

ASSISTED DYING FOR TERMINALLY ILL ADULTS (SCOTLAND) BILL



Response from Humanists UK, August 2024

ABOUT HUMANISTS UK

At Humanists UK, we want a tolerant world where rational thinking and kindness prevail. We work to support lasting change for a better society, championing ideas for the one life we have. Since 1896, our work has been helping people be happier and more fulfilled. By bringing non-religious people together we help them develop their own views and an understanding of the world around them. Together with our partners Humanist Society Scotland (who are responding to this consultation separately), we speak for 120,000 members and supporters and around 100 members of the All-Party Parliamentary Humanist Group. Through our ceremonies, pastoral support, education services, and campaigning work, we advance free thinking and freedom of choice so everyone can live in a fair and equal society.

In general, we provide services and work on matters that are not devolved to Scotland, with our sister charity Humanist Society Scotland (HSS) providing services in and working on matters that are devolved to Scotland. However, given the significant impact of Scotland's assisted dying legislation to the rest of the UK, we have agreed with HSS that we shall respond to this consultation. We endorse HSS's response as well as providing our own.

We have long supported attempts to legalise assisted dying and voluntary euthanasia in the UK and crown dependencies for those who have made a clear decision, free from coercion, to end their lives and who are physically unable to do so themselves. We gave oral evidence to Jersey's citizens' jury into assisted dying, as well as responding to previous consultations on the matter. We gave written evidence to the House of Commons Health and Social Care Committee's inquiry into assisted dying in 2021, and gave oral evidence to the 2005 inquiry. In recent years, we have been part of the UK and Welsh Department of Health and Social Care's Moral and Ethical Advisory Groups, and the equivalent group in Northern Ireland.

In 2019 alongside HSS we co-founded the Assisted Dying Coalition, a network of organisations around the UK and Crown Dependencies campaigning to legalise assisted dying.

Question 1 – Overarching question

The purpose of the Assisted Dying for Terminally Ill Adults (Scotland) Bill is to introduce a lawful form of assisted dying for people over the age of 16 with a terminal illness.

Which of the following best reflects your views on the Bill?

- **Fully support**
- ~~Partially support~~
- ~~Neutral/Don't know~~
- ~~Partially oppose~~
- ~~Strongly oppose~~



Humanists defend the right of each individual to live by their own personal values, and the freedom to make decisions about their own life so long as this does not result in harm to others. Humanists do not share the attitudes to death and dying held by some religious believers – in particular, that the manner and time of death are for a deity to decide, and that human interference in the course of nature is unacceptable. We firmly uphold the right to life, but we recognise that this right carries with it the right of each individual to make his or her own judgement about whether their own life should continue in the face of suffering that the individual finds unbearable.

We therefore support attempts to legalise assisted dying in the UK for adults who have made a clear decision, free from coercion, to end their lives. We believe that any adult of sound mind who is intolerably suffering from an incurable physical condition and who has a clear and settled wish to die should have the option of an assisted death. We therefore **fully support** the move to introduce a lawful form of assisted dying.

We believe that being able to die, with dignity, in a manner of our choosing must be understood as a fundamental human right. We recognise that any assisted dying law must contain strong safeguards, but the international evidence from countries where assisted dying is legal shows that safeguards can be effective.

Which of the following factors are most important to you when considering the issue of assisted dying? (Rate 1, 2 & 3)

- ~~Impact on healthcare professionals and the doctor/patient relationship~~
- **1. Personal autonomy**
- **3. Personal dignity**
- **2. Reducing suffering**
- ~~Risk of coercion of vulnerable people~~
- ~~Risk of devaluing lives of vulnerable groups~~
- ~~Sanctity of life~~
- ~~Risk of eligibility being broadened and safeguards reduced over time~~
- ~~Other, please specify~~

In our view, legislation enabling a lawful form of assisted dying should have compassion at its core. To enable this, it should be developed taking full account of the experiences of people who are dying of terminal illnesses and who are suffering incurably and intolerably. Their lived experience is vital in creating safeguards, systems and processes that are safe, kind and compassionate.

We staunchly supported the case of Tony Nicklinson, a man with locked-in syndrome, when he brought his case to the High Court in a bid to obtain the right to have a doctor end his life without fear of prosecution. In 2005 Tony suffered a catastrophic stroke which left him paralysed from the neck down and unable to speak. He could only communicate via blinking, and described his life as a 'living nightmare'. In 2012, shortly after he lost his case, he refused food and died.



