and others) is critical as is a user-friendly IT system.

A compilation of the 37 research papers this policy briefing is based on is available here:

<https://research.qut.edu.au/voluntary-assisted-dying-regulation/other-resources>

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[www.research.qut.edu.au/achlr](http://www.research.qut.edu.au/achlr)

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August 2021

## Further observations about Australia's assisted dying systems

In addition to the findings summarised in the policy briefing, we make the following further observations based on the two sources of evidence identified:

- The Victorian and Western Australian oversight bodies' reports show that their assisted dying systems are operating safely and as intended. There have not been cases of ineligible patients being wrongly granted access to the assisted dying system. Research participants interviewed have also repeatedly observed how safe the system is.
- Indeed, there appear to be challenges with assisted dying not being sufficiently accessible for terminally-ill eligible patients who want this choice (particularly in Victoria). Although the many safeguards are ensuring the system operates safely, there is evidence that people are dying or losing capacity during the rigorous process, and applying for assisted dying is very challenging. While continued focus on safety is essential, work is needed to ensure assisted dying systems can be effectively used by the patients they are designed to help.
- In particular, the requirement for prospective review and approval in Victoria (e.g. via a government permit) has been a cause of delay in accessing assisted dying.
- The Victorian prohibition on being able to raise assisted dying with patients has generally been seen as problematic, and impeding frank conversations about end-of-life choices.
- To date, there are a relatively small pool of doctors (and nurses where permitted) who have trained and are available to provide assisted dying. This can make access to assisted dying difficult, particularly in some areas.
- Some institutions have objected to assisted dying occurring on its premises. This has led to adverse consequences for some terminally-ill patients and their families.
- The thorough and planned implementation processes prior to the law coming into force ensured assisted dying operated safely as soon as the law began.
- The assisted dying care navigators have been pivotal to the effective operation of the assisted dying system.

## Particular questions in the consultation paper

We briefly address a selection of the questions asked in the consultation paper where the Australian experience or our research is particularly relevant.

We do note first, however, our global position on assisted dying. We support law reform to permit access to assisted dying under strict conditions and with robust oversight. Some discussion of our views on this is available here:

- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).

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

[For the purpose of responding to this question, we assume that the Government of Jersey will require a life expectancy requirement in its assisted dying law.]

We note the Assembly proposed a period of 6 months and the consultation paper is contemplating extending this to 12 months, but only for those with a neurodegenerative disease. If it is accepted that a time limit is required, we consider it is difficult to justify differential times for different illnesses. We understand that the 6 month approach with 12 months for neurodegenerative conditions originally comes from the Australian state of Victoria. But this position in Victoria was the result of a last minute political compromise, and was not part of the original law as drafted. All other Australian states, except for Queensland, have uncritically adopted this 6 or 12 month approach.

Our preferred approach, if a time limit is required, is to have a consistent time for all conditions. However, we consider 6 months is too short. Evidence from Australia suggests that people are dying and losing capacity during the assisted dying process and part of this is due to the 6 month time limit as terminally-ill patients are already very unwell. If 12 months is being contemplated for neurological conditions, we consider that longer period should be available for all illnesses. This is the approach adopted in the Queensland law which has a blanket 12 months approach. We argue that allowing a 12 month period would not meaningfully extend access to new individuals who would not otherwise be eligible; instead, it just gives eligible patients more time to navigate a complex assisted dying process.

Discussion of this issue is available in:

- Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.
- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

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

The residence requirement has produced some difficulties in Australian jurisdictions. One response to this is to have a default residence requirement but allow for discretion in particular cases to avoid injustice. We set out the Queensland 'residency exemption' provision which illustrates this:

12 Residency exemptions



(1) A person may apply to the chief executive for—

- (a) an exemption from the requirements in section 10(1)(e)(i), (ii) and (iii) (an Australian residency exemption); or
- (b) an exemption from the requirement in section 10(1)(f)(i) (a Queensland residency exemption).

(2) The chief executive must grant the exemption if satisfied that— (a) the person has a substantial connection to Queensland; and *Examples*—

- *a person who is a long term resident of a place close to the Queensland border and who works in Queensland and receives medical treatment in Queensland*
  - *a person who resides outside Queensland but who is a former resident of Queensland and whose family resides in Queensland*
- (b) there are compassionate grounds for granting the exemption.

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

We consider that objections by individuals are different from objections by institutions for a range of reasons (discussed in the article below) and so should be treated differently.

Objections by institutions to assisted dying have been a significant practical issue in Australia in the empirical research we have done. Two articles which consider the impact of institutional objection on patients and their families are currently under review (we would be happy to provide copies in confidence if that would be useful).

