TERMINALLY ILL ADULTS (END OF LIFE) BILL

A briefing on the private member's bill introduced by Kim Leadbeater MP.

APRIL 2025

Kim Leadbeater, the MP for Spen Valley, presented her Terminally Ill Adults (End of Life) Bill on 16 October 2024. On 29 November 2024, after a five-hour debate, MPs voted by 330 to 275 to give the Bill a Second Reading. It was then examined by a Committee of MPs, and it was substantially amended. MPs will have a final chance to propose amendments at Report Stage, which was pushed back by the Bill's sponsor to 16 May. The final chance for MPs to vote on the Bill, at Third Reading, may also take place on 16 May, but proceedings could be carried over to the next available Friday (13 June). Should MPs vote to approve the Bill, it would move to the House of Lords. At that point, MPs would only be able to debate and vote on any amendments brought by the Lords, not the Bill as a whole.

This briefing examines the specific features and safeguards of the Bill, drawing on the experience of other jurisdictions to assess the likely impact of legislation.

WHAT DOES THE BILL PROPOSE?

The Bill seeks "to provide for the lawful provision to terminally ill adults of assistance to voluntarily end their own lives".

It would amend the Suicide Act 1961 so that "providing assistance to a person to end their own life in accordance with the Terminally Ill Adults (End of Life) Act 2025" (or a reasonable belief that they were acting in accordance with the Act) would not be included under the offence of encouraging or assisting suicide or attempted suicide.

The Bill contains offences for using dishonesty, coercion or pressure to induce another person to complete any part of the process to request an assisted death, and for falsifying or destroying documentation (ss 31-33). Interestingly, as much emphasis is placed on actions trying to prevent an assisted suicide. This could potentially serve to discourage patients' families from intervening and thereby removing a familial safeguard against assisted suicide due to depression.

WHAT ARE THE ELIGIBILITY CRITERIA?

Applicants must be terminally ill, mentally capable, 18 years or over, resident in England and Wales for at least 12 months and registered with a medical practice.

The person must have a clear, settled and informed wish to end their own life, and have made a request voluntarily without coercion or pressure from any other person. They must then:

- make a first declaration, which is signed and witnessed
- be assessed by the coordinating doctor, who makes a statement
- be assessed by a second, independent doctor, who also makes a statement
- be referred to an assisted Dying Review Panel, which verifies if eligibility criteria have been met
- make a second declaration

If these requirements are met, the coordinating doctor may provide the person with an approved (lethal) substance with which the person may end their own life.

TERMINAL ILLNESS

The Bill states:

1. For the purposes of this Act, a person is terminally ill if —
   - the person has an inevitably progressive illness or disease which cannot be reversed by treatment, and
   - the person's death in consequence of that illness or disease can reasonably be expected within six months.
2. For the purposes of subsection (1), treatment which only relieves the symptoms of an inevitably progressive illness, disease or medical condition temporarily is not to be regarded as treatment which can reverse that illness or disease.

There are several causes for concern around this definition of terminal illness.

Forecasting life expectancy

The Bill assumes doctors can accurately predict a patient's future, but even experienced professionals often struggle to make an accurate forecast of life expectancy. In Oregon, 5% of patients who died under the Death with Dignity Act in 2023 outlived their six-month prognosis.[1] It is impossible to say how many more people who chose to die based on an inaccurate prognosis could have survived longer than six months. Studies show that errors in diagnosis for severe, life-threatening conditions can be as high as 20%.[2]

What is terminal?

Section (2) appears to discount medical treatment which would increase a person's prognosis beyond six months. Conditions such as diabetes "cannot be reversed by treatment", but treatment with insulin can prevent it from becoming fatal. A patient who discontinues treatment with insulin, therefore threatening his or her life, would meet this definition. There are other examples of non-terminal conditions that fit this definition.

