The Church of Scotland

Official Response

Subject:	Assisted Dying for Terminally Ill Adults (Scotland) Bill
Requested by:	The Scottish Parliament Health, Social Care and Sport Committee
Date:	16 August 2024
Prepared and agreed by:	The Public Life and Social Justice Programme Group

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

Space for further comment (*limit 2,000 characters*)

The Church of Scotland has traditionally supported the current law which prohibits assisted dying. This position is being reviewed following decisions at the General Assembly in 2023 and 2024. This process is expected to conclude at the Assembly in May 2025.

We find ourselves living with a diversity of opinion on this issue; we have chosen 'partially opposed' to reflect the historic position which is now under review. This tick box does not fully reflect a corporate view or the depth of nuance with which we were wrestling, but after internal discussion felt it was the best fit of those options on offer to simply describe the complicated position we are in.

The Church affirms the value and dignity of every human life, however "limited" that life may appear. Great care must be taken in seeking to exercise authority over that life.

The Church has extensive experience of walking with people in the final stages of their lives. For many within the Church, the current societal prohibition on killing means that our role in Christ's call to care is clear. For some, this may lead them to support giving terminally ill people the option of an assisted death, but there is a wide range of diversity of opinion among individuals within the church, often informed by profound and intense personal experience.

There is a concern that this proposed legislation not only introduces many uncertainties (of interpretation, application or potential future extension of any law, for example). It would involve more than a simple modification of the law, but would represent a significant shift for the whole of society –a shift from which there would be no return. This would have profound effects not only on those who would be directly involved in the process, but on everyone in the whole of society: how society regards those in our communities who are vulnerable, the elderly and infirm, disabled people, and those who are unable (or who feel unable) to speak up for themselves.

Which of the following factors are most important to you when considering the issue of assisted dying? Please rank a maximum of three options (score 1,2,3)

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

Space for further comment *(limit 2,000 characters)*

The Church believes that all life is sacred, created by God. Human life is particularly special, as we are created in God's image. At the heart of our concern is a conviction that it is the right and duty of the Church, of society, and of each one of us to uphold and protect the dignity and worth of human life.

This principle can lead to divergent opinion on assisted dying. Our historic position has been that we should not seek to end life prematurely. Where there are terminally ill people who suffer, we provide them with the best care and support at the end of their life. Some in the Church support the idea that an individual can make their own mind up regarding their life, and if at the end of their life their suffering is intolerable, a decision to end it should be a matter for them.

Opponents of assisted dying are concerned about the fundamental shift that such legislation would bring about in the way in which society as a whole would views those whose lives might be deemed of less worth. The experience of a person is not determinative of their worth, but their life is inherently sacred as they are made in God's image.

We have seen in other countries where assisted dying has been introduced, there is often pressure to expand the criteria under which assistance can be provided. If financial issues become a consideration, what may have begun as "a right to die" potentially becomes "a duty to die", as a cost-saving measure, to ensure that an inheritance is not depleted, or where someone may be coerced by family or societal pressure.

We note the concerns expressed by many in the medical and caring sector about the difficulties that the availability of assisted dying would present to them,- especially to those who are opposed in principle. An opportunity to opt out of involvement in assisted dying must not be limited to the medical profession; those other than medical staff are potentially involved in the process: e.g. pharmacists, nurses and chaplains.

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**

If you have further comments, please provide these (*limit 2,000 characters)*

The definition of terminal illness in the Bill is could be improved. Notwithstanding the difficulty in predicting the progression of many terminal conditions, it is essential that specificity is provided as to the scope of the Bill.

The risks of this legislation being misapplied, misused or the scope creeping in its practice should be avoided by careful terminology and clarity about what Parliament wants to see around eligibility.

A particular concern is dementia, capacity and whether an advanced directive may override the wishes of a patient who appears to have changed their mind or is not able to understand or unambiguously answer what their wishes were and if they had been changed. Dementia is a terminal process which is lengthy and unpredictable, but it does not mean that every person with dementia should be eligible for an assisted death. Many people with dementia can live fulfilled lives. Improving how people can live well with life-limiting conditions needs to remain as an important focus for discussions, not just issues about dying well. how would the question of capacity and power of attorney in progressive neurological conditions be judged if the person applying has deteriorating capacity before a final decision can be made? This Bill would require very clear definitions of terminal illness to avoid challenges which might widen eligibility, either through subsequent legislative change or through court cases.

