

TERMINALLY ILL ADULTS (END OF LIFE) BILL

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

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Kim Leadbeater, the MP for Spen Valley, introduced her Terminally Ill Adults (End of Life) Bill on 16 October 2024, and published the draft text on 11 November. It will be debated by MPs at Second Reading on **29 November 2024**.

Few issues are more contentious than assisted suicide or are the subject of such passionate debate in Parliament. So far, Parliament has not been persuaded to introduce the concept into UK law. When last voted on by MPs in 2015, the proposal was rejected by 330 votes to 118.

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. It does not examine all the arguments for and against assisted suicide.

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 “provision of assistance to end their own life in accordance with the Terminally Ill Adults (End of Life) Act 2024” (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 (ss26-27). Interestingly, as much emphasis is placed on actions trying to prevent an assisted suicide. This could potentially serve to discourage the patients' families from intervention and therefore prevent a familial safeguard against assisted suicide on grounds of 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.

WHAT IS THE PROCESS?

The person seeking assistance in ending their life must:

- 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
- apply to the High Court for a declaration that the requirements of the Act 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 —
- (a) the person has an inevitably progressive illness, disease or medical condition which cannot be reversed by treatment, and
 - (b) the person's death in consequence of that illness, disease or medical condition can reasonably be expected within 6 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, disease or condition.

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

Forecasting life expectancy

The scheme set out in the Bill is based on the assumption that doctors are able to predict the future of their patients. But even for experienced medical professionals, it can be extremely difficult to make an accurate forecast of life expectancy. Under Oregon's Death with Dignity Act, there were 17 patients (5% of DWDA deaths) in 2023, who 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. Research published by the *Journal of the American Medical Association* shows 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". Treatment with insulin can prevent diabetes 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 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 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.

PROXIES

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 2 years, or (b) a person who is of good standing in the community.

Parliamentarians may find this section worryingly imprecise — the proxy can either be well known to the person, or a stranger, as long as they are of "good standing in the community", which is not defined. There also seems an inherent contradiction that someone who is not capable of signing their own name is expected to self-administer (section 18) the lethal substance to end their life.

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.⁸ 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.

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-recognize depression in medically ill patients.⁹ The Bill's reliance on the impressions formed by two doctors of the mental state of a patient is, therefore, of questionable value.

Failure to recognise coercion. Nor would medical judgement protect patients from emotional manipulation or the undue influence of family members. 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.¹⁰ 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,¹¹ and the Royal College of General Practitioners¹² and the British Geriatrics Society remain opposed.¹³ A 2020 poll commissioned by the British Medical Association found that 76% of palliative care physicians opposed legalisation.¹⁴ A 2019 survey from the Royal College of Physicians (RCP) put support at just 9%.¹⁵ 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.¹⁶

Forced referral

Are the conscience protections in this Bill robust enough to alleviate some of these concerns? While the Bill states that, “No registered medical practitioner or other health professional is under any duty (whether arising from any contract, statute or otherwise) to participate in the provision of assistance in accordance with this Act”, it departs from previous draft bills, such as that published by Lord Falconer, in requiring referral. Section 4 (5) of the Bill says, “A registered medical practitioner who is unwilling or unable to conduct the preliminary discussion mentioned under subsection (3) **must, if requested by the person to do so, refer them to another registered medical practitioner** whom the first practitioner believes is willing and able to conduct that discussion.” This would in fact require every doctor in the land to participate in some way in providing assisted death, through referring the patient to a colleague. This threatens to violate a doctor’s freedom of conscience protected by Article 9 of the European Convention on Human Rights (ECHR).

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 35. 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.¹⁷ 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).¹⁸

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, subsection (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.

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 (MAiD) services and was served with an eviction notice¹⁹ — this lack of explicit conscience protection will worry many in the UK hospice sector.

