

# Assisted dying in Jersey: submission to consultation

Response from Christian Medical Fellowship, January 2023

## Introduction

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

## Background to Consultation

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

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

- a) that a new Assembly was elected in June 2022, and it is a constitutional principle that no government can bind its successor. Has the 2021 decision been tested in the new Assembly?
- b) that many citizens, possibly including Assembly members, having considered these proposals, may conclude that they cannot be safely implemented, and that the original ‘in principle’ decision should therefore be re-visited
- c) that the Proposals document makes significant changes in terminology from that approved by the States Assembly. For example, the Final Report of the Citizen’s Jury in September 2021 excluded ‘mental conditions’ from eligibility criteria by a large majority. Discussions at the time considered dementia but excluded it on safety grounds. Yet the current Proposals have excluded dementia from ‘mental conditions,’ thus including it in the list of eligible criteria. **This is a major change, not approved by the States Assembly.**

**The Proposals refer to ‘tolerable’ alleviations – a thoroughly subjective notion – without any objective criteria to guide those making eligibility assessments.** This is similar to the concept of ‘unbearable suffering’ used in Belgian law, where it has been associated with a one-hundred-fold increase in deaths by euthanasia between 2004 and 2021. As the Belgian Federal Control Committee has itself stated: *‘The unbearable nature of the suffering is largely subjective and depends on the patient’s personality, ideas and values.’*<sup>1</sup>

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<sup>1</sup> Federal Control Committee, First Report, 2004, p16.

## Section 2. Principles

### Definitions

This section begins by stating that “*Assisted dying is not the same as suicide*” (s2.11, p11). This is simply to deny reality. Suicide is defined as ‘the act of taking one’s life.’<sup>2</sup> Assisted dying simply means receiving assistance to take one’s own life. It is disingenuous to imply that there is a substantive difference between the terms suicide and assisted dying. It’s disappointing that the Government of Jersey have adopted the misleading language used by lobby groups seeking a change in the law.

To most people, the term ‘assisted dying’ suggests ‘providing hospice-type care to people who are dying’ or ‘giving people who are dying the right to stop futile life-prolonging treatment.’ It is not generally understood to mean the giving of a lethal dose. Only 42% of those questioned in a July 2021 UK survey realised that it refers to giving lethal drugs to a patient to end their life intentionally.<sup>3</sup>

The Government of Jersey is proposing that both assisted suicide and euthanasia be legalised. If the proposals become law, it is very likely that, as in Canada, the overwhelming majority (99%) of assisted deaths will be acts of euthanasia, where lethal drugs are administered by a doctor or nurse.<sup>4</sup>

## Section 3 Eligibility

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

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

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

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<sup>2</sup> ‘Definition of Suicide.’ 1985. Edwin Shneidman. John Wiley and Sons Inc.

<sup>3</sup><https://www.dyingwell.co.uk/wp-content/uploads/2021/09/Survation-Assisted-Dying-Survey-July-2021-Summary-3.pdf>

<sup>4</sup> ‘Worries grow about medically assisted dying in Canada.’ World Report by Paul Webster. *The Lancet*, September 2022

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

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

On p. 14 the report states that *‘conditions such as dementia, which are conditions of the brain as opposed to mental or psychiatric illness, would fall within the physical conditions criteria’* and thus be eligible criteria for those who have capacity. This would, of course, capture a large cohort of people, as dementia is now so commonly diagnosed and increasingly so in the early years of its expression when capacity is retained. The fearful prospect of losing independence, control and capacity, and associated concerns about ‘loss of dignity,’ or ‘becoming a burden’ to loved ones and to healthcare services, can be experienced as ‘intolerable.’ We are concerned lest many people, depressed following a diagnosis of dementia in its early stages, feel coerced by their fears for the future into applying for assistance to die. Commenting on the 2013 figures for assisted dying in Oregon,<sup>5</sup> Baroness Sheila Hollins, former president of the UK Royal College of Psychiatrists, stated: *‘Researchers have found that some patients who have ended their lives under the terms of Oregon’s assisted suicide law had been suffering from clinical depression. Depression impairs decision-making capacity; it is common in elderly people, and it is treatable. But in some cases in Oregon, it has not been diagnosed by the doctor who assessed the patient’s capacity and prescribed lethal drugs. Oregon’s law requires referral for psychiatric examination in cases of doubt but in some cases that has not happened.’*