In short, the ability of institutions to prevent access to assisted dying can cause harm, and this is particularly the case if a patient is unable to move out of the facility and/or if that facility is regarded as their home (e.g. a long term care facility). For this reason, we recommend that the issue of institutional objection be specifically addressed in the legislation.

We have written an article which outlines the issues and proposes different models to address institutional objection that both respects an institution's views but ensures a patient's access to lawful assisted dying is not precluded:

- Ben White et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) *University of New South Wales Law Journal Forum* 1.

In response, the states in Australia to legislate later have specifically addressed institutional objection in their legislation to provide for the above 'compromise' approach. The best of the Australian models is the Queensland legislation and the institutional objection

provisions are set out in Part 6, Division 2 of that Act. This Queensland model is further explained in the Queensland Law Reform Commission's report.

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

We agree the law should not prohibit professionals from raising the subject of assisted dying. This is the case under Victorian law, and this prohibition was specifically identified as problematic by doctors, family members of patients and many regulators. We discuss this from an empirical viewpoint and also from a conceptual viewpoint in the articles below. We also have further work on this issue under review which we could provide in confidence if useful:

- Lindy Willmott et al, 'Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice' (2020) 10(1) *BMJ Supportive and Palliative Care* 105.
- Lindy Willmott et al, 'Participating Doctors' Perspectives in the Regulation of VAD in Victoria: A Qualitative Study' (2021) *Medical Journal of Australia*.
- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

## Law reform and assisted dying

In this section, we make some observations about our research into law reform and assisted dying, as well as our participation in the six law reform exercises in the Australian states which have legalised assisted dying.

### Law reform processes and assisted dying

We commend the Government of Jersey's wide and inclusive consultation process to deliberate on assisted dying. We share the below book chapter on law reform in the end-of-life area. This chapter was a collaborative effort with international end-of-life scholars on law making and law reform which draws on ten case studies in six countries to identify features that support law reform in this area. Part of this chapter argues that reform is more likely to occur with reliable evidence about how assisted dying systems work in practice:

- White, Ben, Willmott, Lindy, Downie, Jocelyn, Lewis, Penney, Kitzinger, Celia, Kitzinger, Jenny, et al., 'International Perspectives on Reforming End-of-Life Law' in White, Ben P. & Willmott, Lindy (Eds.) *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021) pp. 250-275.

### Law-making on assisted dying must be evidence-based

We advocate for evidence-based law-making, and consider this is particularly important in relation to a contested social policy area such as assisted dying. There is a large body of reliable evidence about how assisted dying systems operate internationally (which we understand the Government of Jersey will be considering). We outline the case for evidence-based law-making in:

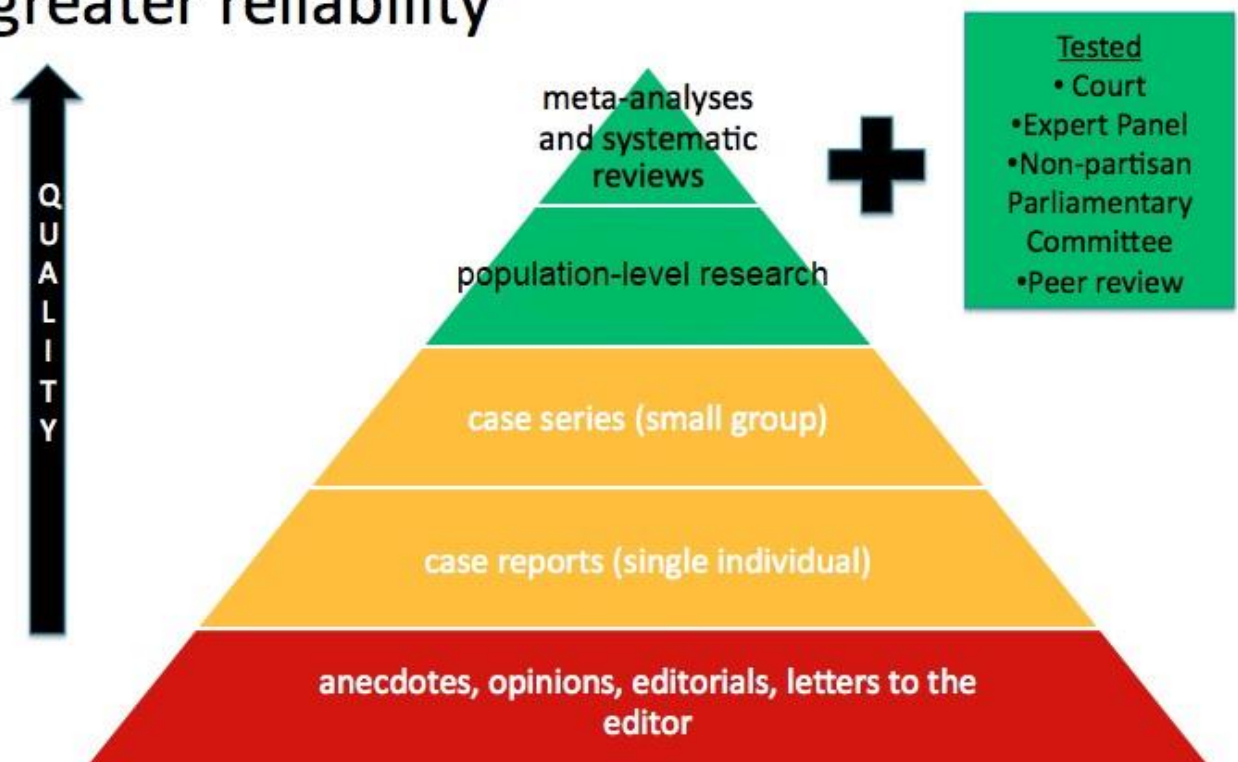
- Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' (2020) 44(4) *Australian Health Review* 544-546

