

# Living and Dying Well Response to Consultation on Jersey Assisted Dying proposals published Oct 2022

In November 2021, the States Assembly of Jersey agreed 'in principle' that a person could be assisted to die either by physician assisted suicide (where lethal drugs are self-administered) or voluntary euthanasia (where lethal drugs are administered by a 'registered medical practitioner'), subject to safeguards. Following this decision, the States Assembly is seeking the opinions about its assisted dying proposal - the following is our submission to this public consultation.

## About Living and Dying Well

Living and Dying well is an independent think tank, established in 2010, to examine issues at the end of life, including assisted suicide and euthanasia. Our patrons and members include experts in the law, the legislative process, medicine, mental health, ethics and other disciplines related to the end-of-life debate. We hold a range of views on all aspects of the debate, but share a common concern that public safety is of paramount importance in this area and that some of the ideas that are being put forward - for example, that doctors should be licensed by law to supply or administer lethal drugs to terminally ill patients - are not compatible with this and would put vulnerable people at serious risk of harm. We recognise that deficits in care exist but have seen no evidence that these will be ameliorated by such legislation. We fully respect the motivations of those who may take a different view but find that the evidence from other legislatures that have gone down this road confirms our conclusion that such legislation jeopardises people at a vulnerable time in their lives and undermines the professional duty of care to patients and their families.

## Summary of issues specific to Jersey

Some specific issues in Jersey need to be addressed urgently in Health and Social Care. We suggest it is not appropriate for the State to provide a free death service when other services that would save life or improve the quality-of-life left are not being provided.

There is an acute shortage of manpower. General Practice has a 15% vacancy factor at present; nurse vacancies remain unfilled at all clinical grades – especially band 6 and 7- and in care homes and in the hospice; there is an acute shortage of allied health professionals with many occupational therapists resigning posts in the past two years; there are shortages in social care for patients in their own homes with no fast track to financial social services support to allow them to be cared for at home.

There is no mandatory mental capacity training for health and social care staff, yet assessment of mental capacity is a core requirement in the proposed system.

There is no ability to provide single shot radiotherapy on the island, yet for those with bone metastases such an intervention can result in dramatic improvement – consideration should be given to such a development in the new hospital construction. The new hospital, able to provide a wider range of modern medical interventions, is long overdue.

Specialist palliative care is provided in the hospice, but currently there are beds closed (only six are open at the time of writing this document) due to staff shortages. Specialist home care provision has fallen as there are now only two nurses in the team and input to the hospital has been scaled back. Modern palliative care requires adequate staffing to work through outreach into community, secondary and tertiary care including into Intensive Care. The team in Jersey is short-staffed, impeding the ability of specialist palliative care to work in conjunction with acute and longer-term treatment services. Input is therefore restricted when people are in the last phase of illness, which inevitably means opportunities for earlier improvement in quality of life are missed. Palliative care services should be equitably provided over the week (7 day

working) with a dedicated helpline number 24/7 for any staff at any grades seeking expert advice on a patient. Ideally relatives should have a single point of contact if concerned as disease does not respect the clock nor the calendar. A standard should be set that referrals are seen within 48 hours with urgent referral seen faster.

The bereavement service is provided by the hospice and depends on voluntary donations, yet the proposal is for state-funded bereavement support for the relatives of those who have had assisted dying. This is inequitable across the population; in particular, this ignores the needs of children bereaved through other causes.

The recent report by Professor Hugo Mascie-Taylor (Review of Health and Community Services (HCS) Clinical Governance Arrangements within Secondary Care [report](#)) made 61 important recommendations that must be urgently addressed. The issues in governance highlighted in the report raise questions as to how current structures would have the capacity to oversee a Jersey Assisted Dying Service without serious jeopardy to oversight of services whose mission is to save life and improve quality of life. Inspection of services currently is restricted to hospital services, but the main governance risks will be in community services and mental health, neither of which are currently subject to independent inspection.

## Executive Summary

This document outlines Living and Dying Well's response to the proposals laid out in the Consultation Report released in October 2022. Addressing each aspect outlined in the report, this paper highlights the serious dangers of the assisted dying proposals. The wide qualifying conditions, the vague descriptions of assessments, the lack of real-time recording, monitoring, training and key safeguards as proposed do not give confidence that an assisted dying system in Jersey would protect the best interests of vulnerable people and society at large.

This consultation response will go through each element of the proposals in sequence, covering the end-of-section questions asked in the consultation document.

Importantly, several peer reviewed papers and official reports from jurisdictions that permit physician assisted suicide and/or euthanasia have been published in the last year. This evidence was not available to the Deputies at the time of debate, nor to the citizens jury. References to some of these publications are provided in this submission.

## Principles

The document states that the States Assembly should not introduce an assisted dying law until they are satisfied that all Islanders can access good palliative and end-of-life services. There is no elucidation, however, on what would constitute "satisfaction". In addition, it does not define what level of palliative care would be satisfactory: **it does not specify whether islanders simply have access to or are experiencing good palliative care, and indeed whether that palliative care is general or specialist, nor whether it is rapidly responsive and integrated with other services.** The States Assembly should act on their recent review of specialist palliative services to ensure that all those who need it are receiving it before any change in the law on assisted suicide. The proposals quote Canada as a place where 82.8% of people who are requesting an assisted death are receiving palliative care. This is highlighted to suggest the synergy between the two. In Canada, however, evidence shows that only 60% of MAiD patients see a **specialist** palliative care team, and many of them (854 in 2020) who receive palliative care receive it after having requested MAiD, preventing the conclusion that people request assisted death *despite* good care.<sup>1 2</sup> A recent publication from Canada

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<sup>1</sup> Munro C., Romanova A., Webber C., et al. Involvement of palliative care in patients requesting medical assistance in dying, *Canadian Family Physician*, vol 66 (Nov 2020); 48

<sup>2</sup> Gallagher R. Lack of palliative care is a failure in too many MAiD requests, *Policy Options Politiques*, October 19, 2020

also reveals that many requests originate through loneliness and/or poverty rather than medical needs perceived as refractory or which are unavailable to that person<sup>3</sup>.

