The UK is currently considering making assisted dying available to patients who are terminally ill. We discuss ethical and practical aspects of this complex issue and outline the potential role of psychiatry. We set out the challenges of implementation of legislation, and potential unintended consequences including the impact on health inequalities.

Living with a terminal illness, and awaiting the inevitable, is a harrowing experience. In addition to knowing one’s fate, having to face one’s mortality and anticipating that this is likely to be painful, and incur severe discomfort and disability, with potential loss of one’s cognitive capacity rendering it difficult to communicate one’s distress, is truly frightening. On top of this, in practice, it is common for dying patients to not have an advanced agreement on end-of-life care, and so they may endure the withdrawal of life-saving interventions, fluctuating consciousness, and periods of dehydration and starvation.

Of course, modern medicine and health practitioners who dispense treatments do their utmost to alleviate such suffering. Palliative care aims to provide compassionate management and support for the individual and their families. This takes a toll on all concerned. Consequently, health professionals, the public and legislators have been increasingly asking whether such an agonising end to life can be avoided, and indeed, given the means of ending one’s life are often imbued with ambivalence and need reflection and consideration of alternatives. However, operationalising procedures for the safe implementation of legislation is less straightforward, as is evident in the House of Lords debates. These include evidence from countries around the world where end-of-life care has already been introduced. This evidence shows the following.

The proposed Assisted Dying Bill

Globally many jurisdictions have already instituted legislation that permits physicians to assist with dying and have elements that are similar to the wording of the Bill proposed in the UK. The UK Assisted Dying Bill requires the attending doctor (to whom the patient has made a request) and an independent doctor (not involved in the care of the patient, not a relative, partner or colleague in the same practice or clinical team of the attending doctor), to examine the patient (independently) and confirm the patient:

(a) is terminally ill,
(b) has the capacity to make the decision to end their own life; and
(c) has a clear and settled intention to end their own life.

Both doctors must make the patient aware of alternatives (including hospice and palliative care). If either questions the patient’s capacity, they must seek an opinion from a specialist doctor, a psychiatrist, and respond to that assessment.

Concerns

On first pass, the Bill seems well intentioned and reasonable, however, there are two principal challenges; first, safe and regulated implementation. Second, people with mental illness already face multiple disadvantages, premature mortality, poor physical healthcare and end-of-life care, and may further be disadvantaged by legislation that is blind to pre-existing inequalities.

The terms of the Bill draw on thinking from prior deliberations undertaken by several groups around the world. Indeed, similar efforts led to rejection of legislation in England and Wales in 2006. Furthermore, judgements about capacity and decisions to end one’s life are often imbued with ambivalence and need reflection and consideration of alternatives. However, operationalising procedures for the safe implementation of legislation is less straightforward, as is evident in the House of Lords debates. These include evidence from countries around the world where end-of-life care has already been introduced. This evidence shows the following.
The quality of services is sometimes undocumented, and as such it is not clear whether guidelines have been followed.

This process itself is not always subjected to independent oversight. In some instances, there appear to be valid concerns of malpractice and poor conduct, and there have been suggestions that physicians and health practitioners, who are legally permitted to end life, may act beyond their remit.

 Patients may be coerced when making their decision not least by family members and friends who are likely to have conflicts of interest. The latter typically include financial matters but may also be a consequence of fatigue because of unrelenting carer responsibilities.

At the heart of the many debates is the key question of who should ultimately decide; and if it is decided to assist in death, then how should this be enacted. Leaving it solely to doctors has proven to be problematic, with some patients taking matters into their own hands if their wishes are not supported. At the same time, it seems inappropriate to direct doctors to assist, especially if it runs against their own ethical, professional, spiritual and personal values.

Similarly, the involvement of family and carers may be fraught with difficulties. Those close to a dying patient are often grieving at some level and understandably consumed by many complex emotions as the person approaches death. Even formulating their personal goodbyes is a challenge, let alone considering more complex matters such as the circumstances and manner in which a life should be ended, and potential ambivalence. And so, involving relatives in end-of-life care decisions may not always be the best course of action, especially if the opinions of relatives/carers do not align with those of the patient.

In addition, the powers invested in the medical profession are also a cause for some concern in light of past atrocities enacted because of both personal and societal prejudices – in which doctors have been seen to collude with dubious political goals, including scientific racism and eugenics (for example the infamous Tuskegee experiments in the USA that involved withholding the diagnosis and treatment of Black males infected with syphilis, and spurious claims of racial inferiority that were investigated by scientists worldwide, in addition to the abuses that occurred at the time of the holocaust in the Second World War under the guise of research). It is therefore understandable that professionals and the public are sensitive to the potential misuse of medical authority.

There are many challenges that need to be overcome to realise the objectives we have outlined above. And so, here we emphasise four fundamental components for implementation before or alongside any future legislation.

(a) Specialist assessment: treatment of most psychiatric conditions results in people achieving symptomatic remission and recovery, but many people have long-term conditions that need continuing active care. A person with a terminal illness and a psychiatric condition who does not benefit from usual care may be deemed to have few additional options, while continuing to suffer. The patient and their carers may consider the latter to be unbearable and thus move prematurely to consider more drastic measures rather than have opportunities for second opinions and more specialist review. Hence specialist assessment is needed to appraise the complex judgements involved in the provision of mental healthcare and need for palliative care.

(b) Resources and equity: mental healthcare is under-resourced and so it is perhaps not surprising that the physical care of people with mental illnesses is also under-resourced. Hence there have been recent calls for parity and more effective interventions to reduce premature mortality in those with severe mental illness. Levelling up resources for psychiatric care, and
palliative care, and for people with mental illnesses developing cancer is a fundamental condition for future legislation. Indeed, were these services better resourced, more modest legislation and new standards for end-of-life care may achieve similar outcomes, aligned with existing care pathways and legislation on advanced directives.

(c) A full economic analysis of options is necessary including levelling up mental healthcare, terminal illness care for people with mental illness, and the costs of legal and clinical reviews and assessments, and scrutiny of trends at a national level. Training programmes and accreditation schemes for ‘approved’ status are likely necessary to ensure standards are agreed and maintained.

(d) Research and oversight: we clearly need more research centred on the perspectives of those likely to be affected by legislation and those contributing to the implementation of legislation. But there should be a programme of research developed prior to the implementation of any new legislation, to inform national monitoring and review processes. Indeed, a national framework and central review process for requests for assisted dying may be better suited to evolving good practice guidance and experience in assessing applications. The meaningful integration of enhanced palliative care services with psychiatric care is long overdue. Although this will not be straightforward, it is essential.

Conclusion

Assisted dying is an emotive topic and it raises complex clinical and ethical questions. Navigating the needs of all concerned will not be easy, but for the sake of our patients, their parents, loved ones and for the people for whom we provide healthcare – including ourselves, negotiating these challenges will be critical. Hence, we hope this editorial will promote further critical discussion.

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Appendix

Assessing domains of capacity-based decisions on assisted dying

Domains
(a) Biological: have all available interventions been adequately trialled?
(b) Psychological: have appropriate preparations for dying been made, such as putting affairs in order and coming to terms with the decision?
(c) Effective interventions: has the decision been made free from the likely impact of underlying illness and its effective treatment and following optimal palliative care?
(d) Social: are there sufficient social assets and resources (for example safe housing, income) to afford the best chances of recovery and managing pain and disability?
(e) Family, spiritual and cultural: are kin on board and supportive of the decision, as well as members of their faith/community with which they identify?

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