We don't believe that people like Tony Nicklinson should be forced to suffer. People who have come to a clear and settled wish to die, and who meet the criteria, should be allowed to take control of their lives, and ultimately their deaths.

Many of our members have personal experiences of incurable conditions that have caused them, or their loved ones, intolerable suffering. Jane Barnes suffered from multiple sclerosis and was left bedbound, in agony, unable to feed herself or travel abroad for an assisted death. She said, 'I wouldn't wish this on my worst enemy. There is so much of me that I have lost and it breaks my heart knowing it isn't there. Can you imagine how awful that is? It breaks my heart.' We supported Jane to speak with her MP and the media. Jane died in 2023.

We don't believe Tony Nicklinson's or Jane Barnes's stories are unique. They paint a picture of unnecessary pain and suffering that exists across the UK. The Office of Health Economics found that at least 5,000 people a year die without any effective pain relief in their final months, even with the best possible palliative care.

Question 2 - Eligibility

The Bill proposes that assisted dying would be available only to terminally ill adults.

The Bill defines someone as terminally ill if they 'have an advanced and progressive disease, illness or condition from which they are unable to recover and that can reasonably be expected to cause their premature death'.

An adult is defined as someone aged 16 or over. To be eligible a person would also need to have been resident in Scotland for at least 12 months and be registered with a GP practice.

Eligibility - Terminal illness

Which of the following most closely matches your opinion on the terminal illness criterion for determining eligibility for assisted dying?

- ~~● No one should be eligible for assisted dying~~
- ~~● Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness should be narrower than in the Bill~~
- ~~● Assisted dying should be available only to people who are terminally ill, and the definition of terminal illness in the Bill is about right~~
- ~~● Assisted dying should be available only to people who are terminally ill, but the definition of terminal illness should be broader than in the Bill~~
- **Assisted dying should be available to people who are terminally ill, and to people in some other categories.**
- ~~● Other please provide further detail~~



We appreciate the effort that has gone into the current Bill's definition of terminal illness, and we consider that definition to be far better and more compassionate than definitions that have been suggested in legislation in the UK in previous proposals. Nevertheless, we believe there will be a group of individuals in Scotland who would either still be forced to travel to Switzerland or face indefinite pain and suffering if other eligibility criteria are not considered.

We believe that there is a strong moral case **not** to limit assistance to terminally ill people alone, on the grounds of compassion for other people who are suffering intolerably and incurably. We therefore want a law that would be responsive to the needs of people who are suffering intolerably and incurably, as well as those who are terminally ill. We campaign for a change in the law to this end.

There are several conditions that can cause an individual considerable pain, suffering, and indignity. Paralysis from trauma (such as car accidents), locked-in syndrome, ataxia and severe spinal stenosis may not be considered terminal by a doctor. There are also a group of conditions such as multiple sclerosis, Parkinson's, progressive supranuclear palsy, and motor neurone disease that are either not considered terminal, or by the time a healthcare professional would diagnose the condition as sufficiently terminal, the patient may be in considerable pain or have lost mental capacity.

People with non-terminal conditions may suffer for longer, with no clear or visible end, compared to people with terminal conditions. We believe a reduction of suffering is a fundamental reason to legalise assisted dying and therefore the bill that reduces the suffering the most will be the best bill.

Eligibility – minimum age

Which of the following most closely matches your opinion on the minimum age at which people should be eligible for assisted dying?

- ~~● No one should be eligible for assisted dying.~~
- ~~● The minimum age should be lower than 16~~
- **The minimum age should be 16**
- The minimum age should be 18
- ~~● The minimum age should be higher than 18~~
- ~~● Other – please provide further detail~~

We do not have a strong view on whether the minimum age to be eligibility for assisted dying should be 16 or 18. We note that, while 18 years is the age of majority in most aspects of UK law, in Scotland a person is deemed to have full legal capacity at the age of 16. We also note that the NHS regards 16-year-olds as mentally competent to make their own health and treatment decisions without the involvement of their parents. We see the choice of both 18 and 16 as consistent with existing practice, and thus appropriate.