It is important that, unless the law changes the definition of suicide, assisted dying is seen as assisted suicide or euthanasia (depending on the method of lethal drug ingestion). Legally, suicide is the taking of one's own life, with or without the help of any other. Regardless of the context or intention of 'assisted dying', it is important that the language remains legally accurate. In assisted suicide the patient ingests by self-administration (usually orally) large number of tablets (up to 200), either crushed or dissolved in a large tumbler of liquid; an alternative of a nitrogen gas 'pod' has been suggested in which the patient is sealed and dies of anoxia. In euthanasia, the clinician injects into a vein a large dose of short acting anaesthetic agent, often with or followed by rocuronium or similar to paralyse the patient who then dies of asphyxia.

## Eligibility criteria

**Prognosis:** The proposals state (paragraph 16) that those with terminal illnesses which are "expected to result in unbearable suffering that cannot be alleviated in a manner the person deems tolerable" and which are expected to bring death within 6 months would be eligible for an assisted death. A prognosis of six months life expectancy is notoriously inaccurate and a probabilistic art.<sup>4 5 6</sup> Experience from the Liverpool Care Pathway found that the tools are not sensitive enough to identify reliably those who will die within hours or days.<sup>7</sup>

The House of Lords Select Committee on the Assisted Dying for the Terminally Ill Bill chaired by Lord Mackay of Clashfern heard:

- **"It is possible to make reasonably accurate prognoses of death within minutes, hours or a few days. When this stretches to months, then the scope for error can extend into years"** – Royal College of General Practitioners
- "Prognosticating may be better when somebody is within the last two or three weeks of their life. I have to say that, when they are six or eight months away from it, it is actually pretty desperately hopeless as an accurate factor"- Professor John Saunders, Royal College of Physicians

**A suggestion of a six-month prognosis in legislation will inevitably result in many people ending their lives very early in the mistaken belief that death is far closer than it is.** A guestimate of prognosis is not a safeguard, there is no test for prognosis that can be verified. Canada has removed their "reasonably foreseeable" death criterion because of the vague nature of prognostication.

Of additional concern is the qualification of the "expectation of suffering". How is it possible to determine whether suffering can or cannot be alleviated if a decision for an assisted death has been made not based on current suffering, but the possibility of future suffering? Such expectations arise from fear or from previous experiences of witnessing failures in care in the past.

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<sup>3</sup> Wiebe E, Kelly M, Spiegel L et al Are unmet needs driving requests for Medical Assistance in Dying (MAiD)? A qualitative study of Canadian MAiD providers. *Death Studies* 2022 <https://doi.org/10.1080/07481187.2022.2042754>

<sup>4</sup> Hoesseini A et al. Physicians' clinical prediction of survival in head and neck cancer patients in the palliative phase. *BMC Palliative Care*, 2020; 19: 176-85. <https://bmcpalliatcare.biomedcentral.com/articles/10.1186/s12904-020-00682-2;>

<sup>5</sup> Warriach HJ et al. Accuracy of physician prognosis in heart failure and lung cancer: comparison between physician estimates and model predicted survival. *Palliative Medicine*, 2016; 30(7): 684-9. <https://journals.sagepub.com/doi/abs/10.1177/0269216315626048>

<sup>6</sup> *House of Lords Report* 86-II (Session 2004-05), p730. <https://publications.parliament.uk/pa/ld200405/ldselect/ldasdy/86/8602.htm>

<sup>7</sup> [More Care, Less Pathway \(publishing.service.gov.uk\)](http://www.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/214442/more-care-less-pathway.pdf), 2013

The expectation of suffering is as unpredictable as the time-prognosis of a terminal illness. **If the notion of “unbearable suffering” is self-determined by the person, then any degree of expectation of suffering cannot be judged merely by a clinician or other health professional, as suffering is not inherently linked to a condition but to an individual’s subjective experience of a given condition, influenced by many social, psychological, emotional, and existential factors including the attitude of those providing care.**

Importantly, the alleviation of physical pain and suffering rests on the diagnosis of the underlying cause of the distress and appropriate administration of medicine and good care.

Paragraph 18 implies that a potentially terminal condition that would with treatment not lead to imminent death, qualifies for assisted suicide. This provision opens a grey area in the law where someone with an incurable physical condition could request assisted suicide on the basis that undergoing treatment that would delay death would cause unbearable suffering. For example, someone with complications of poorly controlled diabetes could decline to continue to use insulin, thereby becoming eligible for assisted suicide.

**Evidence from overseas shows that pain is infrequently a significant factor in requests for assisted suicide.**<sup>8</sup>

If pain does feature, it is usually the fear of pain, rather than unmanaged, painful symptoms experienced. The criteria proposed are heavily based on the potential for suffering - which, as above, is hard to define – even though the feared suffering might never be experienced and may be easily ameliorated.

Finally, given the proven link between physical and mental health, proposals which, in their current format, only apply to people with physical medical conditions could be deemed to discriminate against those with mental conditions. The interplay between mental states and physical experience means that those with mental conditions may present with physical symptoms. This “physical cause” criterion does not ensure that those with suicidal ideation from reversible mental illness will be prevented from being provided with lethal drugs.

**Countries with laws which allow for non-terminal illness to qualify have seen a drastic increase in the number of assisted suicides.**<sup>9</sup> The proposals risk leading to a marked shortening of life, particularly among those who feel or fear being a burden or are coerced to request an assisted death.

