Protecting patients from assisted suicide

The Terminally Ill Adults (End of Life) Bill is a profoundly dangerous piece of legislation.

It seeks to amend the Suicide Act 1961 so that ‘encouraging or assisting suicide’ will no longer be illegal if it is done in accordance with this new Bill. To be eligible, one must be 18 or older, ordinarily resident of England or Wales (for 12 months), registered with a GP in England or Wales and have a ‘clear, settled and informed wish to end their own life’. The patient must be deemed to be terminally ill, to have capacity and to make the request voluntarily.

The Bill is deeply flawed: it is unworkable and unsafe. Furthermore, many of the political arguments made for the Bill do not reflect real-life palliative and end-of-life care.

THE BILL IS UNWORKABLE AND UNSAFE

There are a plethora of serious concerns about the detail of the Terminally Ill Adults (End of Life) Bill.

Broad definition of terminal illness

Clause 2 contains a two-part definition of “terminally ill”. A person must have “an inevitably progressive illness, disease or medical condition which cannot be reversed by treatment”, in consequence of which the person's death “can reasonably be expected within 6 months”. This is broad enough to include people with manageable conditions such as diabetes, should they elect to discontinue treatments. In some jurisdictions, conditions such as hernias, arthritis and anorexia nervosa have been classified as ‘terminal illnesses’ and approved for assisted suicide.[1]

Difficulty of accurate prognosis

Someone meets the Bill’s definition of terminal illness if they “can reasonably be expected” to die within six months. Such projections are notoriously difficult, arguably even more so for neurological conditions and other non-cancer diseases. Palliative care specialists with decades of experience can feel they are getting worse rather than better at prognostication. Professor Mark Glaser, former head of cancer services at Imperial College Healthcare NHS Trust, has said: “I can recall several patients who came to me with a prognosis of months and they are still being cared for by me many years later”.[2] This anecdotal evidence is supported by Department for Work and Pensions data, showing that around 20% of Universal Credit claimants given six months to live are still alive three years later.[3] Predicting survival in those with weeks or months to live – exactly those whom this Bill hopes to define – is the most uncertain. A 2023 study found only 32 per cent accuracy.[4]

Insufficient conscience protection for doctors

The original Bill required doctors who are unwilling to discuss assisted suicide to refer a patient to another doctor to take the process forward (Clause 4(5)). Many doctors will feel this violates their conscience, crossing an ethical line by making them complicit in the process. An amendment to the Bill has been accepted by the Bill Committee which would instead require the doctor to direct a patient to “where they can obtain information”. This will be considered an improvement by many doctors who are unwilling to participate in assisted suicide. However, it is not clear that even this amendment meets the BMA’s Medical Ethics Committee recommendation that, if a law were introduced, it should involve “only those doctors who positively choose to participate”.[5]

Undermining patients' trust in the medical profession

Patients trust healthcare workers to act in their best interests. This is the foundation of the clinician-patient relationship. Under the existing law, patients who are old, frail, impaired or otherwise highly vulnerable can feel completely confident that their doctors are only acting out of a desire to support and heal them. In those times when they are feeling low and suggest they do not want to carry on – common but normally passing in those who are seriously ill – patients know that medical staff will support them through that difficult time rather than validating their despair. The fact that a doctor or nurse could initiate a conversation, or even instigate a hastened death – when a patient is ill, at their most vulnerable and seeking care – will fundamentally undermine that trust. Doctors must not be agents of a national suicide service.

Danger of coercion

It is not clear how doctors are supposed to exclude coercion. Most doctors are not trained to assess coercive control, which can be extremely subtle and is frequently not even recognised by the victim themselves. In the busy and underfunded NHS, there will not be time to look for it thoroughly. Doctors will sign statements saying "to the best of my knowledge" the patient "has a clear, settled and informed wish to end their own life" and is acting "voluntarily and has not been coerced or pressured by any other person" (Schedule 2). This could easily amount to little more than a statement that the doctor has not personally seen any coercion in whatever time they were with the patient. This is hardly a robust safeguard.

The Bill also does not require the assessing doctors to have known the patient for any length of time, further limiting their ability to identify coercion. In jurisdictions where assisted suicide has been introduced, the deaths are overseen by a small percentage of doctors. For example, in Oregon, of the thousands of licensed physicians, only 167 were attending physicians for assisted suicide in 2023. Individual physicians wrote up to 76 prescriptions.[6] Such assisted suicide specialists are not familiar with the individuals they help to die. In Oregon, the median length of time attending physicians had known the dying person had fallen to 5 weeks by 2022, having been 18 weeks in 2010.[7]

Lack of holistic needs assessment

The NICE best practice guideline on end of life care for adults is clear that an adult approaching the end of their life should have a holistic needs assessment.[8] This "considers all aspects of a person's wellbeing, their spiritual and health and social care needs". It requires a multi-disciplinary team, given the complex physical, social, psychological and spiritual needs of those in this situation. The two doctors carrying out the 'independent' medical assessments under this Bill do not have to be specialists and would not have to have cared for or assessed the patient before.

