



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.¹ My area of research specialisation is in health law, in particular the law and philosophy of assisted death and end-of-life decision-making.² I was an expert witness for the Jersey Assisted Dying Citizens' Jury in 2021, presenting on legal eligibility criteria for assisted death.³ I am responding in my capacity as an academic expert in this area.⁴

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).

A. Executive summary

My consultation response contains 10 key recommendations, summarised here.

A.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.

A.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.

A.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.

¹ <https://www.ucl.ac.uk/laws/>

² 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>.

³ See presentation [video](#) (YouTube) and [slides](#) (Govt of Jersey website).

⁴ UCL has no institutional position on the morality of or the legalisation of assisted death.

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 o[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.⁵

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**

⁵ 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).

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.⁶

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:

- (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 action⁷—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;

⁶ Jersey Capacity Law 2016, s 5(1)(c).

⁷ Anthony Skelton, Lisa Forsberg and Isra Black, 'Overriding Adolescent Refusals of Treatment' (2021) 20(3) Journal of Ethics and Social Philosophy 221-247.

- 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.⁸

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.

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.⁹ **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.¹⁰ 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,¹¹ as well as professional guidance,¹² to provide—supportive care/symptom control while the patient is dying. Moreover, **the life-shortening effect of best practice care at**

⁸ Priscilla Alderson, 'Competent children? Minors' consent to health care treatment and research' (2007) 65(11) *Social Science & Medicine* 2272-2283.

⁹ 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.

¹⁰ 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.

¹¹ See eg *R (Oao Burke) v General Medical Council* [2005] EWCA Civ 1003.

¹² See General Medical Council, *Treatment and care towards the end of life: good practice in decision making* (n 9).

the end-of-life is yet to be demonstrated,¹³ 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.¹⁴ 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 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),¹⁵ 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**

¹³ 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.

¹⁴ In these latter cases, doctors may be described as participants in a course of conduct that shortens life.

¹⁵ 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'.

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 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.

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