## Assisted Dying Service

**If the assisted dying service in Jersey is to be free (para 30) and therefore state funded, it should only come into force when all specialist palliative care is fully state funded for all who need it.** No provision of medically assisted death should be prioritised in the public finances above the provision of care for those whose quality of life can be improved.

The Jersey Assisted Dying Service (para 29) will be delivered and managed by the Health and Community Services Department, but this risks the accusation that cost saving becomes a motive or that the hospital or hospice is a ‘death house’. To avoid this the Jersey Assisted Dying Service should be completely outside the health care system for all its activities, with premises away from the hospital. Such premises could provide a place where the person takes lethal drugs (similar to Dignitas) and any bereavement service should be located in such premises, not in the Jersey Hospice. In Canada some funeral homes [offer dedicated rooms for medically assisted deaths](https://www.cbc.ca/news/canada/london/funeral-homes-pivot-to-offer-rooms-for-medically-assisted-deaths-1.6224353)<sup>10</sup>.

Any future private assisted suicide companies (para 33) might be able to make their own rules around provision, conscientious objection, eligibility, and reporting. Any such future initiative must be strictly regulated.

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<sup>8</sup> The Oregon Health Authority reports on the Dignity with Dying Act show pain as a less important factor than others.

<sup>9</sup> Euthanasia, Assisted Suicide, and Suicide Rates in Europe, Journal of Ethics in Mental Health, Vol 11 (2022)

<sup>10</sup> <https://www.cbc.ca/news/canada/london/funeral-homes-pivot-to-offer-rooms-for-medically-assisted-deaths-1.6224353>

In considering staffing, where there are conflicts of interests of workforce distribution, services involved in care must be prioritised over assisted death. Staffing needs in care settings must be prioritised over assisted dying, given the duty of care on doctors to preserve and improve life.

There are important implications for the inter-disciplinary team involved with the ill person. Given the gravity of a request, any professional involved in the care or assessment of a person who has requested an assisted death should be aware of the assisted death request (para 44). This is to inform good conversations around care and ensure that **information relevant to the application** for 'assisted death' is available. It would provide clarity between professional clinical and social support teams and make sure that care to the person in clinical and social settings was adjusted correctly. Without knowledge of an assisted death request, those involved in a person's care would be ill equipped to support and provide appropriate care to that person and to other patients.

## Conscientious objection

An individual doctor or management board of the hospice, hospital, clinic, care home, or other facility where the person has made a written declaration to self-administer lethal drugs must also be under no obligation to participate in any part of the process.

**It is important that any conscience clause in Jersey extends to organisations and not just individuals.** An organisation must have the right to declare openly that it refuses to have assisted suicide or euthanasia conducted on its premises without jeopardising its funding; it is notable that in Canada hospice-closure has been reported because no provision for a conscience clause for organisations was put in place.<sup>11</sup>

Additionally, the law should state clearly that no recognised health body or organisation which operates in the field of health or social care can consider a doctor's refusal to participate in procedures around assisted suicide when making any determination about the employment, promotion, appointment, or career of that doctor. Under para 55, due consideration should be given to conscientious objection in cases where guidance is not complied with.

**If an establishment receives funding from the public sector, legislation must stipulate that the public sector body funding cannot be withdrawn on the grounds that an organisation has a conscientious objection.**

A conscience clause must also make provisions for staff at every grade. This should include judges and legal professionals, not just medical and paramedical practitioners, to abstain from any part of the practice of assisted dying. In the same way that medical professionals might have ethical or conscience objections to participating in assisted suicide, those involved in the legal process of approving and judging on individual cases should be afforded the same conscience rights. Consultations with the legal profession should be made in advance of any introduction of the proposed law as there may be significant concerns relating to the consciences of individual legal professionals.

The proposals state that a conscientious objector must inform the person of their conscientious objection. However, if the patient doesn't need to say they are requesting/have requested an assisted death this would not be possible: in such a situation, a care professional who otherwise may have conscientiously objected may unknowingly participate indirectly in facilitating a person's assisted death (e.g., conducting assessments (para 50 a.) that are used as supporting statements, delivering equipment or medical supplies).

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<sup>11</sup> Bouthillier M-E, Opatrny L. A qualitative study of physician's conscientious objections to medical aid in dying. *Palliative Medicine*, 2019; 33(9): 1212-20. <https://journals.sagepub.com/doi/abs/10.1177/0269216319861921>

Moreover, **if those who are opposed to participating in an assisted death on conscience grounds are obliged to declare their position, then equal rights suggest that those who are willing to participate also declare.**

Those engaged in Jersey Assisted Dying Service must all opt-in (para 56), and processes must protect against doctor-shopping.

Requirement that the lethal drugs are taken/administered in the patient's own home or dedicated Jersey Assisted Dying Service location would protect staff and other patients and allow relatives as much time as they wish with the person pre-death and the body after death. If they are a care home resident, the option of death outside the care home must be available to protect staff and other residents.

## Support systems

The proposals would change the nature of bereavement support (para 71) – there should be no diversion of provision away from families and loved ones in non-assisted death cases, particularly after sudden or otherwise unexpected deaths. The Jersey Assisted Dying Service should instigate their own bereavement support service to safeguard services for those not involved in such cases.

Para 64 requires the doctor to only have been fully registered for 12 months. These doctors will be very junior and while they may fulfil the competency framework of a limited training programme, their broader experience of clinical practice, disease progression, human relationships and family dynamics will be far too immature to ensure they can take on the roles envisaged. Clinicians should be at least 10 years post-registration. It will be important that a clinician with **expertise in the specific condition** has seen the person requesting assisted death as there may be reversible conditions that have been missed, misinformation about the probable course of disease and support that the generalist doctor is not aware of.

All practitioners in Jersey Assisted Dying Service should be subject to supervision for their mental wellbeing. The service should not be remunerated in such a way that it attracts doctors away from other clinical areas and thereby jeopardises the health care of other patients.

