Terminally Ill Adults (End of Life) Second Reading Briefing

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.

The Terminally Ill Adults (End of Life) Bill is not good law as drafted

Wherever one stands on the principle, we suggest that the Terminally Ill Adults (End of Life) Bill ('the TIA Bill') as it stands is not good law, as it:

- Does not appropriately delineate the cohort to whom it is intended to apply;
- Applies a test for determining their ability to seek assistance which is not fit for its purpose;
- Is unclear as to whether the provision of assistance constitutes treatment for the wider purposes of the medical profession;
- Does not appropriately address the place of palliative care;
- Does not facilitate multi-disciplinary consideration of the multi-faceted question of the person's eligibility until too late in the process;
- Provides for advocacy without clarity as to its scope, provision or purpose;
- Establishes an authorisation body – a Panel – which is both over- and under-protective;
- Does not adequately address the situation where a person experiences complications following the provision of assistance;
- Does not provide for appropriate monitoring.

This briefing addresses these key points, and is to be read alongside the version of the Bill to be found here. That version outlines how the Bill would look if it were properly to address these matters, as well as setting out a number of technical amendments required to enable the Bill to operate within the wider context of the law. We have, separately, prepared more detailed briefings on capacity, eating disorders, the preliminary discussion, multi-disciplinary consideration, and the Panel, which set out the issues and our proposed amendments.

The cohort

The Bill, as it stands, is caught between two competing policies. The first is to ensure that the scope is drawn as tightly as possible to only those who are 'truly' terminally ill. The second is centrality of choice. That choice must extend not just to seeking assistance, but also to refusing treatment that the adult no longer wishes, even if that treatment may have the effect of reversing the course of the illness or disease. There will be circumstances where it is not possible to reconcile those two policies.

Consider two common clinical scenarios. First, a man aged 80 who is diagnosed with stage 4 lung cancer. He is offered treatment (chemotherapy) that has a high likelihood of reversing the disease (i.e., of shrinking the tumour) and extending his prognosis. In light of the serious side-effects of chemotherapy, he decides to decline this treatment and to focus on his quality of life. Based on this decision he is assessed as having less than 6 months to live, and he requests assisted dying.

Second, a woman aged 70 who has been reliant on renal replacement therapy (dialysis) for 10 years. She decides to stop having dialysis because she no longer feels the benefits (living longer) outweigh the burdens (regular invasive tests and treatment). She is aware and accepting that without dialysis she is likely to die within days to weeks. She requests assisted dying.

It is unclear from the TIA Bill as drafted as to whether these two cases are eligible, because there are treatments which are either available (in the case of the chemotherapy) or already being delivered (in the case of the dialysis) that are doing more than simply temporarily relieving symptoms of an inevitably progressive illness or disease (S2(2)).

We do not propose amendments to the Bill to address this ambiguity because either way there would be fundamental implications, a dilemma we do not consider that it is our place to seek to resolve. Rather, we highlight that:

- Prioritising the tightness of the medical eligibility criteria would mean drafting the Bill in such a way that no person can take any steps to bring themselves within scope. The cost would be denying people the option of assisted dying if they decline potentially life-prolonging treatments, and of requiring people to have (often burdensome and painful treatments) they do not want in order to become eligible;
- Prioritising 'choice' would mean drafting the Bill in such a way that would mean that people with chronic conditions can take steps to bring themselves in scope. The cost would be allowing people - including people with conditions such as diabetes - the option of assisted dying by abandoning treatments.

A linked, but separate, issue arises in relation to eating disorders, which pose significant challenges for the drafting of the Bill given what we understand to be its policy intent of excluding eating disorders from eligibility. We address the complexities of eating disorders in this briefing here. Again, we do not propose amendments here, because this issue goes to core of the policy of the Bill. We note, however, that the insertion of clause 2(2) (concerning voluntarily stopping eating and drinking) is only tangentially relevant here, because at the heart of many of the most difficult dilemmas in the context of eating disorders is the issue of whether the person with the disorder is making voluntary (which includes, but goes beyond capacitous) decisions about eating and drinking.