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

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

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<sup>5</sup> Levene I, Parker M. Prevalence of depression in granted and refused requests for euthanasia and assisted suicide: a systematic review. JME 2011;37:205

amenable to medical treatment. We believe there is a better way to deal with the problem than by eradicating the patient.

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

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

## Palliative care

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

**By legalising assisted dying, the incentive to invest in palliative care will be reduced rather than increased.** *'Evidence shows that palliative care and 'assisted dying' do not, and cannot, co-exist harmoniously. They do not rise and fall together because they are not complementary but are diametrically opposed both in theory and practice. One can truly flourish only at the exclusion of the other.'*

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

*A similar pattern of diminution in palliative care has been observed since 2012 in the Netherlands, where investment is a third less than in the majority of European countries which prohibit assisted death. The same has occurred in Belgium since 2008 where promised increases in palliative care failed to materialise while the workload in doctor-assisted deaths climbed incrementally, sparking*

*mass departures of palliative care specialists angry that their units were being turned into 'houses of euthanasia' and their functions reduced to preparing patients and their families for lethal injections.*<sup>6</sup>

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

## Ethical concerns

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

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

The quotient of compassion in the caring professions and respect for human life in society in general would inevitably ebb.<sup>7</sup> Little wonder that organisations representing disabled people are among the most vociferous opponents of these proposals. It is our conviction that the calibre of a civilised society can be measured by the investment it is willing to make in the care of its most vulnerable members.

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

The long-term effect on doctors and nurses themselves could be equally damaging. They could become hardened to causing death, and even begin to see their most vulnerable patients as 'disposable'.<sup>8</sup> Such patients might then decide not to ask for medical help, for fear that they be encouraged to consider assisted dying by doctors whom they feel they can no longer fully trust.

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

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<sup>6</sup> Caldwell S. Palliative care and assisted dying – never the twain shall meet. Published in Conservative Woman, 19 November 2021. <https://www.conservativewoman.co.uk/palliative-care-and-assisted-dying-never-the-twain-shall-meet/>

<sup>7</sup> Wyatt J. Matters of Life and Death. Nottingham, England: IVP, 2009 (2nd Edn):207

<sup>8</sup> Keizer B in Ross W. Dying Dutch: Euthanasia spreads across Europe. Newsweek, 12 February 2015

day. It was terrible.” But he said that the second case was much easier and the third case – I quote – “was a piece of cake.” We found that very chilling indeed.<sup>9</sup>

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

## Section 4: assisted dying service

- **A ‘voluntary, settled and informed wish’**

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

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

- **Family involvement**

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

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<sup>9</sup> McColl I. Lords Hansard, 6 June 2003: Column 1681

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

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

- **Conscientious objection**

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

- i) *The assisted dying law will state that no-one can be compelled to **directly** participate in the assessment, approval or delivery of an assisted death*
- ii) *However, there may be certain elements of a person's job that may relate **indirectly** to assisted dying. A right not to participate in these indirect tasks would not be covered by a conscientious objection clause*

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

The GMC recognises that onward referral brings with it moral complicity. To coerce a doctor (or any person) to act against their conscience is unethical, causing moral injury and harm. The World Medical Association has recently voted to protect conscientious objection for medical personnel concerning assisted suicide and euthanasia by excluding a provision that would mandate 'effective referral' in its International Code of Medical Ethics.<sup>10</sup>