For an example of a critical analysis of an article which claimed to be reliable evidence for the New Zealand assisted dying referendum – but was in fact not reliable evidence, see:

- Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, 'Assisted dying and evidence-based law-making: A critical analysis of an article's role in New Zealand's referendum' (2020) 133(1520) *New Zealand Medical Journal* 83-90

In particular, we note the utility of an evidence pyramid (see below and in the article) to critically evaluate factual claims about assisted dying.

Higher up pyramid + tested =  
greater reliability



\* Originally developed by Professor Jocelyn Downie (see article)

Concrete testing of eligibility criteria

We also support the concrete testing of eligibility criteria to understand properly the boundaries of a proposed assisted dying law. We undertook (with colleagues) an analysis of five assisted dying laws (three Australia models, Oregon and Canada) across nine different medical conditions to determine which models might permit access to assisted dying and for whom. One key finding was that Australian models like Victoria and Western Australia, and Oregon, which include a proposed time until death are unlikely to change which medical conditions would grant access to assisted dying, when compared to our Model Bill (which does not have a time frame). Those two papers also include a range of recommendations about law and regulation that we consider are important for parliaments and law-makers considering assisted dying laws:

- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

#### Avoid incoherent law by ad hoc addition of safeguards

A final observation about the law-making process, based on what we have seen in the six Australian law reform processes, is the need to avoid the ad hoc addition of safeguards which are awkwardly tacked on to already sound law. This leads to the assisted dying law being incoherent or inconsistent in important ways.

An example of this is eligibility for assisted dying depending on a variable time period

– 6 or 12 months until expected death – depending on the nature of a patient's illness. As noted above, this change in timing was a political compromise in Victoria which has since been uncritically adopted and replicated in all other states in Australia except Queensland. Yet this was only a last-minute addition to the Victorian Bill as a result of political compromise.

Our research has shown that the Victorian assisted dying law fails to meet its own stated policy goals in important respects, sometimes because of these later ad hoc additions during the law-making process:

- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.

For this reason, we argue that any proposed changes to the Bill must be carefully scrutinised in light of the Bill as a whole:

'When thinking about the politics of reform, it can be tempting to only consider each safeguard or process individually. Each may have merit and advance a particular policy goal. It may also be difficult politically to argue that a specific safeguard is not needed, particularly if it appears to achieve at least some useful



purpose. However, when the safeguards are aggregated, the VAD system as a whole can become very complex and unwieldy, and slowly take the legislation away from its policy goals. This “policy drift by a thousand cuts” – the incremental loss of policy focus through accumulation of individual safeguards without reference to the whole – is a key issue for other states to consider when evaluating their proposed VAD reforms. It is suggested that each part of the law be evaluated both on its own, and also for its impact on the functioning of the overall system. This is needed to enable VAD laws to meet their policy goals, in particular, the two key goals at the core of the design of the VAD Act: safeguarding the vulnerable while respecting the autonomy of eligible persons who wish to access to VAD.’<sup>54</sup>

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We have also written on this point in ‘Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks’:

‘Taking a holistic view is also an important consideration more generally when designing VAD regulation. While it may be politically attractive to add numerous safeguards to VAD legislation, including in the eligibility criteria, there is a risk of what we have called elsewhere “policy drift by a thousand cuts” if the cumulative effect of these individual safeguards is not properly considered. For example, it is possible that a series of provisions designed to make VAD legislation safe, when aggregated, can in fact make access to VAD cumbersome or even unworkable.’<sup>55</sup>

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<sup>54</sup> Ben White, Katrine Del Villar, Eliana Close and Lindy Willmott, ‘Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?’ (2020) 43(2) *University of New South Wales Law Journal* 417, 451.