Capacity

Eligibility for assistance under the TIA Bill includes a requirement that the person have that capacity to seek such assistance, 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, and simply making capacity for purposes of the Bill refer to that Act leads to some significant problems.

The amendments proposed to clause 3 of the Bill maintain the centrality of the Bill's idea that a person must be able to make the decision to end their own life, but do so by making the concept of capacity work within the context of the TIA Bill.

Treatment

The TIA Bill gives several key roles to medical practitioners (doctors) and includes the provision of substances which may be considered medical in nature (although whether support to access a pod containing lethal gases, as clause 25 allows for, would ordinarily be understood to be 'medical' is a question that Peers may wish to consider).

However, the Bill is silent on whether doctor involvement is a treatment involvement and whether the provision of lethal medical substances is a provision of a treatment. As we discuss in this article, and one of us has discussed at greater length in this article, conventionally doctors are professionals who give treatment, and fundamental to the concept of medical treatment is (any) intervention aiming to improve a patient's health or quality of life. But from a conventional medical standpoint patient health or quality of life are not intelligible in death.

Basic to the Bill is a power of personal choice it gives to eligible patients to obtain assistance to end their own life. For this reason and for the reason that assisted dying cannot improve a patient's health because the outcome is death, this briefing proceeds on the basis that a request for assisted dying is a personal choice concerning life and death rather than a treatment. Practical consequences follow from this position that include:

- Doctors do not have a duty to raise assisted dying with patients under their care who may be eligible (and there is no medical negligence for not raising it comparable to a failure to raise treatment options).
- Preliminary discussions with patients and multi-disciplinary assessments (including assessment of capacity) for patients seeking assistance must include information that assisted dying is a personal choice concerning life and death and not a treatment.
- Doctors acting as coordinating professionals, independent professionals, panel members or in monitoring roles are not acting in their conventional treatment roles. Their training must ensure they understand that their roles in the TIA Bill are different: to ensure that patients are giving valid requests for assistance and that the procedures around the provision of lethal substances are as safe as possible.

We propose amendments in relation to clauses 3, 12 and 25 to clarify that a request for assistance under this Bill is not a request for medical treatment, the provision of assistance for the purpose of a person ending their own life under this Bill is not the provision of medical treatment, and that doctors who are involved in the Bill are discharging professional functions under the Bill, rather than the role of a treating doctor.

Palliative care

Research shows that palliative care is effective at alleviating physical, psychological and other forms of suffering and distress, but many people who might benefit from palliative care currently do not receive it. When people with terminal illness do not access palliative care, this results in unnecessary suffering, fewer opportunities to discuss what is important to them, and care that is not aligned to their values and preferences. Importantly, palliative care can alleviate the wish for a hastened death. Thus, without input from palliative care specialists, some people who might otherwise choose to live will be assisted to die. Misunderstandings about palliative care are common, among both the public and professionals. Patients may decline the offer of a palliative care assessment because of a false understanding about what it is.

As we address in greater detail in our briefing on the preliminary discussion, *offering* a referral to a specialist in palliative care is not enough. We therefore propose an amendment to clause 5 to require that everyone who requests an assisted death should receive a palliative care assessment. This would help ensure that reversible forms of suffering are addressed, and would mitigate against current known inequality in access to palliative care.

Multi-disciplinary consideration

Determining eligibility to seek assistance in ending one's own life is inherently multi-faceted. That, in turn, means that multi-disciplinary consideration is vital. The Bill's sponsor has sought to introduce such a multi-consideration assessment at the Panel stage. This is, however:

- Too late: that consideration is required at the earliest possible stage,
- With the wrong people: by definition, members of the Panel could not be involved in the care and treatment of the person, and multi-disciplinary consideration should, where appropriate, include such professionals.

- In the wrong form: a court-like body is not a place for conversations of the kind required to enable multi-disciplinary consideration.

These matters, and our proposed amendments to address them, are explored further in this briefing here.