This is not true simply where involvement is direct. The same complicity and moral harm results from indirect involvement of all kinds, whether for medical, nursing or supporting staff. **The issue should not turn on the threshold of involvement but on the threshold of objection.** For example, one person's conscience would be troubled by providing administrative support for appointments with doctors assessing eligibility for assisted dying. For another, whose conscience is calibrated differently, only direct involvement in the delivery of the dying substance might trigger objection. People vary in the thresholds at which they experience moral complicity and thus moral injury. It is simply not possible to draw up tidy categories – these activities represent 'direct' involvement and thus qualify for conscience rights to be respected, whereas those activities represent 'indirect'

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<sup>10</sup> <https://www.wma.net/policies-post/wma-international-code-of-medical-ethics/>

involvement and do not qualify – and we suggest that no survey will be able to draw lines that are workable in practice. **It is our view that nobody should be required to participate in any related activity that offends their conscientiously held beliefs, religious or otherwise.** To coerce such involvement would contravene human rights legislation<sup>11</sup> and is unacceptable.

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

1. a **statutory** right of conscientious objection be included, that will apply equally to all healthcare professionals, and cover both direct and indirect involvement, rather than relying on the guidance published by professional regulatory bodies
2. an **institutional** right of conscientious objection, so that individual hospices etc can decide not to provide assisted dying, without risking their funding. If this is not present in draft legislation, it would place an intolerable strain on the ethos of many existing services

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

Reflections on the dying process as outlined:

- The proposals, as they stand, envisage a scenario where one Administering Practitioner (AP) visits the chosen location of the person seeking assistance to die. It is quite likely that family members, and possibly even friends, will be gathered there, in a state of high emotion. We suggest that a minimum of two APs should be in attendance
- The barbiturate cocktail is unpleasant to take orally, and may be regurgitated, or simply not fully effective. The common misconception is that the patient will fall asleep quickly and die within minutes. The reality is often different. It may take much longer before the patient dies, and sometimes they do not die following the prescribed dose. These are very distressing scenarios, for the patient if still aware, and especially for the family. It is not clear from the Proposals document how the AP should respond in these very difficult situations. Under para 296 the AP is told to stay with or nearby the patient until they die but no direction is given if they do not die. We are simply asked to accept that *'Detailed protocols will be developed should an unexpected medical event occur.'* Whatever those protocols look like, we suggest that no AP should be expected to cope alone in such circumstances. Again, **we recommend that a minimum of two APs be in attendance as a matter of course.**
- CMF welcomes the proposal that the Death Certificate would reference the administration of the assisted dying substance as the cause of death, both in the interests of transparency and to enable accurate audit and review processes
- We also welcome the proposal that the Jersey Care Commission (JCC) provide independent regulatory oversight of the Jersey Assisted Dying Service and any internal review and audit procedures. However, we are not aware that the JCC has any experience of regulating community services in Jersey, so we are sceptical of their capacity to delivery on this aspiration.
- We note that, as yet there is no HCS Service Delivery and Assurance Board, no Assisted Dying Service, no training programmes, clinical protocols or clinical governance or complaints procedures, let alone an Assisted Dying Review Committee that will be charged with the

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<sup>11</sup> <https://www.equalityhumanrights.com/en/what-european-convention-human-rights>



responsibility of reviewing every assisted death. Should 'assisted dying' legislation is passed in Jersey, **we strongly appeal that it should not come into force until after all the boards, commissions and committees involved in audit and review are up and running.**

- There is clearly a danger that an administrative review process amount to little more than a box-ticking exercise. Alongside the administrative review procedures, we ask that urgent consideration be given to the development of clinical review processes, where independent physicians (not involved clinically with assisted deaths) are given the mandate to monitor and audit the clinical pathway in every case. We suggest this is necessary for the development of public confidence in the service and should include the right of family members to register their concerns directly with clinicians, before and/or after the death.

RJT January 2023