Encouraging 'doctor shopping'

In jurisdictions where assisted suicide is legalised, some doctors have become 'specialists', sanctioning hundreds of premature deaths.[9] In many cases, these are not deaths of long-term patients, but those who come to them because they were understood to be more likely to approve applications for assisted suicide. Clause 10(1) encourages such 'doctor shopping' by providing that a second opinion can be sought if an independent doctor refuses to make a statement approving the patient for assisted suicide. If a patient does not get the answer they want from one independent doctor, they can seek out another who is more likely to agree. Moreover, there is no limit on how many times a person can request assisted suicide. As no prior connection between the patient and a doctor is required, someone can keep trying different doctors until they get the answer they want.

Not patient-led

The Bill as drafted (Clause 4(2)) would make it explicit that a doctor or nurse could decide to bring up the topic of assisted suicide with a patient who has not mentioned it. Vulnerable patients could be made to think they should consider assisted suicide when it had not previously occurred to them. Arguably, a doctor offering assisted suicide as a treatment option could be considered coercive in itself. It is certainly highly suggestive: ‘why would my doctor have mentioned it unless I should be thinking about it?’

Risk of rushing

Someone diagnosed with a terminal illness may immediately have feelings of despair and hopelessness. But, given time, many will come to terms with their illness and live fulfilled lives. The two reflection periods in the Bill total just 21 days, meaning the process could theoretically be completed in around three weeks. For most ordinary people, this is completely insufficient to allow them to adjust to a life-changing diagnosis.

Inadequate psychiatric assessment

At the time of writing, there is no requirement in the Bill for the patient’s mental capacity to be assessed by a psychiatrist, even where an assessing doctor has doubts. Clause 9(3)(b) merely says that in these circumstances a doctor “may” refer the patient to a psychiatrist or specialist in assessing capacity. It would be extraordinary for a doctor not to be required to seek a second opinion even when uncertain about the patient’s capacity. The patient having capacity has been presented as one of the key alleged safeguards in the Bill, and is certainly a crucial issue. Yet it would be left open for a doctor – who may have little experience in assessing capacity – to approve someone for assisted suicide when they still have doubts on this point.

It is possible this “may” will be changed to a “must”. But it would only apply where the assessing doctor has doubts. This raises the prospect of a doctor inexperienced in such assessments having misplaced confidence in a patient’s capacity. Given the life and death implications, and the contradiction between this Bill and mainstream suicide prevention protocols, it should, at the very least, be a requirement that all those requesting assisted suicide undergo a thorough psychiatric assessment.

At the time of writing, Kim Leadbeater, the MP behind the Bill, has proposed an amendment removing the requirement that the High Court be involved in approving a patient for assisted suicide. This is to be replaced with a panel that includes a psychiatrist. This downgrade is likely to make things worse for patients because it takes psychiatrists away from caring for them and re-directs them to filling in paperwork to facilitate them ending their own lives. The panel would be tasked simply with checking that the assessments ticked the right boxes, rather than using their expertise to offer the patient a psychiatric assessment or psychological help. Focusing the panel on checking that the paperwork demonstrates capacity under the Mental Capacity Act (a tool the

Royal College of Psychiatrists says is inadequate)[10] does not constitute proper medical care of the patient, nor does it constitute a meaningful safeguard.

Lack of clarity on level of assistance

Under Clause 18(6)(c), a doctor may assist a patient "to ingest or otherwise self-administer the substance", while 18(7) says "the final act" must be taken by the patient. Under Clause 18(6)(b), the assistance can include preparing "a medical device which will enable that person to self-administer the substance". Yet it is left unclear just how far the doctor's assistance can go. If the lethal substance is being taken orally, how close to the mouth can the doctor help the patient's hand? Could the "final act" done by the patient simply be swallowing what the doctor places in their mouth? If an intravenous device is being used, how close to the button can the doctor place the patient's finger? The Bill does not give detail on these points.

Silence on doctors' responsibility if the process does not work

The Bill says nothing about what a supervising doctor should do if the substance does not kill the patient efficiently. Should they try to tackle symptoms of distress? How long should they wait before concluding that the process has not worked? Would their normal medical duty to uphold life be reengaged at any stage? There is no indication of what the doctor is supposed or allowed to do if death is very delayed or if the person awakes after becoming unconscious. Palliative care professionals are the most experienced in managing symptom control in dying patients but are the least likely to be willing to be involved in assisted suicide. (Doctors specialising in palliative medicine and care of the elderly overwhelmingly reject changes in the law to decriminalise doctor-assisted suicide, as reflected by the position statements of the Association for Palliative Medicine and the British Geriatrics Society.)[11]

Controversial use of syringe drivers

Preparing a medical device to enable the patient to self-administer the substance (Clause 18(6)(b)) will include syringe drivers to deliver lethal substances intravenously, likely activated by pressing a button. Many would consider use of an injection device in this way to be tantamount to, if not actually, euthanasia. Use of syringe drivers for euthanasia will look identical to their use for symptom management, conflating the two and making it impossible for patients and families to distinguish between them. This may lead to anxiety in palliative care patients. They may fear that the process of connecting them to a syringe driver for symptom control is preliminary to offering them assisted suicide. It will also increase scope for abuse. A doctor or relative may be the one pressing the button to activate the syringe driver and no-one would know.