## Assessment processes

There are major deficits in the proposals over the assessment process. It is essential that it is audited from real-time recording of the consultation. This can be undertaken using a body worn camera as worn by police, ambulance personnel and some emergency medicine staff in resuscitation procedures. The widespread use by the police and ambulance personnel has shown that confidentiality is not jeopardised. Such systems protect all parties from subsequent allegations and would allow the quality of the consultation to be audited to ensure that the assessor did not provide leading questions or fail to pick up important non-verbal cues. Specific steps must be laid out through which the diagnosis is verified, mental capacity is assessed by someone appropriately trained, all reversible causes of suffering have been identified and options discussed with the person, and that processes are in place to detect coercion.

Hourglass' survey in 2022 identified that 1 in 5 people over the age of 65 years have been affected by abuse, that most (37%) is financial abuse, 33% is psychological (often coercive control), and 21% is neglect. 83% of abuse occurs in the person's own home – doctors are very poor at detecting these main types of abuse. In part this is because they cannot normally ask questions about financial and other affairs, but also because the victim is usually very reluctant to disclose that their own child or grandchild is perpetrating abuse.

## Assisted dying process

The short **cooling off period of 14 days (74)** fails to recognise the **fluctuating nature of a wish for death over weeks and even years**, as many people say they are glad they are still alive when supported out of those times of despair and when they realise they are still of value and of worth despite being ill.

Indeed, in many illnesses, some symptoms or the effects of progressive disease can take more than a fortnight to resolve. **The proposed reflection period would prevent a person from reassessing their wish to die when symptoms had settled.** In the context of someone who has been alive for at least 18 years, and given the gravity of an assisted death request, 14 days is a drastically insufficient time-frame for reflection.

Furthermore, no assessment or interaction with doctors pertaining to the assisted dying process should take place during the period of reflection. **The current proposals do not allow for true, sufficient, independent reflection,** given the ongoing assessments that would be taking place in the 14 days.

Paragraph 76a suggests that 14 days would not “unduly extend suffering”. Not giving assisted suicide is not the same as prolonging suffering. Describing it as such gives the impression that a doctor is harming a patient by “forcing” them to live and would give undue pressure to complete an assisted death as soon as the 14-day period is over, rather than give as much reflection time as necessary. During the 14 days all measures should be focused on ensuring comfort and dignity.

If a person is about to die anyway, what benefit is brought on by taking away their life? Moreover, if they lose decision making capacity to consent, that means they also lose decision making capacity to withdraw consent, so reducing the reflection period opens the door to coercion and non-consensual deaths.

The proposals mention that Canada doesn’t have a reflection period, with the rationale that by the time a person has made a request they have already decided on their wish to die. There is no evidence provided for that statement. Those who have given careful consideration will have registered in advance with Jersey Assisted Dying Service. **A desire for death usually fluctuates and can be dependent on the care received<sup>12</sup>.** No assumptions should be made at all about a person’s request. Timeframes add a layer of safety to allow due consideration of the major decision to end life prematurely and allow for a therapeutic response to a therapeutic intervention.

Paragraph 77 states that simple regulation in the future can be made for the timeline to be reduced. This is an explicit proposal that will open the door for reductions and eventual removal of reflection periods. This should be removed from the proposals and only primary legislation, not regulations, should be able to shorten timeframes.

#### Information and referral

The imbalance between patient and doctor (84) means that the line between encouragement to suicide and an open discussion about options is entirely blurred and cannot be safeguarded against.<sup>13</sup> In the doctor patient relationship, there is an inherent hierarchy and advice about a course treatment is often requested by the patient. **A doctor raising assisted dying as a “treatment option” is perceived as suggesting that the patient should consider ending their life, with a subliminal message that what lies ahead is so terrible that the patient would be better off dead. Assisted dying should be entirely separate from healthcare to protect the doctor-patient relationship, leaving the patient the free choice to seek Jersey Assisted Dying Service, and removing the risk of subliminal coercion by the doctor.**

Guidance on having conversations (para 85) will not stop coercion. Licensing professionals to suggest assisted dying opens the doors to coercion. There is no safeguarding of the context in which a doctor might suggest assisted dying, for example in cases of despair or to cover up clinical error.

The suggestion that Jersey should follow the Canadian model is inherently dangerous (para 86). Doctors should not be allowed to initiate discussion of assisted death, as it results in a rapid increase in premature

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<sup>12</sup> Downman TH Hope and hopelessness: theory and reality. J R Soc Med 2008; 101: 428–430. DOI 10.1258/jrsm.2008.080193

<sup>13</sup> Shastri A et al Recognition and treatment of depression in older adults admitted to acute hospital in England. *Clinical Medicine* 2019; 19(2): 114-8. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC6454375/>

deaths, often for reasons of chronic illness aggravated by social isolation or financial hardship.<sup>14</sup> The problem of language as a barrier to Jersey Assisted Dying Service information will require all literature to be bilingual in English and Portuguese with the option of Jersey Assisted Dying Service provided translators when the person initiates contact with the service. The service should take place outside the remit of “health and social care”.

## Care navigator

Paragraph 88 inadequately sets out what information will be given to a person – it should not just include the principle of ending life, but the processes, potential complications, and the details of what the assessments will involve.

There are no care navigators routinely provided for other situations in health and social care, although in some cases a professional may advocate for them to receive the support, treatment or intervention they require.

However, the proposed care navigator will be coercive by steering a person through the system. It does not allow the person freedom to exercise their autonomous choice. Dignitas is a service outside Swiss healthcare and those who are determined to end their life approach Dignitas. The States of Jersey should not provide persons to steer its citizens towards an early death.

## First request

It is not clarified in the proposals (para 91) how an electronic request is verified. What classifies as a clear and unambiguous gesture of confirmation? Mental incapacity is often commensurate with lack of communication. For this reason, all requests must be verbal (independently witnessed) or written.

