Terminally Ill Adults (End of Life) Second Reading Briefing: mental capacity

Introduction

This briefing is prepared by Professor Gareth Owen, Professor Alex Ruck Keene KC (Hon) and Professor Katherine Sleeman, all members of the Complex Life and Death Decisions Group (CLADD). CLADD is a King's College London based group with expertise in psychiatry, palliative care, bioethics, public policy and law. We are neutral as to whether assisted dying / assisted suicide should be made law. We are committed to the principle that it is for Parliament to decide. We are equally committed, however, to the principle that any law that is passed must function as a workable framework which protects the interests of patients, professionals and wider society.

In our broader briefing, we set out why the Terminally Ill Adults (End of Life) Bill ('the TIA Bill') as it stands is not good law. We have prepared a version of the Bill which remedies the key problems that we identify in that briefing. This briefing looks in more detail at the issue of mental capacity, the problems with the approach to capacity in the Bill, and our proposed amendments relating to capacity.

The policy intent and the problem

TIA Bill provides that eligibility for assistance under the Bill includes a requirement that the person has the capacity to decide to end their own life, applying the Mental Capacity Act 2005 ('MCA 2005'). The idea that the person needs to have the ability to decide for themselves is undoubtedly very important in this context.

However, the MCA 2005 was not designed to be a universal framework for determining capacity. It is primarily a workaround for the inability of a person to give consent to actions required to secure their health and social care needs. In the MCA 2005, the principles applying to and the test for capacity apply in a context where a decision can be taken on a 'best interests' basis for the person if they lack capacity. It is not obvious why they should apply in the context of the TIA Bill, where no such best interests decision could ever be made.

The MCA 2005 principles applying to capacity are:

1. *Principle 1: A person must be assumed to have capacity unless it is established that he lacks capacity.* This would mean that an inability to resolve a doubt about the person's capacity would require the assessor / Panel to conclude that they had capacity to decide to end their own life.[1]

2. *Principle 2: A person is not to be treated as unable to make a decision unless all practicable steps to help him to do so have been taken without success.* This would impose a duty to support the person to take the decision to end their own life.

3. *Principle 3: A person is not to be treated as unable to make a decision merely because he makes an unwise decision.* This would mean that a person is not to be treated as unable to make a decision to end their own life merely because their decision is unwise.

[1] Note: much of the debate in the House of Commons focused on the presumption of capacity in the context of a question of whether and under what circumstances it was necessary to seek further input as to the person's capacity. It is arguable that the Bill, as drafted, already makes this aspect of the presumption irrelevant because it contains multiple statutory requirements to consider capacity. This second aspect, which is arguably more fundamental, was the subject of much less consideration.

The test for capacity under the MCA 2005 is set out in s.2-3 MCA 2005. The Supreme Court has authoritatively confirmed that this means:

1. *Being specific about the decision that the person is being asked to take.* Our research has shown a number of different ways in which the decision in this context has been approached around the world. The Bill is clear that the decision is a decision to end own's life. The clarity of this position is welcome, not least because it reinforces that this is not the same as a decision to refuse life-sustaining treatment. However, whilst the clarity is important, it is necessary to be aware that this is a decision which has not previously been considered by the courts in England & Wales. It is therefore a new decision, both in statutory terms, and in terms of a body of case-law through which it can be approached.

2. *Being clear about information that the person needs to be able to process.* It is not clear what information is relevant to a decision to end own's own life.

3. *Asking whether the person can understand, retain, use and weigh that information, and communicate their decision.* Recent research shows that there are no validated tests which could be used to assist practitioners in assessing capacity to seek assistance in dying without further normative and empirical work. Further, preventing assessors asking why a person may be seeking assistance will inevitably limit their ability to assess capacity.

4. *If the person cannot process the information, showing that this is because of an impairment of or disturbance in the functioning of their mind or brain.* A person who cannot process information, but for no identifiable reason, will be deemed to have capacity to make the decision to end their own life.

5. *Assessing the person's capacity at the 'material time.'* This gives rise to two problems. The first is that the TIA Bill does not require specialist advice to be sought after the Panel has granted a certificate of eligibility, but where there may be doubts as to the person's capacity. The second is that there will be conditions where a person's decision-making capacity either becomes progressively more impaired, or fluctuates, such that, whilst they may have had capacity at all stages prior to the moment at which assistance is provided under clause 25, they do not have it at that point.

Amendments

The version of the Bill to be found here sets out a mechanism by which the policy intention – to follow the model of the MCA 2005 – can be made to work within the framework of the TIA Bill, including:

- Clarifying (in clause 3) that there is no presumption of capacity, such that it will be for the assessor / Panel to be satisfied that the person has the capacity to decide to end their own life.

- Clarifying (in clause 3) the information relevant to the decision to end one's own life.

- Making technical amendments in transposing in clause 3 the language of the MCA 2005 to make it fit within the scheme of the Bill.

- Clarifying (in clause 12) the assessment process for the coordinating and independent professionals, including requiring them to consult with others with knowledge of the person's circumstances who may have information relevant to their capacity. This would be expected in any complex assessment of capacity under the MCA 2005; the assessment of capacity under the TIA Bill is a paradigm example of a complex capacity assessment.

Peers may wish to note that the proposed drafting of the opening of the revised clause 3 is inspired by the drafting of a Bill in Hong Kong, which is one of the very few pieces of legislation of which we are aware which contains a statutory requirement for the positive consideration of capacity, applying a functional model akin to the MCA 2005.[2]

The proposed amendments do not address two issues:

1. What happens if the person cannot make a decision, but for reasons that may not be conventionally considered as impairment related. Of particular note here are forms of interpersonal coercion or pressure, considered in this research involving two of the authors of this briefing. We cannot identify a way in which to propose an amendment to address this issue which would not make the model of capacity fundamentally different to that set out in the MCA 2005, in circumstances where we anticipate that Parliament will wish to maintain consistency insofar as possible. Parliament needs, however, to be aware of the issue that we have identified here before reaching any final conclusion on the wording of the Bill. At a minimum, such a situation should be identified in any relevant secondary legislation and Code of Practice as a situation constituting 'doubt' for purposes of clause 12(6)(b), meriting specialist assessment.

2. What is to happen if a person either temporarily or permanently lacks capacity to make the decision to end their own life at the point of assistance being provided under clause 25. It may be that a person who has temporarily lost capacity comes back within the scope of the Bill through the passage of time. It would not be possible to make amendments to address a permanent loss of capacity without fundamentally changing the policy of the Bill. The Jersey legislation will take a different approach, by including a 'waiver of final consent,' to cater for the potential of a loss of capacity. This represents a different policy approach, and one with significant implications for those with dementia; very few people with dementia will come within scope of the TIA Bill as currently drafted, whereas the Jersey legislation builds in the potential for many people with dementia to make advance requests for assistance in dying.

Further information

For more detail about any of the matters set out above, please contact alexander.ruck_keene@kcl.ac.uk.

More information about CLADD can be found here.

Alex Ruck Keene maintains a resources page on the TIA Bill here.

[2] See clause 3 of the Advance Decision on Life-sustaining Treatment Ordinance (Ord. No. 30 of 2024). The Ordinance requires contemporaneous confirmation of capacity (in clause 12(3)(b)). The MCA 2005 contains provisions relating to advance decisions about treatment, which refers to the person having capacity, but has no requirement for contemporaneous confirmation of capacity, and does not therefore need to address the problem that the Ordinance and (in this context) the TIA Bill addresses.