Vague obligation for doctors

The Bill says the doctor must "remain with" the patient once the lethal substance has been provided (Clause 18(9)). However, it also says the doctor "need not be in the same room" (Clause 18(10)). It is unclear how not being in the same room can constitute remaining with the patient, or how far away the doctor is able to go and yet still be considered "with" the patient. The Bill is silent on how much awareness the doctor needs to have of what is happening in the room. This is not just a hypothetical issue. It is a significant safeguard. Clause 18(7) states that the final act of administering the substance must be taken by the person dying. If the doctor is not in the room, how can this be guaranteed? What will prevent a relative taking the final act? In the event that the patient decides at the last moment against taking the final act themselves, what is there to prevent an unscrupulous relative overriding their wishes and e.g. pushing the button? Cases in both property and criminal law show the elderly are too often regarded as soft targets for fraud and undue influence.

Time-intensive

Requiring a doctor to remain with a patient throughout the process will draw resources away from other services, such as palliative care. Oregon's 2023 annual report shows death may occur anywhere between three minutes and 137 hours after the substance is ingested.[12] Since 2001, 30% of deaths took between one and six hours, with 6.6% taking longer. In the current NHS, it is completely impractical to expect a doctor to remain with a patient for several hours, especially when in the patient's home.

Exempting assisted suicide cases from coroner investigation

Clause 29 exempts deaths under the Bill from the usual legal requirement that violent or unnatural deaths are investigated by the coroner. It is concerning that this important check and balance on the process is being removed. It guarantees that less official information will be available to help Parliament assess how the legislation is working in practice.

MPS' ARGUMENTS FOR THE BILL DO NOT REFLECT MEDICAL PRACTICE

There were a number of arguments made in support of the Bill at Second Reading in the House of Commons that simply do not reflect the reality of palliative and end-of-life care.

There is no "maximum dose of sedatives"

Kim Leadbeater MP gave an example of a patient, Ann, who had reached "the maximum dose of sedatives" and was therefore beyond further help of palliative care.[13] However, there is no such thing as a maximum dose of sedatives or analgesics in specialist palliative care. Based on an individual assessment of the patient's specific needs (considering psychological distress, pain, urinary retention, etc.), different forms of medication are used at appropriate levels. The medications can be titrated either up or down as necessary, to allow the patient to sleep peacefully and also have opportunity to speak to loved ones.

Morphine is not given in doses that kill patients

Dr Simon Opher MP expressed his view that “almost all doctors in terminal care” have “doubled the dose of morphine knowing that it might curtail the patient’s life”.[14] This is a commonly held misconception, particularly among patients and families, but also some healthcare professionals. It is not borne out by the published evidence and there are no palliative care standards anywhere in the world that would favour using morphine or other opioids in such a way. Quite apart from the ethics of this, it could well be counter productive – agitation can be triggered if doses of morphine or other opioids are raised too high too quickly.

Withdrawal of treatment is a completely different issue

Lizzi Collinge MP argued in favour of the Bill on the basis that “people are already legally able to die early through withdrawal of treatment”.[15] It is entirely wrong and misleading to equate withdrawal of treatment with giving lethal substances. Ethicists and doctors have long been clear on the distinction. ‘First, do no harm’ has been a central principle of medicine and medical ethics back to Hippocrates. Removing a burdensome treatment is to avoid doing harm, not to kill. Actively enabling someone to kill themselves is very different from withdrawal of treatment.

Most deaths are peaceful

Layla Moran MP seemed to speak for many on this issue when she quoted one of her constituents who said: “I am terrified that I will suffer a long, painful death”.[16] This belief that the normal dying process is long and painful is widely held, but mistaken. Palliative care specialist and bestselling author Dr Kathryn Mannix has said that “normal human dying” is “a really gentle process” that has become “the really best kept secret in medicine”.[17] Once this is explained to many patients and families, their fears are quickly and drastically reduced.

Lack of access to proper care is the real problem

The distressing examples and personal experiences described in support of the Bill, whether in the Second Reading debate or in other settings, are invariably failures of care. They should not have been allowed to happen. Most of those situations would have been completely different if timely access to specialist palliative, social and psychological care had been available. Successive governments have failed to invest sufficiently in palliative and end-of-life care, and this must urgently change. According to Hospice UK, up to 25% of patients who need it do not get access to appropriate palliative care.[18] This lack of availability in so many cases means that patients would be more likely to choose assisted suicide, because of the absence of adequate alternatives.

How much better things would be if the amount of time spent in Parliament debating assisted suicide had instead been dedicated to palliative care.

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