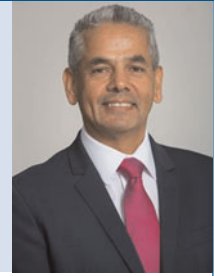


## Editorial

# Proposed Assisted Dying Bill: implications for mental healthcare and psychiatrists

Kamaldeep Bhui and Gin S. Malhi



## Summary

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.

## Keywords

Assisted dying; end-of-life care; mental illness; legislation; inequality.

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Assisted Dying Bill is being considered as a potential solution, and one that may provide a pathway through this complex terrain.

## The proposed Assisted Dying Bill

The Assisted Dying Bill,<sup>1,2</sup> recently the subject of debate in the UK parliament, has been proposed to help navigate the complex process of maintaining an individual's autonomy and dignity while ensuring the role of doctors and healthcare staff remains lawful. The Lords record shows it stems from a virtuous footing and is compassionately aimed at balancing the needs of individuals seeking assisted death with those who care for them and who have assumed legal responsibilities.

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 without pain and suffering are at hand whether the current situation is defensible especially when individuals are capable of making informed decisions and providing an advanced directive that sets out how they wish to end their life – with dignity and minimal suffering.

In recent years there have been a growing number of high-profile cases where people have wanted to plan their death because of an intractable illness and have asked those caring for them – physicians and family – to assist in any way they can. However, in most instances, even though many have wanted to help on compassionate grounds this is simply not possible because it is unlawful. It is in this context that the proposed

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<sup>1</sup> 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 health-care 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.<sup>2</sup> These include evidence from countries around the world where end-of-life care has already been introduced. This evidence shows the following.

- (a) The quality of services is sometimes undocumented, and as such it is not clear whether guidelines have been followed.
- (b) 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.
- (c) 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.

### Psychiatrists, mental health systems and equity

The UK Assisted Dying Bill pertains largely to patients with terminally illnesses such as cancer. Although there is concern that permitting such legislation to pass will lead to a ‘slippery slope’ and will be relaxed to include other disorders, we do not consider this a sound reason to not promote critical discussion and reconsider the views of patients, the public and clinicians. Legislation in some European countries permits euthanasia for non-terminally ill people, on grounds of ‘unbearable suffering’. Of note, the research suggested some patients with psychiatric disorders met the ‘unbearable suffering’ criteria of the legislation in Belgium, potentially because of a lack of effective care and social adversity including poverty.<sup>3</sup> The paper outlined several potential sources of suffering, namely, medical, intrapersonal, interpersonal, societal and existential, and this means that the assessing physicians will need to pay attention to more than the biological appraisal of a terminal illness. Social, spiritual, psychological and cultural influences also need consideration (see the Appendix).

Other publications suggest gender differences, with more women seeking euthanasia in the Netherlands.<sup>4</sup> Therefore, assisted dying is not purely a medical matter, but rather reflects wider social and political factors that must be evaluated, alongside issues of morality, faith, spirituality, ableism and potential misuses because of prejudices.

Psychiatrists will need to make judgements of capacity among patients who are terminally ill. What of comorbidities, such as terminal illness in patients with dementia who are unable to consent to treatment? What of people with intellectual disability and psychosis, who cannot be judged to have capacity but seek an end to their lives? There is little in the Bill on these groups. Psychiatrists can play an important collaborative role to ensure that all patients receive optimal mental healthcare, and do not end up concluding their suffering is unbearable and untreatable. This means providing effective mental healthcare to all and tackling the unequal access to evidence-based treatments. We must confront the drivers of health inequality by age, gender, ethnicity and geography, and recognise that legislation designed to be implemented in optimal conditions may in fact exist in an imperfect world. As a consequence, there will be unintended consequences, including sustaining or worsening inequalities for those who are in the most marginalised groups. For example, those with financial resources are most likely to be able to procure specialist assessments and access clinics both locally and abroad.

In addition to suffering psychologically, those with severe mental illnesses are more prone to die prematurely from cancer, heart disease, respiratory and gut disorders, and are clearly more vulnerable to suicide. This issue is all the more critical given the accumulating evidence that people with severe mental illness are less likely to receive effective and timely care for physical health conditions, including cancer.<sup>5</sup> Therefore, people with mental illness who also develop a terminal medical disease should receive a specialist assessment, as they are unlikely to receive appropriate care. Palliative care should be tailored to the needs of people with severe mental illness.

### Challenges

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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K.B. drafted the manuscript, and G.S.M. and K.B. jointly reviewed and revised the editorial.

## Declaration of interest

K.B. is the Editor-in-Chief of *BJPsych* and College Editor at the Royal College of Psychiatrists. G.S.M. is on the editorial board of *BJPsych*. The authors have played no part in the decision-making and review of the editorial. There are no other conflicts of interest.

## 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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