Paragraph 96 says that a person may discontinue the process, but does not state what help a person is given to change their minds? **The doctor is not simply a tool to be used to advance the patient’s medical wishes, but a health advisor who has expertise to offer in the course of the person’s best interests** – they are not morally neutral, and thus must be able to offer advice throughout the course of the process about alternatives.<sup>15</sup>

## First assessment

The proposals suggest that the first assessment should be an opportunity to explore the fears and anxieties leading to an assisted death request (100a). It is imperative that the person is required to inform those providing professional care to ensure conversations are had and that proactive action can be taken to mitigate any fears or anxieties which may *lead* to progressing an assisted death request. Jersey Assisted Dying Service must also be required to explore fears as soon as a person makes contact.

**Indeed, all care, information about support and other services should be received as a pre-requisite to an assisted dying request.** A person should not have to request an assisted death before those assessments of the adequacy of care provisions are made. In this way, carers and other health professionals should be informed of an assisted death request (102c) (as mentioned above): how can those who request assisted death because of failings in care change their mind or withdraw consent if the professionals involved in their care are unaware of a request, or indeed the inadequacy of the services they provide?

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<sup>14</sup> Alexander Raikin. No Other Options. Winter Essay 2023 New Atlantis. On line 16 December 2022.

<https://www.thenewatlantis.com/publications/no-other-options>

<sup>15</sup> Rutherford J et al. What would the doctor prescribe: physician experiences of providing voluntary assisted dying in Australia. *Omega- Journal of Death and Dying*, 2021; July 20. <https://journals.sagepub.com/doi/10.1177/00302228211033109>



The proposals outline that a doctor must not speak to family or other carers without the consent of the person. **In order to sufficiently assess the person's eligibility for assisted death, it is paramount that the assessing doctor is able to talk to people close to the person to gain further understanding.**

The proposals (105b, 107) state that the person must consent to the assessing doctor seeking opinions from specialists in order to complete assessments. Given this provision is made for the situations in which a doctor cannot make an assessment without such specialist opinion, if a patient does not consent, the process must stop. The proposals do not make this clear, but **a person should not be allowed to continue in the assisted dying process if determinations of eligibility cannot be made**, especially when consent is not given for specialist assessment in the cases of doubt.

Given assisted suicide involves the intentional ending of one's own life, there is likely to be a high component of suicidal ideation. Indeed, intolerable suffering, as a largely psycho-social phenomenon, cannot be assessed reliably on the basis of physical symptoms by an individual unqualified to examine mental health.<sup>16</sup> It follows, therefore, that **considerations of mental health and capacity should be assessed by a specialist such as a psychiatrist**, psychologist or other qualified mental health professional.

The proposals state that such experts should only be consulted in the cases of doubt, but given the integration between mental health, suicidal ideation and assisted dying requests, psychiatric assessments undertaken by mental health professionals should occur in every request.

The report written after the first request (para 110) should contain every detail of the assessment – status of care, provision of care, duration of care, ongoing plan, reasons for request, capacity assessment.

Paragraph 115 entitles a person to second opinion in the case where the first assessment has deemed the person ineligible. Given there has been an appeal, and a second opinion is being sought, **the second opinion assessment must be more rigorous**, given the issues that have arisen from an appeal about eligibility. In addition, the second assessment must take into account any appeals that were made on the basis that eligibility was not originally confirmed.

Regardless of whether a person is eligible or ineligible, the right care and support should be made available to them throughout the course of their illness.

## Withdrawal

For every opportunity for consent given to the patient, the offer of withdrawal must also be offered. As currently laid out, the proposals state only that the patient must give consent to move forward, but doesn't provide explicit opportunity for withdrawal. Such provision is necessary to prevent coercion by the doctor.

In the event of withdrawal (para 138), reasons for withdrawal must be noted for monitoring and reporting processes. If there is another request following a withdrawal (para 140), due consideration must be given to the fact there was a withdrawal and its reason.

## Consent to proceed

**The provision of consent to proceed is deeply problematic** (para 142). A doctor is supposed to uphold best interests – they cannot do this whilst euthanising a person who might have otherwise lived and has no capacity to respond or withdraw consent. What is a best interest when someone is supposed to be dying but isn't dying – to keep them alive or to actively bring about their death?

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<sup>16</sup> Select Committee on Mental Capacity Act 2005- Report of session 2013-14.  
<https://publications.parliament.uk/pa/ld201314/ldselect/ldmentalcap/139/13902.htm>

Under paragraph 144 - it is unclear what provision is put in place if there is no consent to proceed with ending the patient's life, but there are complications? Should the person be managed in a life-saving way (clear the airway of vomit etc) when the aim is death?

**The proposals under the "consent to proceed" section demonstrate that any assisted dying process should not be undertaken by doctors**, given the contradictions between upholding best interest decisions and procuring and administering death.

## Waiver of final consent

It is good that advanced decisions are not included in the proposals. The waiver of final consent, however, is problematic (para 148). The waiver of final consent still gives rise to the problems that arise from an advanced decision: **how can a determination be made that a person has not changed their mind about an assisted death if there is a period of time between a waiver of final consent and the assisted death taking place**. No assumption should be made that a person might not want to change their mind, regardless of how short the period of time in between a request and death.

Part of the process outlined in the consultation document is the emphasis on consent to move forward with the next step of the process, and that the process is entirely in the patient's hand. This is inherently undermined if provision is made for consent to no longer be necessary in the cases of persons who do not have capacity to give (and therefore, not give) final consent to an assisted death. It would enable serious cases of abuse and deep uncertainty in the reporting of assisted deaths.

