Terminally Ill Adults (End of Life) 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.

This briefing is prepared on the basis that the Bill that Lauren Edwards MP has announced she will bring forward in September 2026 is the same as the Bill previously sent to the House of Lords by Kim Leadbeater MP.

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') 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 appropriately address the interaction between suicide prevention and assisted dying;
- 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. We have, separately, prepared more detailed briefings on eligibility, capacity, eating disorders, the preliminary discussion, multi-disciplinary consideration, and the Panel, as well as a briefing explaining the difference (in clinical and legal terms) between refusing treatment and assisted dying.

When the Bill was before Parliament previously, we sought to set out amendments which would bring the Bill as close as it could be to good law: see this briefing here. However, it appears to us unlikely that it would be possible for those amendments (and those set out in our more detailed separate briefings) to be included in the current Bill given the way in which it is being progressed.

Further, and more fundamentally, there are areas where the Bill's internal inconsistencies, and its inconsistencies with the broader law, are simply not fixable by way of amendment. We highlight these below.

We therefore consider that the problems with the Bill are so great that the House of Commons should pause legislating on assisted dying/assisted suicide and take steps to establish an independent review to enable a twin-track process of (1) 'operationalising' the processes required; and (2) placing Parliament in a position to make an informed choice as to who should be eligible for assistance. We explain this in more detail in this article for

The House magazine here.

Eligibility

As we explain in more detail in this briefing here, the TIA Bill 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:

- 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.

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. This briefing, and this video, explain more about the problems. We draw Parliament's attention to the fact that the assisted dying legislation adopted by the States of Jersey (subject to Royal Assent) is based upon a 'bespoke' model of mental capacity which preserves its core features, but tailors them to be suitable for the task in hand.

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 the Bill allows for, would ordinarily be understood to be 'medical' is not an easy question to answer).

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 two of us have discussed in more detail here, 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. Classifying the provision of support to die as 'treatment' therefore strains at the conventional definition of medical treatment. It also gives rise to significant practical implications. In particular, if assistance is viewed as a treatment, then protections for doctors who do not wish (for whatever reason) to participate become irrelevant: just as a doctor could not conscientiously object to providing cancer treatment, a doctor could not conscientiously object to providing assistance under the TIA Bill framework if it is viewed as a 'treatment' for the person seeking assistance.

Service provision and compatibility with the NHS Act

As appears to have been recognised in the course of the debates about the TIA Bill, there is a fundamental incompatibility between the Bill and the aims of the NHS as set out in the NHS Act 2006 as it stands at present (in terms materially unaltered since 1946). We do not comment on how this incompatibility should be resolved but suggest that this reinforces the need for an independent review.

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.

The Bill is predicated on a policy that offering a referral to a specialist is sufficient. For the reasons set out in our briefing on the preliminary discussion, we suggest that this is not enough. But this is not a problem which can be addressed within the four walls of the Bill alone: only an independent review can properly address how the law should framed as to as to strike the right balance, and the right allocation of resources, between supporting access to palliative care and access to assistance in dying.

Suicide prevention

In significant part because the Terminally Ill Adults (End of Life) Bill represents the outcome of a sustained campaign focused on a single issue, it does not account for other priorities adopted by or imposed upon the State, including the prevention of suicide. This blog by Alex Ruck Keene identifies the legal problems that are caused in consequence given the State's obligation to protect life. We have not prepared amendments to address this issue because it raises fundamental questions of policy that can only be addressed by Parliament having regard to the entirety of the statute book, aided – we suggest – by the work of an independent review.

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. Leaving such consideration to the Panel stage (as it appears that the Bill will do) is:

- 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 are explored further in this briefing here.

Advocates

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 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, 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 further in this briefing.

Complications

The Bill 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. Under the Bill, the doctor could 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. Either the Bill, or the law of murder, must be changed.

Monitoring

Detailed reporting 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.

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

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.