We note that the reality in other jurisdictions has been that criteria put in place in legislation has been extended. Both Canada and Colombia passed assisted dying legislation in 2016, which was limited to those with terminal illness. By 2021 criteria in these countries had been extended to include people who do not have a terminal illness. There are many in the Church of Scotland who believe that once the decision to permit assisted dying for terminally ill people has been taken, a widening of eligibility will inevitably follow.

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**

If you have further comments, please provide these (*limit 2,000 characters)*

This is not a question that the Church's General Assembly has expressed a particular view on, and it is possible that there is a diversity of opinion within the Church of Scotland.

However, in our internal discussions about the Bill and in drafting this submission there was widespread and significant concern that if this Bill were passed that the minimum age should be at least 18 or higher.

Scotland is already an outlier in that it is the only jurisdiction in Europe where the 'age of majority' is 16. However, even then, for many different aspects of interaction with the law and state other, higher, ages are seen as a more appropriate threshold. These importantly include areas where major life decisions are involved, such as access to and use of tobacco, alcohol and gambling services, and applying for a gender recognition certification. We are aware of conversations now taking place which could see the age of marriage likely to increase in Scotland from the current 16 to 18. Scottish Sentencing Council research and guidelines indicate that for some people, their emotional development and understanding should only be considered to be fully formed by 25 (see, for example https://www.scottishsentencingcouncil.org.uk/media/4d3piwmw/sentencing-young-people-guideline-for-publication.pdf and https://www.scottishsentencingcouncil.org.uk/media/mi0aavav/20200219-ssc-cognitive-maturity-literature-review.pdf) .

We therefore would propose consideration, if the Bill were to pass, that the minimum age that someone can become eligible for assisted dying should be from their 26th birthday.

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?

- o I do not agree with the procedure and procedural safeguards because I oppose assisted dying in principle
- o The procedure should be strengthened to protect against abuse
- o The procedure strikes an appropriate balance
- o The procedure should be simplified to minimise delay and distress to those seeking an assisted death

Other – please provide further detail

If you have further comments, please provide these (*limit 2,000 characters)*

For those in the Church of Scotland who are opposed to assisted dying, the view is simply that the most robust safeguard against abuse is the one which is currently in place- the prohibition of assisting another person to end their life. There is particular alarm at how similar legislation has been implemented in other jurisdictions, where there has been a rapid extension of the criteria which permits assisted dying. Opponents noted the views of palliative care specialists who are largely opposed to legislation to allow assisted dying. It should not be forgotten that this debate is not taking place in a vacuum, and that there remains an urgent and pressing need to improve the availability and access to palliative care.

Views expressed by members of the Church of Scotland's Disability Inclusion Group included reflecting some of the anxieties shared by other disability rights advocates, which is that a potential future widening of the scope for assisted dying might devalue or diminish the dignity and worth of disabled people. There were however some other voices from this group who could see some merits in the content of this Bill, so long as there was not going to be any widening of the criteria, and that the definition of terminal illness was clearly set out

While it is necessary to attempt to avoid people being coerced into ending their own lives, if assisted dying became part of the options available to people, to relatives and to clinicians, will there inevitably be a risk that many will feel the need to choose to end their own lives, either because they perceive themselves (or feel that they are perceived as) a "burden" to their loved ones- or worse, to society or the NHS?

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**

If you have further comments, please provide these (*limit 2,000 characters)*

In our internal discussions about this response we found that an individual's personal view about assisted dying determined how they answered this question.

For those in the Church opposed to assisted dying being legalised, there was a view which said that the process of supplying a toxic substance to end the life of another person is not simply one which involves the medical profession alone. Others, including pharmacists and nurses, will inevitably be involved. In addition, on many occasions it may be necessary for carers (whether paid or unpaid) to take a role in the practicalities of the process.