A recent study on physician-assisted suicide for eating disorders found cases where anorexia had been reported by name as a terminal illness. In Colorado, an official noted a growing number of cases for which the terminal condition was identified as "severe protein calorie malnutrition". Twelve cases were reported between 2021 and 2023 — including nine in 2023 alone — compared to zero cases in previous years.[3] It is also clearly possible not only for eating disorders to be treated as a terminal condition, but for a non-terminal condition to become so by refusing food. Alicia Duncan told Liz Carr in her documentary *Better off Dead* that her mother Donna was approved for Medical Aid in Dying (MAiD) in Canada after she stopped eating. She insists that her mother "wasn't terminal and she wasn't facing imminent death... However, if you're depressed, and you starve yourself to the point that you are malnourished they can bump you up to track one and you can die right away."[4]

Extending eligibility

A further concern is that there is already pressure to expand the criteria beyond a six-month terminal diagnosis. The campaign group My Death My Decision, on the day the Bill was published, expressed disappointment that it doesn't include conditions that "can make life intolerable for the sufferer well before they can be described as terminal",[5] while campaigner Esther Rantzen said she regrets that the Bill would not apply to people with "chronic illnesses that can cause months of unbearable pain and distress". Dame Esther said: "I understand that politics is the art of the possible, and having these narrow criteria makes it possible politically to get this reform through, which is so crucial."[6]

When New Zealand passed its End of Life Choice Act in 2019 it required a patient to have a terminal prognosis of six months or less. Supporters of the law are now campaigning to have that condition removed. David Seymour, the MP who sponsored the Act, told reporters: "The six months limit was a political compromise...

I never supported it. I never wanted it. I didn't introduce it that way. I had to compromise because if I didn't get the votes, there'd be no law at all."[7]

Canada's Medical Assistance in Dying (MAiD) legislation, passed in 2016, was also limited to people thought to have only six months to live. This was removed in 2021 following a challenge in the courts.

Tom Gordon MP, one of the members of the Committee, has tabled an amendment that would extend eligibility to 12 months for those with neurodegenerative diseases.[8]

PROXIES AND INDEPENDENT ADVOCATES

Section 15 of the Bill allows for the person requesting assisted death to have the first or second declaration signed by a proxy if "they are unable to sign their own name (by reason of physical impairment, being unable to read or for any other reason)".

The proxy can be (a) a person who has known the person making the declaration personally for at least two years, or (b) a person of a description specified in regulations made by the Secretary of State.

Parliamentarians may find this section worryingly imprecise — the proxy can either be well known to the person, or potentially a stranger, depending on what is eventually specified in the regulations. There also seems to be an inherent contradiction that someone who is not capable of signing their own name is expected to self-administer the lethal substance to end their life.

Section 20 also requires regulations for the appointment of independent advocates to provide support for those who have substantial difficulty in understanding the assisted suicide process. The Bill specifically identifies people with learning disabilities, a mental disorder or autism. This section raises disturbing questions about the mental capacity of those who will be helped to end their lives. Can someone who experiences substantial difficulty in understanding the assisted suicide process really be said to have made a clear, settled and informed decision?

THE ROLE OF DOCTORS

The involvement of two doctors is proposed as a key safeguard in this Bill.

An immediate concern is the stipulation that nothing "prevents a registered medical practitioner exercising their professional judgement to decide if, and when, it is appropriate to discuss the matter with a person". While it is welcome that doctors are not under a duty to raise the topic of assisted suicide, as in some jurisdictions, they are free to do so even if the patient doesn't raise the issue first. This could result in some doctors routinely suggesting assisted suicide to anyone seen as eligible, potentially planting the idea into a patient's head.[9]

Given the high level of trust commonly afforded to the medical profession, a physician suggesting assistance to die could be highly influential to a vulnerable person. On the question of doctors raising assisted dying, Dr Rachel Clarke told the Committee: "I would suggest that stating it broadly like that is a form of pressure and that you are potentially unintentionally coercing that patient. The very act of raising assisted dying in that way will make that vulnerable patient think, God, is this doctor telling me that my life is not worth living any more?' Autonomy is much more subtle and complicated than we assume from outside."[10]