<sup>55</sup> Ben P White et al, ‘Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks’ (2021) 44(4) *University of New South Wales Law Journal* (forthcoming) 1, 53.

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## APPENDIX – PUBLISHED RESEARCH REFERRED TO ABOVE

*The below list of publications is presented in the order in which they are cited.*

- Lindy Willmott and Ben White, 'Assisted Dying in Australia: A Values-based Model for Reform' in Ian Freckelton and Kerry Peterson, *Tensions and Traumas in Health Law* (Federation Press, 2017).
- Ben White and Lindy Willmott, 'A Model Voluntary Assisted Dying Bill' (2019) 7(2) *Griffith Journal of Law and Human Dignity* 1.
- Ben White et al, 'Does the Voluntary Assisted Dying Act 2017 (Vic) Reflect Its Stated Policy Goals?' (2020) 43(2) *University of New South Wales Law Journal* 417.
- Ben White et al, 'Comparative and Critical Analysis of Key Eligibility Criteria for Voluntary Assisted Dying Under Five Legal Frameworks' (2021) 44(4) *University of New South Wales Law Journal* 1663.
- Ben White et al, 'Who is Eligible for Voluntary Assisted Dying? Nine Medical Conditions Assessed against Five Legal Frameworks' (2022) 45(1) *University of New South Wales Law Journal* 401.

- Ben White et al, 'Legislative Options to Address Institutional Objections to Voluntary Assisted Dying in Australia' (2021) *University of New South Wales Law Journal Forum* 1.
- Lindy Willmott et al, 'Restricting Conversations about Voluntary Assisted Dying: Implications for Clinical Practice' (2020) 10(1) *BMJ Supportive and Palliative Care* 105.
- Lindy Willmott et al, 'Participating Doctors' Perspectives in the Regulation of VAD in Victoria: A Qualitative Study' (2021) *Medical Journal of Australia*.
- White, Ben, Willmott, Lindy, Downie, Jocelyn, Lewis, Penney, Kitzinger, Celia, Kitzinger, Jenny, et al., 'International Perspectives on Reforming End-of-Life Law' in White, Ben P. & Willmott, Lindy (Eds.) *International Perspectives on End-of-Life Law Reform: Politics, Persuasion and Persistence* (Cambridge University Press, 2021) pp. 250-275.
- Ben White and Lindy Willmott, 'Evidence-based law making on voluntary assisted dying' (2020) 44(4) *Australian Health Review* 544-546
- Ben White, Lindy Willmott, Jocelyn Downie, Andrew Geddis and Colin Gavaghan, 'Assisted dying and evidence-based law-making: A critical analysis of an article's role in New Zealand's referendum' (2020) 133(1520) *New Zealand Medical Journal* 83-90

## 14. Gay Lee

### Submission to the Jersey Consultation on Assisted Dying

**Gay Lee, Retired Palliative Care Nurse.**

**Before I retired nearly 3 years ago, I was a palliative care nurse for 22 years: in a English hospice as staff nurse, ward sister and subsequently a bank ward staff nurse, with a few months working as a hospice-at-home nurse also.**

**I want to share with the consultation an account of one of the patients under my care, which I believe demonstrates the limits of our current end of life provision and the need for greater choice, including the option of an assisted death for dying patients with mental capacity.**

The patient had motor neurone disease. Joe (the name has been changed) was in a hospice for symptom control and could still walk and swallow soft food, but he was terrified about the manner of his dying. He had a very supportive family but spoke frequently and eloquently about his severe anxiety about the future. He never asked the staff directly for help to die nor even tried to discuss the idea.

After being discharged home the hospice staff heard he had travelled to Dignitas, with his family, for assistance to die. His son came to the hospice afterwards and talked informally to nurses about what a positive experience it had been. For his father to have been able to control the timing of his death and to avoid his worst fears was very important to them. His son felt that Dignitas's role was sensitively performed, but knew it would have been far better if they could have had that experience without having to travel abroad. ***If assisted dying were legal in this country, the patient would have had a choice***, a chance to discuss the issue and his feelings with hospice staff, and would have had more time to enjoy with his family, instead of going to Dignitas early, while still able to travel.

