

Terminally Ill Adults (End of Life) Bill: Questions on the Bill

Note:

1. These questions have been prepared by Alex Ruck Keene KC (Hon) on the Bill as presented to Parliament on 11 November 2024. They are materially the same as on the annotated version to be found [here](#), but are set out this way for those who find it easier to read the questions in sequence.
2. All of these are questions which I would suggest Parliament needs to consider to ensure that any law passed is good law. In this context, some might find to be useful as a stress-test for interrogating the proposals the work of David Goddard, to be found via his website [Making Laws That Work](#).
3. For wider observations about the context of the Bill and a comparison with the approach being taken in Jersey, some might find this [post](#) I wrote of some use. For thinking through arguments for and against assisted dying / assisted suicide, some might find this [video](#) of some use.

All references below are to clauses in the Bill

Clause 1(1)(c): what consideration has been given to the operation of Articles 8 and 14 ECHR as regards the prohibition of those who are ordinarily resident elsewhere in the United Kingdom from accessing assistance with dying?

Clause 1(2)(b): Note: the reference to the person making the decision that they wish to end their own life voluntarily and has not been coerced or pressured by any other person into making it focuses on external coercion / pressure. It does not address the situation where the person has internalised (for instance) a feeling of being a burden to others. Query: what consideration has been given to identifying and responding to such internalised pressure? Or is it outside the scope of the Bill (and, if so, should this be made express)?

In clause 2:

- Is a person considered to be terminally ill if they have a chronic condition but decline further treatment, such that their death in consequence can reasonably be expected within 6 months?
- What consideration has been given to the operation of Articles 8 and 14 ECHR as regards the argument that excluding those who wish assistance but who are not terminally ill (including those who wish it because of suffering caused by mental disorder) is discriminatory? Even if there is no obligation under the ECHR to provide for a framework for assistance with dying, what consideration has there been given to the question of whether, if one is set up, it has to be set up in a non-discriminatory fashion?
- In light of Kim Leadbeater's clear [position](#) that "eating disorders are absolutely not within the scope of the bill," what, if any, steps are required to ensure that anorexia (or severe malnutrition consequent upon anorexia) are not considered as potential terminal illness as appears to have been the case in Oregon (see the Death with Dignity Act 2021 data).¹

Clause 3: Given that capacity is defined by reference to the Mental Capacity Act 2005, does the presumption of capacity apply? And are doctors involved under a duty to support the person to make the decision to end their life? For more on these issues see [HSC-Committee-CLADD-Research-Group-evidence-January-2023.pdf](#)

Clause 4(4): In relation to initial discussions with registered medical practitioners, does 'explain to and discuss' cover 'recommend' in relation to e.g. counselling or treatment? And what should the response be if the person declines to accept any recommendations made as regards available

¹ Which lists under "underlying illness, other illnesses" as including "deaths due to anorexia, arthritis, arteritis, blood disease, complications from a fall, hernia, kidney failure, medical care complications, musculoskeletal system disorders, sclerosis, and stenosis" (see page 14 of [here](#)).

palliative, hospice or other care (see also the question under clause 2 above in relation to the refusal of treatment).

Clause 9(2)(b): In relation to assessments by the coordinating and independent doctor, does ‘explain to and discuss’ cover ‘recommend’ in relation to e.g. counselling or treatment? And what should the response be if the person declines to accept any recommendations made as regards available palliative, hospice or other care (see also the question under clause 2 above in relation to the refusal of treatment).

Clause 9(2): In relation to the mandatory requirement to discuss with the person their wishes in the event of complications arising in connection with the self-administration of an approved substance, what is to happen if complications do ensue? Can the attending doctor provide medication to address those complications so as to bring about the person’s death? And, if so, how can they do that consistent with clause 18(8)?

Clause 9(3)(b) provides for discretionary (but not mandatory) referral in the case of doubt as to the person’s capacity.

- Why is there a difference between this discretionary duty and the mandatory duty to refer in the case of doubt as to whether the person is terminally ill (in clause 9(3)(a)), given that both are necessary criteria?
- This clause does not specifically address whether the starting point for the person receiving the referral would be that the person has capacity (i.e. would the presumption of capacity apply)?
- Would there be circumstances under which a psychologist or social worker be better placed to consider capacity? (And pedantically, “capability” is not a term used in English law in this area).

Clause 10(2). Query: is the coordinating doctor required to inform the second independent doctor of the reasons why the first independent doctor refused to make the relevant statement?