Other reasons why the involvement of two doctors may not constitute a sufficient safeguard include:

Failure to recognise depression

Studies of the relationship between depression and the wish for a hastened death have found repeatedly that clinicians under-recognise depression in medically ill patients.[11] An amendment to specify that the second doctor be a specialist in psychiatry was voted down by the Committee.[12]

Failure to recognise coercion

Evidence from other jurisdictions shows that many people request assisted suicide because they do not wish to be a burden on their family or caregivers. In 2023, 43.3% of people who died through assisted suicide in Oregon said they feared becoming a burden on family, friends and caregivers.[13] The experience of other jurisdictions shows that the so-called right to die can quickly become a "duty to die". Although the attending doctor and the independent doctor must be satisfied that a patient is not acting under coercion, it is unrealistic to assume that medical professionals will always make an accurate assessment of what is a non-medical matter.

CONSCIENCE PROTECTIONS

It is known that many medical professionals are concerned about legalising assisted death. The majority of UK doctors, especially those working closely with dying patients, do not support assisted suicide. When last polled, 82% of members of the Association for Palliative Medicine of Great Britain & Ireland rejected the legalisation of assisted suicide,[14] and the British Geriatrics Society remain opposed.[15] A 2020 poll commissioned by the British Medical Association found that 76% of palliative care physicians opposed legalisation.[16] While the Royal College of GPs recently changed to a stance of neither supporting or opposing assisted suicide, their poll of members actually showed that support for changing the law had fallen considerably to 33.7%, down from 41% in 2019 (opposing a change was the preference of the majority, 47.6% of respondents).[17] A 2019 survey from the Royal College of Physicians (RCP) put support at just 9%.[18] If it was legalised, most doctors caring for the terminally ill would be unlikely to participate in assisted suicide. The RCP survey showed only 24% of doctors were willing to prescribe lethal medication. Only 18% of doctors in geriatric medicine, 24% in medical oncology and 5% in palliative care stated that they would be willing to participate.[19]

Assisted death specialists?

A further consideration is that if there were insufficient numbers of personnel to implement the scheme consistently, then the guarantee of conscience rights could face a challenge in the courts or be downgraded as part of the five-year review stipulated in section 46. In some jurisdictions, this situation has given rise to a small contingent of doctors taking on most of the workload. For example, of the 108 deaths by euthanasia or assisted suicide in Queensland in 2023, 23 doctors participated in some way with 11 to 20 patients, and 14 dealt with over 20 patients.[20] This means that the small number of willing participants are less likely to know the patient well. In Oregon between 1998 and 2021, the median duration of the doctor-patient relationship before death by assisted suicide was 11 weeks (range 0–2138 weeks). By 2023 this had fallen to just six weeks (range 0–1197).[21]

Hospices and care homes

In addition, the Bill says nothing about the rights of institutions — hospices, care homes, etc — not to take part in assisted suicide procedures. However, section 28 (2) not only prevents employers from subjecting an employee to any detriment for exercising their right not to participate in the provision of assisted suicide but also for participating in it. The management of an institution with a policy of not facilitating assisted suicide will not be able to discipline employees who violate that policy. Amendments ensuring that hospices and care homes would not be penalised for non-participation were voted down in Committee, with one MP suggesting that they should lose public funding if they denied this "legal service".[c]

Given that hospices in other jurisdictions have been penalised for not offering medically assisted death — the Delta Hospice Society in British Columbia lost $1.5 million in annual public funding over a decision to stop offering medical assistance in dying and was served with an eviction notice[23] — this lack of explicit conscience protection will worry many in the UK hospice sector.

HIGH COURT REPLACED WITH PANELS

The second key safeguard proposed in the original text of the Bill was the involvement of the High Court. Once the coordinating doctor and the independent doctor had made declarations that the patient met the criteria, the High Court was to declare that the terms of the Act had been fulfilled.