THE ROLE OF THE HIGH COURT

The second key safeguard proposed in this Bill is the role of the courts. Once the coordinating doctor and the independent doctor have made declarations that the patient meets the criteria, the High Court can declare that the terms of the Act have been fulfilled. The Court can carry out any examination the judge sees fit — for example, interview the patient, the doctors or anyone else who is relevant.

The role of the Courts was also a feature of the Bill brought by Baroness Meacher in 2021, and a draft bill published by Lord Falconer in 2024. They, unlike this Bill, specified the involvement of the Family Division of the High Court.

Concern at high levels

As the lack of this detail does not seem to negate concerns about the role of the Family Division, it seems relevant to cite them.

In June 2024, Nick Emmerson, president of the Law Society, described the Family Court system as “broken” and “in dire straits”.²⁰ Referring to figures published by the Ministry of Justice, there were, he said, 27,445 children involved in new family cases between January and March 2024.²¹ “Children are forced to wait almost a year in limbo, as they are failed by a system that should aim to protect them,” he said.

When examining Lord Falconer’s proposal to involve the Family Division of the High Court, Sir James Munby, former President of the Family Division, raised concerns²² about the judicial role in approving requests to end life, which he argued may conflict with traditional judicial functions. Key issues for him include procedural transparency, judicial discretion, conscientious objections, and the potential for judicial rubber-stamping. Sir James questions if judges should be involved in such decisions, given the ethical and procedural complexities.

Court capacity

Is it realistic that this system would be able to cope with an influx of assisted dying cases? In 2022, there were 13,241 MAiD deaths reported in Canada, accounting for 4.1% of total deaths (a growth rate of 31.2% on the 2021 figure).²³ If this rate was replicated in England and Wales it would result in 23,663 cases of assisted suicide. If the rate in the Netherlands in 2023 (5.4%) were to be seen in England and Wales there would be approximately 31,393 deaths.²⁴

When debating in 2021, Lord Carlile of Berriew pointed out other problems with the proposal, stating:

“Let us suppose that 25% of those judges objected to the jurisdiction on grounds of conscience, which would have to be respected, and that there were 1,000 cases a year — a very conservative estimate, given that legislation of this kind, tends to create its own culture change, as experience elsewhere has shown. Each case would be bound to take two or three days before the court. In a sentence, the Family Division would be swamped by those cases; it would not be able to do anything else — and this is something that has been wholly and dangerously overlooked, even without asking those judges.”²⁵

CAN SAFEGUARDS BE MAINTAINED?

Previous sections have looked at the particular safeguards in 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.²⁶ Hawaii reduced its statutory waiting period from 20 days to five.²⁷ In California, this was reduced from 15 days to 48 hours,²⁸ which may explain the sudden surge in assisted suicides from 522 in 2021 to 853 in 2022.²⁹ 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.³⁰ In the Netherlands, the number of dementia patients killed by euthanasia rose from 12 in 2009 to 162 in 2019.³¹

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”.³²

APPROVED SUBSTANCE

It is worth examining the means by which assistance would be given to end life under this Bill. Section 18 (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 20) with which the person may end their own life”.

Section 20, in turn, states:

- (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.³³ 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 process; the safety and effectiveness of previous and current combinations of lethal drugs is largely unknown. Canada’s MAiD protocol concedes this.³⁴

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.”³⁵

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, an analysis of the safeguards contained within it leaves much room for concern. In particular, the involvement of two doctors and a high court judge in the process to approve an assisted death does not seem to guarantee that people will not be subject to coercion and abuse. Even the eligibility criteria are subject to broad interpretation, and risk being expanded. Some key points, such as the means used to end life, are left to future regulations. Medical professionals may also be concerned about the lack of conscience protection.

MPs will have to consider whether the time allotted to debate this Private Member’s Bill will be sufficient to rectify these concerns, and, indeed, if it is possible for the state to involve itself in the ending of human life without adverse consequences.

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ENDNOTES

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