Question 3 – The Assisted Dying procedure and procedural safeguards

The Bill describes the procedure which would be in place for those wishing to have an assisted death. It sets out various procedural safeguards, including:

- examination by two doctors
- test of capacity
- test of non-coercion
- two-stage process with period for reflection

Which of the following most closely matches your opinion on the Assisted Dying procedure and the procedural safeguards set out in the Bill?

- ~~● I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle~~
- ~~● The procedure should be strengthened to protect against abuse~~
- **The procedure strikes an appropriate balance**
- ~~● The procedure should be simplified to minimise delay and distress to those seeking an assisted death~~
- ~~● Other – please provide further detail~~

We regard the assisted dying procedure and the procedural safeguards set out in the Bill as appropriate. Bill drafters and politicians must bear in mind that, as the Bill itself requires, anyone moving through this procedure is terminally ill and therefore should be treated with the utmost compassion and support, both physical and mental.

This Bill strikes the right balance, and it would be wrong for someone with severe health conditions, facing potentially the last days or months of their lives, to be forced to jump through additional bureaucratic and judicial hoops. No other medical procedure would require a more stringent process than that currently laid out in the Bill.

The test of non-coercion and the introduction of an offence for coercing an individual are welcome inclusions in the Bill, as they will reassure the public and politicians of the safety of assisted dying. There are no cases we are aware of from international jurisdictions where any individuals have been coerced into an assisted death, and most jurisdictions have external reviews. There is also no credible evidence from jurisdictions that have legalised assisted dying, that vulnerable people will be pressured to end their lives, which has been confirmed by several studies from individuals such as Professor Battin and James Downar.

Overall, in our view the Bill's safeguards strike a balance between protecting patients on the one hand, and ensuring that they can carry out their own wishes about their deaths on the other.



Question 4 – Method of dying

The Bill authorises a medical practitioner or authorised health professional to provide an eligible adult who meets certain conditions with a substance with which the adult can end their own life.

Which of the following most closely matches your opinion on this aspect of the Bill?

- ~~● It should remain unlawful to supply people with a substance for the purpose of ending their own life.~~
- ~~● It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill~~
- ~~● It should become lawful to supply people with a substance for the purpose of ending their own life, as proposed in the Bill, and it should also be possible for someone else to administer the substance to the adult, where the adult is unable to self-administer.~~
- **Other – please provide further detail**

We believe the Assisted Dying Bill should strive to have the most compassionate and safest law possible. In countries where doctor-administered assisted dying is legal, the preferred method is overwhelmingly by doctor administration. In New Zealand in 2022-23, 92% of patients opted for an injection administered by a healthcare professional. In 2022 across Canada there were 13,241 assisted deaths, but fewer than seven deaths were self-administered.

We believe patients choose doctor administration as they trust the processes more when there is a medical professional present and in control. They believe the process will be safer if the medical professional is directly involved.

However, patients should be allowed the choice of how the end-of-life medication is administered.

Question 5 – Health professionals

The Bill requires the direct involvement of medical practitioners and authorised health professionals in the assisted dying process. It includes a provision allowing individuals to opt out as a matter of conscience.

Which of the following most closely matches your opinion on how the Bill may affect the medical profession? Tick all that apply.

- ~~● Medical professionals should not be involved in assisted dying, as their duty is to preserve life, not end it.~~
- **The Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out.**



- **Assisting people to have a “good death” should be recognised as a legitimate role for medical professionals**
- ~~Legalising assisted dying risks undermining the doctor-patient relationship~~
- ~~Other—please provide further detail~~

We are fully committed to freedom of conscience, belief, and expression and a society where human rights are valued and where there is equality before the law. However, this right must not be deliberately misinterpreted or abused so as to allow people with religious convictions, or religious institutions, to block individuals from having an assisted death.

In our view, the Bill strikes an appropriate balance by requiring that there are medical practitioners involved, but also allowing those with a conscientious objection to opt out. We also agree that assisting people to have a ‘good death’ should be recognised as a legitimate role for medical professionals; however, this is something that may develop in the medical profession and society generally in the wake of assisted dying becoming established as an option in Scotland.

We would support any additional safeguards in this area, such as ensuring that a medical professional is not discriminated against for choosing to contribute or opt out of assisting a death. However, we would be against this right to conscientious objection being extended to organisations or institutions; only individuals should be able to make this choice. Employers should not be able to make or influence this choice for their employees.