There had been unease at high levels about this provision in the run-up to the debate at Second Reading. Sir James Munby, who retired in 2018 as the senior family judge of England and Wales, expressed concerns about the judicial role in approving requests to end life, which he argued may conflict with traditional judicial functions.[24] Key issues for him included procedural transparency, judicial discretion, conscientious objections, and the potential for judicial rubber-stamping. He and others also questioned whether the Courts had the capacity to take on this extra role.

Despite these concerns, this provision remained in the Bill when MPs debated it at Second Reading. Indeed, at least 61 MPs said in the run-up to the debate that the High Court safeguard was a key reason for their support, while a further 20 cited "judicial protections".[25]

On Monday 10 February, Ms Leadbeater announced that the sign-off by a High Court Judge was to be scrapped in favour of an "expert panel".[26]

Ms Leadbeater told the media that what she was proposing could be termed "judge plus". However, the amendments agreed by the Committee on 25 March would no longer require any involvement by serving judges. Under the Bill as amended in Committee, there would be a voluntary assisted dying commissioner, whose main responsibilities would be:

- receiving documents made under the legislation;
- appointing people to sit on assisted dying review panels;
- referring cases to these panels; and
- deciding applications for reconsideration of panel decisions.

The review panels would consist of a legal member, a psychiatrist member and a social worker member. The legal member, who would chair the panel, could be:

- a former or serving judge of the High Court or a more senior court;
- a lawyer or judge who has previously been authorised to sit part-time in the High Court; or
- a King's Counsel

MPs may consider that this change in procedure makes the Bill fundamentally different to that voted through at Second Reading. It is also not clear that it solves the problem of lack of judicial capacity; both the Royal College of Psychiatrists[27] and British Association of Social Workers (BASW)[28] have raised the issue of workforce shortages.

Sir James Munby, in his analyses of the proposed changes, raises significant concerns about the tribunal process, emphasising its lack of procedural safeguards and transparency.[29] He notes that the bill does not specify who should be involved in proceedings beyond the patient, making it difficult to detect coercion or external pressures. Additionally, there are no clear guidelines for how the panel should evaluate key legal criteria such as terminal illness, capacity, and voluntariness. The bill also lacks provisions for independent evidential investigations, funding for legal representation, and mechanisms for challenging evidence. Sir James warns that without rigorous procedures, the involvement of a judge would be improper, "little more than a rubber stamp providing a veneer of judicial approbation — and that is fundamentally unacceptable." He further questions the secrecy of the process, including decisions on private hearings and publication of reasons. Finally, he highlights a critical flaw: the commissioner can

only review refusals, meaning flawed approvals cannot be reconsidered — raising the alarming possibility that patients could die based on erroneous decisions.

He concludes that, "All in all, in relation to the involvement of the panel in the process, the Bill still falls lamentably short of providing adequate safeguards."[30]

CAN SAFEGUARDS BE MAINTAINED?

Previous sections have looked at the safeguards particular to this Bill. However, it is worth briefly noting the experience of other jurisdictions around safeguards. Once it is introduced, safeguards come to be seen as barriers, and the criteria for assisted suicide are invariably widened or removed. Oregon and Vermont have recently removed residency requirements.[31] Hawaii reduced its statutory waiting period from 20 days to five.[32] In California, this was reduced from 15 days to 48 hours,[33] which may explain the sudden surge in assisted suicides from 522 in 2021 to 853 in 2022.[34] Since arguments for assisted suicide and voluntary euthanasia are so similar, its legalisation in some places has led to vulnerable groups like disabled infants or dementia patients, who have not requested death, being euthanised. The laws of Belgium and the Netherlands, now permit the non-voluntary euthanasia of children. Reports from Belgium and Holland up until 2010 show that between 7% and 9% of all infant deaths involved active euthanasia by lethal injection.[35] In the Netherlands, the number of dementia patients killed by euthanasia rose from 12 in 2009 to 162 in 2019.[36]

