Terminally Ill Adults (End of Life) briefing

Eligibility

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), along with Dr Rob Elias, a consultant nephrologist at King's College Hospital. 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.

We have prepared a number of briefings on the Terminally Ill Adults (End of Life) Bill, to be found here, alongside a version of the Bill including proposed amendments to make the Bill good law.

This briefing focuses on two key problems concerning eligibility.

The problems

The first problem is that 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.

The second problem is that it is difficult to know how to interpret aspects of the eligibility criteria in Clause 2, most notably whether the illness or disease *cannot be reversed*[1] *by treatment* and whether treatments *only relieve the symptoms temporarily*. Is a treatment that shrinks a tumour from the size of an apple to the size of a grape *reversing* that disease? Would a treatment that allows someone with organ failure to live for decades, but if stopped leads to death within a few days, be considered only working *temporarily*? If a treatment relieves the symptoms *and* stops progression of complications of an incurable illness, allowing a patient a normal life span should they adhere to it, would it be considered to be a treatment that can *reverse* the disease?

Consider four 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 for 1-2 years. In light of the serious side-effects of chemotherapy, he decides to decline this treatment – a decision which is not uncommon – 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 death.

In clinical terms, there is a treatment available that would do more than relieve the symptoms of his disease, and which would reverse the disease. This would take the man out of the scope of the Bill. The implication might be that someone in this position would need to undergo burdensome, unwanted and expensive treatment in order (at the point that the treatment stops being effective) to bring themselves within scope of the Bill. We

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[1] Note: an inevitably progressive disease cannot, by definition, be reversed, so one view, the words "which cannot be reversed by treatment" in clause 2(1)(a) are redundant and should not be included given that legislation should only include terms which are performing an actual function. What we understand is meant by the concept is, perhaps, reversal of aspects of the impact of the disease on the functioning of the body.

anticipate that many Parliamentarians supportive of the Bill's purposes would consider this man to be paradigmatic of the sort of person who should benefit from assistance.

Second, a woman aged 70 has chronic kidney disease, and has been reliant on renal replacement therapy (dialysis) for 10 years. If she continues on this therapy, her prognosis is likely many 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 death.

In clinical terms, the woman does have an inevitably progressive illness or disease. However, while she is still receiving dialysis, she would not be expected to die within 6 months, and therefore is out of scope of the Bill. If she decides to stop the dialysis (a decision that many people make), she would appear to come within scope of the Bill at that point. It is debateable as to whether there would be considered to be a treatment that can reverse the disease (i.e., re-starting the dialysis). Assuming she is considered eligible at the point that she stops dialysis, it is likely that she would die before it was possible to complete the necessary steps required under the Bill's framework. Therefore, in real terms, this woman would not have the option of assisted death.

Three, a woman aged 30 has had Type 1 diabetes treated with daily insulin since she was 13. With good adherence to diabetes management she has a good lifespan. She becomes depressed following a break-up. She tells her GP she is thinking about stopping taking her insulin. She knows she will likely die in days without it, and requests assisted death.

In clinical terms, diabetes is an inevitably progressive disease. Insulin works to relieve its symptoms, and to prevent further complications, but it is unclear as to whether the insulin would be regarded as a treatment that can reverse the disease. While she is taking insulin, her death could not reasonably be expected within 6 months, but should she decide to stop taking insulin her death would be expected within days. On the face of it, therefore, it is unclear whether this woman would be in the scope of the Bill.

Four, a man aged 70 diagnosed with Motor Neurone Disease twelve months previously. He has managed to maintain a good quality of life, with the support of his family and carers. His disease has progressed gradually and is now starting to affect his breathing and swallowing. Without respiratory and nutritional support his death can be reasonably expected within 6 months. With such support, his prognosis would be longer than 6 months.

In clinical terms, respiratory and nutritional support would slow (and to an extent, could reverse) the overall deterioration that has occurred as a result of his Motor Neurone Disease, but they do not reverse the disease itself. On the face of it, he is therefore within scope of the Bill if he chooses not to receive nutritional or respiratory support.

The solution

We do not propose amendments to the Bill to address the tension between the competing policies between which it is caught. Either way there would be fundamental implications, a dilemma we do not consider that it is our place to seek to resolve.

Rather, what we suggest to solve the problems identified above is that it is necessary (at a minimum) for there to be placed on the record in Hansard whether cases such as those set out above are within or outside the scope of the Bill. This is particularly important given, that, as the relevant Ministers have repeatedly emphasised during the debates to date, a person excluded from the Bill without objective and reasonable justification is very likely to be subject to discrimination contrary to Articles 8 and 14 of the European Convention on Human Rights. In this regard, the courts will look with particular concern to see: (1) whether Parliament has expressly considered the issue; (2) what its answer is; (3) and whether that answer has taken into account all relevant factors.[2]

We note that the potential for unjustified differential treatment is particularly stark where:

- Prioritising the tightness of the medical eligibility criteria means 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' means 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 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.

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.

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[2] Even larger issues of differential treatment arise in respect of: (1) degenerative conditions such as dementia which will impact upon the person's decision-making capacity, so as to be very likely to take them out of scope of the Bill either at the point of assessment / confirmation by the Panel or at the point of receipt of assistance; and (2) conditions which render the person unable to carry out the final act. The focus of this briefing, however, is on those situations which bring into tension the two irreconcilable aspects of choice highlighted above.