Including this provision could lead to coercion, and would cover over any abuses. Consent to proceed should always be affirmed. Any action other than actively signalled agreement to proceed to death should be taken to indicate doubt and the process deferred or revisited at a later time. It is not safe enough to leave the extent of 'objection' to the judgement of onlookers. **Assumptions of consent, especially when it comes to the ending of life, must not be made.**

**Paragraph 151c could lead to pressure to waive final consent**; persons being told they are at risk of not being able to consent to assisted death, so they must do it before it is too late. This would make it very hard to judge if a person was pressured or coerced into assisted suicide based on of a medical prognosis that may be inaccurate.

Decisions relating to the withdrawal of treatment should not be made by doctors in the assisted dying service, but by palliative and other attending doctors in normal healthcare settings. Conflating treatment refusal with the assisted dying process would confuse the aims and understanding of end-of-life care in the public eye, and undermine the confidence of those not wishing an assisted suicide.

## Supporting opinions

It is concerning that the proposals do not require an expert in the person's condition to be consulted for Route 1 patients. **How can proper assessments be made of a condition in which an assessing doctor is not an expert?** Indeed, what assurances are there that an assessment, not undertaken by an expert, which deems a person eligible, has been made with full appreciation of the specificities of the given disease and how they may affect capacity and prognosis?

**At least one assessing doctor should be a specialist in the condition**, given that eligibility is connected to prognosis, and prognosis is dependent upon specialist knowledge about a disease.

Whilst anyone providing a supporting assessment may not be required to have undergone assisted dying training (159), it should be paramount that they understand the reason for which they are giving an opinion, which should impact their assessment accordingly.

If no determination can be made, and the person does not consent to a further opinion, then the request should be treated as ineligible. Given the gravity of the choice, the assumption should be ineligibility, not eligibility.

**To prevent abuses, any law should state that a coordinating doctor should not be allowed to judge a person eligible if any opinions he or she has received indicate that the person is ineligible** (para 164). Indeed, any disputes in medical opinion should be settled by an independent judge in a court or tribunal having examined the evidence. The current proposal allows a coordinating doctor to forego the advice offered by experts, which would allow abuses to occur and go unreported.

## Second formal request – written declaration

The ability to review and revise wishes in the case of a person who retains decision making capacity (para 186) discriminates against those who might want to review wishes but appear to have lost some capacity, whether or not they have signed a waiver of final consent. This is why assisted dying is problematic and opens a path to abuse, coercion, and involuntary euthanasia.

## Approval process

Concerns were raised with any court's involvement placing an unnecessary burden on the person requesting an assisted death and resulting in an unnecessary cost. However, something is only unnecessary if carrying it out has no valid benefit. **The courts can consider personal and social factors in an individual's life beyond that which is recorded in the clinician record** (and beyond those which doctors have access to) and are able to ensure that individuals do not fall victim to abuses of the system. This means the court can balance the rights of some against the protection of others. There is great benefit to society in having the court protect in this sphere and in this way. The majority of Citizen's Jury members (77%) recommended involvement of a Court or Tribunal (para 188); this should not be ignored, especially not for the reason of keeping up with other jurisdictions as quoted.

## Decision making

### Objectivity and subjectivity

Any assessment of 'time remaining' cannot be exact, as the consultation acknowledges. This is true in both R1 and R2 situations. By separating the two it is all too easy to presume it is complicated in the latter and easy in the former. Since it is often a terminal diagnosis which is the trigger for an assisted death, the need to consider the prognosis as accurately and as carefully as possible is significant. Either consciously or unconsciously, a doctor may feel pressured to alter their prognosis to qualify the individual for an assisted death. The participation of a court or tribunal provides protection against this and should be encouraged when it is matters of life and death at play. This rationale is provided by the consultation when it comes to R2 cases, but remains the same in R1 cases. As in R2 cases, there is no remedy for a faulty assessment in R1 cases unless the court is involved and can provide such a remedy.

**To provide these much-needed safeguards the court needs to go beyond merely reviewing the doctor's confirmation. The court's assessment is otherwise already influenced by the doctor's bias. Instead, they need to approve or disapprove the assisted dying requests themselves, by objectively reviewing the same evidence that has been put in front of the doctor.** This points to the quality of the evidence put before the court being significant in the quality of a judgement, and therefore also safeguard, they are able to provide. For this reason, the relevant information should include oral statements from doctors, other health and social care professionals family and friends from the start and not just if the tribunal is not satisfied with the information initially provided. The medical member of the tribunal should not just have relevant experience but be an expert within the field. The person requesting the death must be heard and the process should

end if they don't give consent to the court to make the determination. Only if all these elements are realised can potential abuses of the system be spotted.

This safeguard provided by the court is even more significant given that under the current proposal the law will not provide a fixed framework to understand suffering through. Although suffering is subjective and does depend on a number of factors, the law is not easily swayed by this. It has defined 'harm', an equally subjective subject, as it has 'loss'. The law is not intimidated by the difficulties and complexities of human emotion but provides a much needed and clear overlay so that they can be properly assessed for legal purposes. Without this, eligibility for assisted dying will struggle to provide consistency and fairness and be influenced instead by subliminal biases of a doctor in an individual case.

With any framework created to define suffering, a fear of disease progression and deterioration should not move an individual closer to an assisted death. Instead, it should prompt conversations about care and the support available. It would otherwise be a capitulation and abandonment of the principles of care and care provision to allow the fear of pain to qualify someone for death.

## Appeals

Given that in medical disputes, private citizens and medical professionals (under the auspices of healthcare organisations) may initiate legal proceedings and appeal medical decisions made by doctors, it should follow that appeals may be made on the grounds of prognoses given by doctors, and the level of care that is or isn't being provided to a person requesting an assisted death. These grounds should be included, as well as those outlined in paragraph 244a and 244b.