Clause 12.

- What level of judge is, in fact, required? Note this [interview](#) on 23 November 2024: “Leadbeater acknowledges in written correspondence after the interview that the bill does not specify it must be a High Court judge – under the Senior Courts Act, that technically means a district judge could provide the safeguard. However, she says, “from my discussions, the clear expectation is that the number of cases in the first few years of operation would be relatively small and this would certainly be a High Court judge”.”?
- Does the wording of clause 12(2) mean that the High Court is required to make the declaration if it considers that the person satisfies the criteria but is making the request because (1) they consider that they are a burden? Or (2) they are making the choice because they do not consider that they have access to suitable palliative care?
- In relation to clause 12(4),
 - will the procedure come at cost to the person making the application? And will legal aid be available?
 - will the hearing take place in public or in private?
- In relation to clause 12(5), under what (if any) circumstances, would the High Court be required to involve a person to argue against the application being made?
- Note in relation to clause 12(10), this would be an unusual provision in English law, because the Court of Appeal does not exercise a first instance jurisdiction - this would be directing the Court of Appeal to sit as a first instance court and hear evidence.

- In relation to clause 12(11), is there a route of appeal from the Court of Appeal to the Supreme Court? And what is an interested party supposed to do if they consider that the High Court erred in making the declaration?

Clause 15: in relation to signing by proxy:

- If “any other reason” for a person being unable to sign their own name is not intended to cover cognitive impairment (which is presumably the case), does this need to be made clear? how does clause 15 interact with clause 18?
- If a person is unable to sign their own name by way of physical impairment, are there any circumstances under which they can authorise a proxy to carry out the final act? If not, should it be made clear in clause 15 that such a person should not be allowed to start the declaration process?

Clause 18: in relation to the provision of assistance:

- How does clause 18 interact with clause 15? If a person is unable to sign their own name by way of physical impairment, are there any circumstances under which they can authorise a proxy to carry out the final act? If not, does this need to be clarified?
- In clause 18(7), where complications ensue, what, if any, steps may the coordinating doctor take? See the query to clause 9 above).

Clause 20: in relation to “approved” substances will have a very specific meaning, because there are (as far as I am aware) no drugs approved anywhere in the world specifically for purposes of ending life.

Clause 22: in relation to recording matters in medical records, is the reference in clause 22(1)(b) to the procedure failing limited to situations where the procedure fails to bring about death, or does it mean where complications ensue and further steps had to be taken by the practitioner?

Clause 23: What, if any, duty is a person under who does not wish to provide assistance? Does the person need to give reasons? And does it apply to a specialist who is being asked on referral under section 9? Does this clause and the other relevant provisions of the Bill need to be further clarified to meet the need to be further clarified to meet the BMA’s requirements for the service to be an ‘opt-in’ one, as set out in its [briefing](#) ahead of Second Reading?

Clause 26: In relation to the offences involving dishonesty, coercion or pressure: does this need to be clarified in light of the answer to the question above in relation to supporting decision-making capacity? I.e. at what point (if such is acceptable) supporting a person to have capacity to make a decision to request assistance constitute coercion or pressure to make the request?

Clause 30(1)(a)(i): How would such a code relate to the MCA Code, given that capacity is directly cross-referred to the MCA 2005?

Clause 32: Note: it is important to identify that this is a model which is not just about legalising assisted dying, but is about the active provision by the State of assistance, including as part of National Health Service.

- Under what circumstances would the Secretary of State be anticipated to make such regulations?
- Under what circumstances (if any) would it be anticipated that private providers be involved?
- If it is to be provided as part of the health service, does this imply that it is free to the person requesting assistance?

Note: the Jersey proposals may make a useful comparison in terms of implementation of an “Assisted Dying Service” : see <https://statesassembly.gov.je/assemblypropositions/2024/p.18-2024.pdf>

Clause 34: in relation to monitoring, should this should this include complications that have ensued upon administration of the approved substance?

Clause 35: in relation to the review of the Act by the Secretary of State, this is a macro-level review. Query whether there needs to be express provision for reviews of individual cases by an appropriate body if concerns have been raised about the operation of the provisions of the Bill in any given case?

Clause 41: in relation to extent, what, if any, relevance does the (non-binding) vote of the Senedd on 23 October 2024 have, given that the Senedd voted against against a non-binding motion calling on the Welsh Government to back the principle of assisted dying: [Plenary 23/10/2024 - Welsh Parliament](#)

24 November 2024