Terminally Ill Adults (End of Life) Second Reading Briefing: the preliminary discussions and proposed amendments

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 preliminary discussions, and explains the amendments we recommend.

The preliminary discussion

The purpose of the preliminary discussion is that the registered medical practitioner must explain to and discuss with the person their diagnosis and prognosis; any available treatment and its likely effect; and all appropriate palliative, hospice or other care. Clause 5(5) of the Bill as drafted provides that the medical practitioner, as part of the preliminary discussions, must 'offer to' refer the person to a registered medical practitioner who 'specialises in palliative, hospice or other care, including symptom management and psychological support'.

The problem with the preliminary discussion

We argue that *offering a referral* to a specialist in palliative care is not enough; that everyone who requests an assisted death should receive a palliative care *assessment*. The reasons for this are:

- 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.
- 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.
- There are current inequalities in access to palliative care. Groups shown to have worse access to palliative care include older people, people from minority ethnic groups, people from lower socioeconomic backgrounds, and people with conditions other than cancer. Mandating a palliative care assessment for everyone as part of the assisted dying process would go some way to addressing this inequity.

- In Committee stage, it was stated that mandating a palliative care assessment for everyone requesting an assisted death would have resource implications. We suggest that resource implications should not be used to argue against this additional safeguard.

Amendment to strengthen the preliminary discussion

We propose an amendment to clause 5 of the Bill to require that a referral is made to palliative care.

Palliative care works best when provided early and is most effective when started at least 3 months before death. Therefore, a single palliative care assessment is unlikely to provide optimal symptom control. However, we suggest that this is a pragmatic way to improve the current Bill. Some patients will have a single palliative care assessment, and thereafter continue seamlessly with the assisted dying process. For others, the palliative care assessment will identify alternative strategies that they decide to try before continuing (or not) with the assisted dying process.

Conclusion

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

More information about CLADD can be found here.

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