Human rights barristers and legal scholars have warned that the law could be dramatically widened by challenges to the European Court of Human Rights on discrimination grounds. Alex Ruck Keene KC, who argued a landmark 2017 Supreme Court case on behalf of Noel Conway, a motor neurone disease patient, said that, once the ban on assisted suicide is lifted, it is "entirely realistic" that a UK court or the European Court of Human Rights (ECtHR) "would find that any legislation which placed restrictions upon who could access assistance with dying breached the non-discrimination provisions of the ECHR".[37]

APPROVED SUBSTANCE

It is worth examining the means by which assistance would be given to end life under this Bill. Section 23 (2) of the Bill provides that once all the process has been completed, "the coordinating doctor may, in accordance with this section, provide that person with an approved substance (see section 25) with which the person may end their own life".

Section 25, in turn, states:

Meaning of "approved substance"

1. The Secretary of State must, by regulations, specify one or more drugs or other substances for the purposes of this Act.

2. In this Act "approved substance" means a drug or other substance specified in regulations under subsection (1).

The Bill, therefore, leaves it to future regulations to decide what substances are to be used to end life. There is a popular perception that there exists an easily prescribed drug that consistently brings about death quickly and painlessly. However, evidence from jurisdictions where "assisted dying" is practiced reveals that hastening patient death is not so simple.

As a paper in the *British Medical Bulletin* lays out, no single or combination of drugs is agreed to be most effective for ending a human life.[38] Drugs used for medical purposes are required to undergo a stringent approval process in order to assess efficacy and safety. But the drugs being used for "assisted dying" have not undergone such a process; the safety and effectiveness of previous and current combinations of lethal drugs is largely unknown. Canada's MAiD protocol concedes this.[39]

> *The pharmacokinetics and pharmacodynamics listed for the medications below are at typical therapeutic dosing, not MAiD dosing. There has been little to no research into their parameters at such high doses as seen with MAiD... There is no peer-reviewed literature to guide best practice in compounding these medications.*

There are also concerns that an assisted death is not the peaceful and painless process of popular imagination. In 2021, Dr Joel Zivot, a practising anaesthesiologist and intensive care medicine specialist with more than 26 years of experience, gave expert testimony to the Canadian Senate regarding the effects of the lethal drugs used in the MAiD scheme, stating that:

> *"...when a person dies by lethal injection, they basically drown. Their lungs fill with fluid, and I would describe that the experience of dying under that circumstance is more akin to death by waterboarding, which we recognise to be cruel... it should be clear to the Canadian public that the kind of death that they will experience as a consequence of MAiD will be something other than the way it is represented. It could be exceedingly painful and more akin to drowning."*[40]

The lack of any commonly agreed protocol for ending life with drugs, and the possibility of assisted deaths actually being painful and distressing, is something that should be considered by parliamentarians, and not left to regulations.

CONCLUSION

There are many factors for parliamentarians to take into account when voting on this Bill, including the impact on palliative care, the risk of a change in UK social perceptions towards the preservation of human life and towards suicide, and concerns from the disabled community. These are all vitally important, but could not be covered in this briefing, which focuses on the specific provisions of The Terminally Ill Adults (End of Life) Bill.

Kim Leadbeater has stated that her Bill is "the strongest most robust piece of legislation on this issue in the world". However, her most vaunted safeguard, sign-off by a High Court judge, has controversially been dropped after Second Reading. Questions have been raised as to whether the new panel, and the involvement of two doctors, can guarantee that vulnerable people will not be subject to coercion and abuse. Even the eligibility criteria are subject to broad interpretation and risk being expanded. Many essential matters are left to be decided by future regulations, including what training doctors will receive on assessing capacity and identifying coercive control, as well as the means that will be used to end life. Section 7.7 (c) proposes "reasonable adjustments and safeguards" for people with a learning disability but what this actually entails will only be decided in later regulations.

MPs will also consider whether the process of a Private Member's Bill (there has been controversy around the make-up and conduct of the Committee) will prove sufficient to rectify these concerns. More fundamentally, individual members will have to weigh up whether it is possible for the state to involve itself in the ending of human life without adverse consequences.

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