Advocates

At present, the provisions relating to independent advocacy are:

- Unclear as to whom they should apply.
- Unclear as to their purpose.
- Leave open the possibility that a family member or friend could be an independent advocate.

The amendments proposed to clauses 22 and 52 address all of these matters, so as to secure that those eligible for independent advocacy are supported by truly independent advocates who can serve as navigators for those requiring additional support (which might include additional support to understand options other than assistance in dying).

The Panel

The idea of a final body designed to provide confirmation that the person meets the relevant criteria is one that appears to be central to the policy of the Bill. However, as drafted, the Panel:

- Is unnecessarily complicated for cases clearly meeting eligibility criteria;
- Does not have the powers or the expertise to address more complex cases;
- Is not subject to an appropriate route of challenge to address the fact that a decision to approve an application, as well to refuse an application, may be wrong.

We address these matters, and our proposed amendments to resolve them, in this briefing.

Complications

The Bill as drafted places those seeking assistance and doctors in an impossible position if complications arise (which are recorded in up to 10% cases in Oregon), by requiring the doctor to be present, but preventing them taking appropriate steps in the event of complications. The proposed amendments to clause 25 seek to address this conundrum, although we note that they can only go so far consistent with the policy of the Bill (and the law of murder) that a doctor cannot directly administer a lethal substance. A doctor could therefore only provide medication or other treatment to seek to alleviate pain and distress caused by complications consequent upon the person themselves taking the approved substance. A person taking 'too long' to die could not, itself, be considered a complication, and a doctor could not take steps to carry through what they understood to be the will of the person in such a situation.

Monitoring

Annual reports are important mechanisms for identifying participation rates, reasons for participation, who is participating (in terms of both patients and practitioners) and patient safety including the drugs and drug combinations used to bring about patients' deaths. Transparent reporting of the practice of assisted dying is also essential to build public and professional trust in this new practice.

In considering this area, we have drawn on a 2022 paper published in BMJ Supportive and Palliative Care in 2022 by Worthington et at which examined the reporting in 16 jurisdictions where assisted suicide or euthanasia is legal. The paper highlighted the need to understand not just who has an assisted death, but who is deemed ineligible and why, to understand how safeguards are functioning. Concern around pressure on vulnerable groups warrants the detailed reporting of patient demographics. This is needed to ensure patient safety because it allows monitoring of trends to determine whether there is disproportionate participation by vulnerable or minority groups, and the reasons for their participation. Knowing whether patients have received care from hospice or palliative care services provides an understanding of whether patients have been provided with alternative end-of-life care options. Understanding the number of clinicians participating in assisted dying and their specialty is important to understanding both the willingness of clinicians to participate as well as how the clinical demand for assisted dying is being distributed across specialties and practitioners. Information on the drugs used in assisted deaths, and any complications, is critical in order to understand safety and efficacy of different drugs and drug combinations.

Importantly, strengthening data collection, reporting and monitoring will not make the process harder or more lengthy for the person requesting assistance. It just makes the system safer and stronger.

We have proposed a number of amendments to clauses 28 and 49 to address these issues.

Technical problems

The Bill as drafted has a number of technical problems which will have (inadvertent) consequences for other areas of the law. We have proposed amendments at a number of points in the Bill.

Service provision

We note, finally, that we have not addressed how assisted dying will be delivered as a service in this briefing. These matters raise complex policy questions, largely (and, it appears, deliberately) unresolved on the face of the Bill. We note, however, two points:

1. As the Bill stands, it is not possible for an organisation such as a hospice to decline to participate in the framework provided for in the Bill. Peers will no doubt wish to consider the balance between securing equitable access to those eligible for assisted dying, and the risk that hospices (in particular) will cease operating if they have an institutional concern about the delivery of assisted dying that cannot be assuaged.

2. The policy intention of the Bill, enshrined in clause 25, is to the effect that a person can choose to receive assistance in any place of their choosing. Combined with the requirement that a medical practitioner be present throughout, a significant challenge will be posed in supporting the presence of such practitioners in any setting other than a hospital or hospice, or designated 'assisted dying unit.'

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.