With regards to the expiry of approval, whilst there may be risk that an expiry date may induce some pressure to end their life, it would provide an opportunity for a person to think carefully about whether or not to go ahead with an assisted death. **Moreover, if the eligibility criteria are based around unbearable suffering, an approval that is not acted upon throws doubt upon the "unbearableness" of the suffering.** Indeed, suffering that is unbearable should not be remediable by the palliation of approval (as described in 255c). Fear of suffering should not be seen as unbearable and certainly should not form the basis of a law. **The option to have an assisted death should not be given as a medicine - comprehensive, accessible, specialist palliative care should fulfil that function.**

Finally, if approval is given on the basis of a time-specified prognosis (less than 6 months), then a person who outlives the prognosis which contributed to the approval in the first place should have that approval nulled and voided, and be subject to reassessment if they wish. A person requesting an assisted death, for example, told they will die within 6 months, and remaining alive several months later should not be able to undergo an assisted death under the same approval. Approval should be made on the basis of a prognosis given at the time of the assessment, that, once outlasted, should give rise to reassessment.

An expiry date on approvals should, therefore, be put in place to protect against unnecessary deaths and deaths occurring from redundant assessments.

## Planning and Preparation

Hospitals have always been, and should remain, places of healing and restoration. Allowing them to become possible places for an assisted death undermines and contradicts their purpose. **A lack of distinction between places of treatment and places of deliberately ending life would undermine confidence in the hospital system both by the individual patient (when they witness assisted suicides on their ward) and by the population in general.**

The possibility of failure to die in an assisted death (para 276) must be addressed. There is no need for a health care professional to be present when the lethal drugs are ingested. The desired outcome is death, but supposing the patient vomits and starts choking or when fitting occurs? In such situations the healthcare

professional is expected to clear the airway etc, but in this situation this would resuscitate the patient. In the context of assisted dying the normal “care” that a doctor might show by managing a patient whose assisted death may be going wrong could be considered as harm and contrary to the patient’s wishes, with the doctor deemed to have failed to “care” for the patient. In Oregon nine patients have reawakened after taking lethal drugs, but did not proceed to a second attempt at assisted suicide. If a fatal injection had been administered as they awakened, that would have been contrary to their wishes following their first attempt, **In this scenario, the line between that which constitutes harm and that which constitutes help becomes very complex, and demonstrates again that assisted dying should not take place in healthcare, as it contradicts and manipulates the medical profession’s duty of care.**

## Assisted dying substance

While much is made in the consultation about the holding of substances securely, which is to be supported, little is made of which substances are to be used. **In other jurisdictions, the lethal drugs used have never been subject to proper scientific scrutiny.**<sup>17 18 19</sup> Previously, large doses of barbiturate were used, but a shortage of supply and escalating prices have meant different drug combinations are now being tried to induce sedation with toxic levels, precipitating a heart arrhythmia and death by asphyxia. In Oregon, a mixture of four different classes of drug have been used over the last seven years, but have resulted in longer median times to death.<sup>20</sup>

In the Oregon reports, information on complications is only reported when a physician or other health professional is present at the time of death. These reports, from 42% of Oregon’s assisted deaths, record a complication rate of 6.3% over 23 years, with a complication rate of 8% in 2021.<sup>21</sup> This rate suggests a different picture to the ‘idealised death’ portrayed by those campaigning for such legislation.

The suggestion of pharmacy training is positive, although guidelines for this training need to be published in advance so they can be scrutinised and strengthened by a range of stakeholders. There is currently no indication that this will be the case. Avoiding drug error by the wrong patient being given lethal drugs will be decreased if the drugs can only be supplied to a patient in their own home.

## End of Life

The proposals state (para 290) that if the person “demonstrates a refusal or resistance to the administration of the substance by words, sounds or gestures” the process will end, regardless of whether there is a waiver of final consent. It also says that reflexes and involuntary movements would not constitute refusal.

**This gives rise to several problems.** Firstly, resistance may indicate grief, pain or fear, despite the presence of consent. Wincing or struggling in pain may not constitute a withdrawal of consent (particularly if someone has requested assisted dying **because** of their pain). Thus, resistance may be hard to distinguish. Secondly, given that in other circumstances (such as initially requesting assisted dying) gestures would constitute approval/consent (para 91), it seems inconsistent that certain gestures as laid out in para 290 should be disregarded or assumed to be reflexes.

This raises the issue that gestures are hard to interpret, particularly in the case where someone cannot verbally communicate or has lost decision making capacity. Gestures which signify refusal should be acted on

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<sup>17</sup> Smets T et al. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ*, 2010; 341: c5174. <https://www.bmj.com/content/341/bmj.c5174.short>;

<sup>18</sup> Raus K et al. Euthanasia in Belgium: shortcomings of the law and its application and of the monitoring of practice. *Journal of Medicine and Philosophy* 2021; 46: 80-107. <https://academic.oup.com/jmp/article-abstract/46/1/80/6118631>;

<sup>19</sup> Kotalik J. Medical assistance in dying: challenges of monitoring the Canadian program. *Canadian Journal of Bioethics*, 2020; 3(3): 202-9; <https://www.erudit.org/en/journals/bioethics/1900-v1-n1-bioethics05693/1073799ar/abstract/>

<sup>20</sup> Worthington A, Finlay I, Regnard C. Efficacy and safety of drugs used for ‘assisted dying’. *British Medical Bulletin*, 2022, 1–8 <https://doi.org/10.1093/bmb/ldac009>

<sup>21</sup> Oregon Death with Dignity Act, 2021 Data Summary

– but identifying the line between involuntary movements, movements which signify pain but in keeping with consent (like wincing under a voluntarily-taken cold shower) and actual movements communicating refusal are blurred. In cases of assisted dying, these determinations cannot be mistaken.

The proposals state that the administering practitioner does not have to be in the same room as the person while they take the substance (294b). This would lead to grave oversights and gaps in the data collected in reporting. **The practitioner should be in the same room to monitor the process, the person and any complications.**

Finally, it is a dangerous assumption to state that supporting self-administration would be an “extension of care” (para 295). There should be clear regulations set out as to who, if anyone, the person consents to have to help them administer the lethal substance, should the need arise.