This true story illustrates several points about the limitations of palliative, hospice and end of life care.

So much of health and ill-health care is about choice. You can choose where you die, at least in theory. You can choose who will be with you, what drugs you will take, what other palliative treatment you want. But (if you want to, and not everyone does) you can't choose **when** you die. This choice should be part of the spectrum and the holism of palliative care. Joe was not allowed that choice as part of his care though it was clear it was central to his concerns.

Joe was, at that stage, in the hospice for symptom control. One of his worst symptoms was anxiety and yet we were helpless to do anything other than take the edge off this existential pain with drugs.

Joe felt completely unable to discuss with staff the momentous decision he made to ask his family to go with him to Dignitas. We only knew about it because - unusually - the family felt able to come back and tell us what they had done despite the risk that they could face prosecution.

If assisted dying had been legal it is quite probable that Joe's openly-expressed anxiety about how he would die would have developed into a discussion about whether or not he wanted an assisted death, the pros and cons, and an opportunity to discuss it with a spiritual carer and a therapist. Perhaps being in control - ie having a choice - would have meant that he was **less** likely to ask for an assisted death. There is evidence from Oregon (where assisted dying has been legal for over 20 years) that the drugs placed in the house to end the patient's life are often not used - such is the central importance of control over one's life. When you have it, you often don't need them.

Control is what is lacking, particularly with neurological diseases like motor neurone disease. When you need someone to scratch your nose when it itches, when you have no control over your bowels and you don't know if you are going to suffocate or choke to death, life is very frightening and the best palliative care in the world cannot help, unless it includes a choice about when you die. This is what Joe wanted and he was in the fortunate position of having a family who would risk prosecution to allow him to have it.

I lost count of the number of times patients or members of their families told us that 'we wouldn't let a dog suffer like this' or of patients who said how much they longed to die. Yet not many families or patients asked directly for help to die though more people hinted at it. In the latter situation I tried to hear what they were saying and often told them directly that we could not help because it was illegal. However I would also encourage them to express their fears and ask them why they were saying those things. But many health professionals are understandably reticent about even discussing the issue of assisted dying, for fear of overstepping the mark and risking prosecution for encouragement to, for example, travel to Dignitas. Joe and his family kept it completely secret that they were intending to go there, knowing that there would either be disapproval or discomfort from staff.

Over the years, I formed the distinct impression that nurses rather than doctors were beginning to be more sympathetic to the idea of assisted dying and felt more able to openly discuss it. I think they fear sanctions less than doctors but also I think nurses see more suffering that they feel helpless to alleviate than do doctors who don't spend as much time with patients, especially on the basic 'activities of daily living' which patients find so difficult at the end of life.

Palliative care cannot alleviate all suffering near the end of life. It cannot give back patient autonomy and dignity, but some (apparently) physical symptoms cannot always be alleviated either. The Office of Health Economics recent research found that 17 people a day will die in pain even with the very best palliative care.

Cecily Saunders, the founder of the modern hospice movement, used the concept of 'total pain' to describe intractable and distressing pain and discomfort which ever-increasing amounts of different kinds of drugs could not alleviate. This is existential pain related all the things that have happened to the patient over the course of their life. It manifests itself at the end of life and is not necessarily resolved before death. This is why palliative care **as it is now** cannot be the panacea for everyone, essential though it is in a humane society, and however many strides it has made towards perfection over the decades, We need assisted dying to be an integral part of palliative care and not see it as a defeat.

Currently the law is very unsafe not least because so many people take their own lives alone and unsupported. Recent ONS data has found that terminally ill people are more than twice as likely to take their own lives, often in very distressing circumstances, in secrecy and alone.

From research in countries where it is legal, we know it allows communication about existential issues, where people have the chance to discuss their suffering and make safe choices with support from others.

**So to summarise, from my clinical experience, I support a change in the law for the following reasons:**

- Choice about when one dies should be included in the many other choices available to people at the end of their lives
- Symptoms of acute and chronic anxiety and depression, caused by feelings of fear of the unknown, lack of control and loss of dignity could be alleviated if the choice of an assisted death were available
- Conversations and communication generally at the end of life would be more open, honest and constructive if assisted dying were allowed
- There would be fewer distressing suicide attempts and 'successes' and arguably fewer assisted deaths also, if assisted dying were legalised here.
- There would be overall **better quality life** for patients if assisted dying could be incorporated as one aspect of palliative and terminal care. A good quality of the life that's left is after all the overarching goal of good palliative care.