Question 6 – Death certification

If a person underwent an assisted death, the Bill would require their underlying terminal illness to be recorded as the cause of death on their death certificate, rather than the substance that they took to end their life.

Which of the following most closely matches your opinion on recording the cause of death?

- ~~I do not support this approach because it is important that the cause of death information is recorded accurately~~
- **I support this approach because this will help to avoid potential stigma associated with assisted death**
- ~~Other—please provide further detail~~

We support the provision in the Assisted Dying Bill that requires recording the underlying terminal illness as the cause of death on the death certificate. By focusing on the terminal illness as the primary cause, the legislation acknowledges the suffering and medical condition that led to the decision for assisted dying, rather than emphasising the act itself.

This sensitive and compassionate approach aligns with our commitment to supporting individuals’ rights to make autonomous decisions about their end-of-life care, without subjecting them or their families to unnecessary stigma or judgement.



Question 7 – Reporting and review requirements

The Bill proposes that data on first and second declarations, and cancellations, will be recorded and form part of the person’s medical record.

It also proposes that Public Health Scotland should collect data on; requests for assisted dying, how many people requesting assisted dying were eligible, how many were refused and why, how many did not proceed and why, and how many assisted deaths took place.

Public Health Scotland would have to report on this anonymised data annually and a report would be laid before the Scottish Parliament.

The Scottish Government must review the operation of the legislation within five years and lay a report before the Scottish Parliament within six months of the end of the review period.

Which of the following most closely matches your opinion on the reporting and review requirements set out in the Bill?

- ~~● The reporting and review requirements should be extended to increase transparency~~
- The reporting and review requirements set out in the Bill are broadly appropriate**
- ~~● The reporting and review requirements seem excessive and would place an undue burden on frontline services~~
- ~~● Other – please provide further detail~~

The data collection and reporting provisions proposed in the Assisted Dying Bill will ensure transparency, accountability, and continual evaluation of the legislation’s effectiveness and ethical integrity. A systematic approach helps safeguard against misuse or errors, providing a clear and accountable framework that respects the rights and wishes of individuals while ensuring that all actions are thoroughly documented.

Furthermore, the requirement for Public Health Scotland to collect detailed data on various aspects of assisted dying, including the number of requests, eligibility, refusals, reasons for non-progression, and the number of assisted deaths, ensures a comprehensive understanding of how the legislation is functioning in practice. The annual anonymised reports to the Scottish Parliament will facilitate ongoing scrutiny and public accountability, enabling legislators and the public to assess the Bill’s impact.

Additionally, the mandated five-year review by the Scottish Government ensures that the legislation is continuously evaluated and refined, based on empirical evidence and evolving ethical standards. We support this comprehensive oversight mechanism as it aligns with our commitment to evidence-based policy and the protection of individual rights, ensuring that, over time, the legislation remains both effective and compassionate.



Question 8 - Any other comments on the Bill

Do you have any other comments in relation to the Bill?

We strongly support the Assisted Dying Bill, recognising the comprehensive and thorough process that has led to its development. The Bill is a product of extensive consultation with a wide range of stakeholders, including medical professionals. This rigorous approach ensures that the legislation is both ethically sound and practically robust, addressing the complex concerns associated with assisted dying. By incorporating diverse perspectives and expert insights, the Bill has been crafted to provide a compassionate and dignified option for those suffering from incurable conditions, while also implementing stringent safeguards to protect vulnerable individuals.

Moreover, the Assisted Dying Bill aligns with our core principles of advocating for personal autonomy, dignity, and the alleviation of suffering. We believe that individuals facing the end of life should have the right to make informed decisions about their own bodies and futures. The meticulous effort invested in the Bill's creation reflects a deep respect for human rights and individual choice, ensuring that those who wish to pursue assisted dying can do so in a safe, regulated, and supportive environment. This legislation not only honours personal autonomy but also provides a humane response to the profound suffering experienced by some individuals at the end of life, embodying the values of compassion and respect that we as humanists hold dear.

Even though we have suggested some changes to the Bill, we fully support it and we hope that it progresses through the legislative process.

For more details, information, and evidence, contact Humanists UK:

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