## After assisted death

If a change in the legality of assisted dying aims not only to change the law but also to reduce stigma around death and dying, it needs to do so not by hiding its reality but by proclaiming it openly. Assisted suicides should be recorded as such.

While the law will be legalising assisted dying, it is not seeking – nor should it seek– to change the definition of ‘suicide’, as this would have far-reaching consequences beyond those which have been consulted on. **For this reason, the explicit cause of death should be labelled as ‘suicide’ since it is the intentional ending of one’s own life.**

Aside from the details of reporting in individual cases, transparency in data publication is significant for medical research. Data in public documents, including the MCFCD, should record assisted deaths as suicide by lethal drugs. Otherwise, **data on fatality rates and prognoses of diseases will be skewed: if the underlying condition is recorded as the cause of death**, the data on this disease, over time, artificially changes, making it hard for medical research to assess the nature of the disease.

Verification of death can occur in the persons own home after the person bringing drugs and removing any unused drugs has left the dead person’s home.

## Regulation oversight

**Regulation and monitoring need to be robust and maintain a high level of scrutiny**, particularly with regards to who it is that is being given, and is giving, lethal drugs and the background to that decision. Other countries have struggled in this area: 40% of cases going unreported in Belgium and data in Oregon being disposed of after a year. Since it is easy for forms of abuse or coercion to arise, in an area dealing with the difference between life and death, the need for strong regulation cannot be understated.<sup>22</sup>

**The law should prescribe the content of the administrative review to include care history, length of relationship with the administering doctors and a review of all the relevant assessment documents.**<sup>23</sup> This is to avoid a situation where completing the administrative review becomes a quick and meaningless tick-box exercise which fails to evaluate and assess the assisted death. The current proposals lack these details and equate to a poorly detailed legislative framework.

The same need for prescription arises in relation to the annual report that the Jersey Care Commission will be required to publish. This report must include an identification of groups of people with similar characteristics. This should be based on ethnic background, reason for requesting assisted dying,

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<sup>22</sup> Smets T et al. Reporting of euthanasia in medical practice in Flanders, Belgium: cross sectional analysis of reported and unreported cases. *BMJ*, 2010; 341: c5174. <https://www.bmj.com/content/341/bmj.c5174.short>

<sup>23</sup> Worthington A, Regnard C, Sleeman K, Finlay I. Comparison of official reporting on assisted suicide and euthanasia across jurisdictions. *BMJ Supportive & Palliative Care* 2022;0:1–7. doi:10.1136/spcare-2022-003944

complications, length of relationship to the doctor, drugs used and the length of time between ingestion and death. The JCC annual report should be published every year, including any years where there are no assisted deaths in Jersey. The latter situation provides an opportunity to review and assess the requests made and the assessments that have led to disapproval.

While the current proposal suggests that committee members may be experts in end-of-life care, medical ethics or social care, it must be assured that each member is an expert in one of these fields. Without this, the regulative process will not provide the necessary knowledge and expertise needed for a weighty review.

The need for careful consideration when setting out a legal test on capacity should not be underappreciated. The Mental Capacity Act 2005 came into being after a lengthy period of scrutiny and review and is regularly updated by a mental capacity forum which provides up to date assessment guidelines. It seems doubtful that a robust legal test addressing the same area can be made within 18 months. More detail needs to be provided on the test, who will be drafting it and the level of scrutiny that will be given to it. Significantly, any change within this area of the law will have consequences for mental capacity more generally and alter the law on consenting to harm - an already contested area of the law.

An example of the complexity of this area can be found in assuming that an assisted dying decision can be communicated through gestures or other means. These same gestures are interpreted as involuntary when it comes to the administration of drugs and not used to stop the assisted dying process at this stage. Consistency in what is seen to amount to 'capacity' is paramount.

## Final comments and conclusion

**A proposed bill is not going to solve deficits in care, but it may result in people not being offered the care that they need at the end of life.** Inadequate integration of palliative care with acute services leaves many patients unable to benefit from modern techniques - such as palliative radiotherapy or opioid rotation - which could benefit them. Advanced pain management techniques such as nerve blocks are also likely underutilised. Diverting resources away from these areas to involve staff in processing eligibility and providing lethal drugs will only worsen this situation.

The evidence in jurisdictions where assisted suicide and euthanasia has been in place for some time, such as the Benelux countries, reveals that many doctors have changed their minds and become critical of the reality of implementation. Doctors have reported a major emotional toll from such involvement. The health workforce is exhausted and demoralised; it does not have capacity or resilience to take on additional complex legal responsibilities to end life when all efforts during the pandemic have been to enhance and protect quality of life, while accepting the inevitability of death.

Recent evidence from Canada has revealed difficulties in monitoring an assisted dying service.<sup>24</sup>

**It is our concern that sufficient safeguarding cannot be achieved in Jersey's current health and care system to make an assisted dying law workable safely, and that the proposals have been arisen through fear and a reaction to deficits in care. We suggest there has been inadequate consideration of the factual evidence that points to the inherent dangers, particularly recent evidence for other jurisdictions.**

## Route 2

The track 2 proposals should be abandoned completely. Suffering is a complex subjective experience with many interacting domains (physical, social, psychological, grief and loss, anger, loneliness, poor self-worth, spiritual issues, social and financial problems, etc.). This proposal destroys Jersey's recent suicide prevention

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<sup>24</sup> J Kotalik. Medical Assistance in Dying: Challenges of Monitoring the Canadian Program *Can J Bioeth / Rev Can Bioeth*. 2020;3(3):202-209

initiatives, allows Jersey to abandon its developing mental health services and will abandon any meaningful rehabilitation and support services.

**Living and Dying Well**

**10<sup>th</sup> January 2023**