Statistics indicate that an increasing percentage of people in Scotland will spend the last days of their lives in care homes. As the name indicates, these are homes first and foremost, where people are cared for, not simply institutions where people go to wait to die. Care homes are real, functioning communities. As such, when a member of the community dies, there is a profound sense of loss, as that person may have been a part of the community for many months, often for years. Staff, carers and residents experience a process of grief and bereavement. In the Church people who oppose assisted dying believe that this would have a profoundly negative effect on many who care in this context.

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**

If you have further comments, please provide these (*limit 2,000 characters)*

We acknowledge that this question is about, and for, medical professionals and so our response will be limited to the Church's direct engagement with healthcare.

CrossReach is the social care arm of the Church of Scotland. We are a large employer of people who act as carers, including in care home settings, and who do so partly as an expression and outworking of their Christian faith. Many Church members also act as volunteers to CrossReach services. The issue of assisted dying is not limited to medical healthcare provision, but decisions that a person takes will impact those around them. How the wider community of professional carers, volunteers and other staff are equipped to respond to issues of assisted dying will be as important as work within the healthcare sector. This needs to allow for the reality that a large number of people who look after others at the end of their lives will find the concept of assisted dying extremely difficult.

Parish ministers in particular, as well as healthcare, hospital and hospice chaplains, elders and church members who work as medics, are actively involved in providing pastoral, spiritual and medical care for people at all stages in life. For those who do not support assisted dying, the impact of how conscientious objection might also apply and be respected also arises. Clergy and church members already have experience of supporting people at the end of their lives, and understand how important it is to be able to die well, with dignity and love. If the Bill were to pass, is there a role for the Church (and other faith and belief groups) to share this experience, for instance in the production of guidance or training for health workers, care workers, families and friends? Should there be a requirement in the Bill to require Scottish Government Ministers to consult and produce such guidelines or to develop a programme of training and support?

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**

If you have further comments, please provide these (*limit 2,000 characters)*

In our internal discussions about this submission, it became clear that an individual's personal view on the principles of assisted dying determined their response to this question.

Opponents of assisted dying were deeply concerned that a legal process around death certification was open, honest and transparent. It was felt that matters around stigma, attitudes and feelings were not appropriate to be covered in this way through legislation.

Others felt that this was not a significant issue, and that if the Bill were passed it would be more pastorally sensitive to the person seeking an assisted death, and to their families and executors, who will be the ones who would need to use the death certificate for the various legal processes that would arise following a death.

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**

If you have further comments, please provide these (*limit 2,000 characters)*

The Church of Scotland has not considered in detail the reporting and review requirements set out in the Bill. It is likely that there will be a diversity of views within the Church, which would be dependent on an individual's support for or opposition to the principle of allowing assisted dying.

In our internal discussions about the Bill it was suggested that it may be beneficial to confer powers on Scottish Government Ministers to request the publication of data returns more frequently than annually, if it was deemed to be in the public interest. Monitoring data and analysis of underlying terminal illnesses would seem to be of practical use and public interest.

We also heard recommendations that in published regular reporting there should be a requirement for a review (independent from the patient's immediate care team) as to whether that patient's access to and experience of a good standard of palliative care has been assessed. This review should not be determinative of a patient's ability to seek an assisted death: but it is important that the Government (and general public) can track whether those seeking assisted dying have been able to access adequate palliative care. The answer to that question is of significant public interest: no one should be dying/led to seek an assisted death because the palliative care on offer was inadequate.

Question 8 – Any other comments on the Bill

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

Church of Scotland – review of position

The Church of Scotland has traditionally opposed the introduction of legislation which will allow assisted dying, euthanasia and other forms of assisted dying in Scotland.

At the General Assembly in May 2023 there was recognition that there exists a range of theological views and ethical opinions on assisted dying within the Church. A working group was formed to explore such views and opinions; this group is expected to report to the General Assembly in May 2025.

Video recordings of the General Assembly discussions in 2023 and 2024 are available online

2023 – from 2:01:45
https://www.youtube.com/watch?v=qz67eMy6Zv0&list=PLcE1-KuB42WKphW44xiPKVB8H5PeiDEM3&index=29

2024 –
https://www.youtube.com/watch?v=1tGSqTqC-Pw&list=PLcE1-KuB42WIyniZLGxB40OW79sgnEXSt&index=29

Our experience

Through the work of parish ministers, chaplains and others involved in the life of the Church of Scotland. we have extensive experience of walking with and supporting those who are close to death, and of their families and friends.

In addition, through our social care arm, CrossReach, we are one of the largest not-for-profit providers of social care in Scotland.

As such, and having seen the effects of stigma and discrimination on the client groups which they support, there remains significant concerns about the potential for abuse within this Bill. We are an organisation which fundamentally supports personal autonomy as it relates to the principles of choice and control and believe that all people have the right to a full life and dignified death. However, we are alert to the fact that the right to good support, which can help achieve both of those ends, can be eroded in situations where other factors take priority. These would include challenging financial situations for those who have a statutory responsibility for commissioning care services where we are already seeing people made to feel that they are a financial burden, and where care packages are being cut to balance the books. They could also include situations where people feel personally burdened by the care and support needs of another and we have witnessed the devastating effects of that.

People affected by alcohol or drug problems are specifically excluded from the protection of mental disorder, yet so often these substances have a significant effect on a person's mental health. We see huge positive changes in mental health when people get good levels of support.

We are aware that some disabled people and others supported because of their mental health, frailty, or addiction at a point in time have also expressed these concerns, as have groups

advocating for them. We would support the calls for further safeguards and clarifications to protect those with direct experience of stigma and discrimination, along with guarantees about what processes would have to be followed should the scope of the Bill be widened. If this Bill were to pass, it would be important that every effort is made in law, policy, practice and culture to avoid eligibility creeping wider beyond what Parliament intended. There are serious and sincere concerns that have yet to be answered about what the potential impact this change could have on disabled people and people in poverty, the pressures that they would face, and ultimately what this has to say about perception of their worth, dignity and value as human beings.

The challenge of capacity

Being a provider of specialist dementia services, we are particularly concerned about the question of capacity. The Bill does not specifically address dementia and we do not believe that wrapping it up as a neurological condition goes far enough. We are aware that some countries do make provision for assisted dying for those with advanced dementia despite the question of capacity, often where an advance directive is in place. We are also concerned about those with co-morbidity of dementia and another disease, such as Parkinson's disease and how the question of capacity will be judged if the person applying has deteriorating capacity before a final decision can be made.

Care Homes

We would want to see further clarification on the place of care homes, and under what conditions assisted dying would be carried out there as well as what safeguards would be in place, other residents, staff and families.

The rights of social care employees

The Bill does not address the complexities for those employed in social care and we believe that there are significant impacts for employees both in terms of their rights and their wellbeing.
We are concerned about the right of social care employees to object as a matter of conscience if put in the situation where they are providing direct care, including the need to support a person to eat and drink and take medication. The Bill as it stands covers health professionals only. It is entirely possible that care workers are put in an impossible situation, should the scope of the Bill be widened, wanting to support a person to exercise their rights and choices but also having a fundamental objection to assisting someone to die. There needs to be consultation with providers, Care Inspectorate and SSSC on this issue.
The Bill makes provision for a medical professional to withdraw from the room in section 15:6 once having prescribed and issued the lethal drug but does not address the situation of a care worker. We believe that needs further attention.

Not–for-Profit Social Care Providers

We note that one of the principles is that those participating in assisted dying would be exempt from criminal or civil liability but believe that the way in which the Bill is written covers those working in the NHS and primary health roles. It does not cover care homes. Further consideration needs to be given to those working in social care and providing services in care homes and communities. Social Care Providers unlike NHS are not covered by Government indemnity. This

became a major factor for social care organisations over the Covid-19 pandemic where insurance cover was not provided by an organisation's own insurers, nor Government, leaving the not-for-profit and independent sectors at high risk. We believe that this Bill holds similar risk for providers of social care unless the fundamental issue of assisted dying within social care settings is addressed and would urge further consultation with Providers, membership bodies and regulators.