

Proposed Assisted Dying for Terminally Ill Adults (Scotland) Bill

Introduction

A proposal for a Bill to enable competent adults who are terminally ill to be provided at their request with assistance to end their life.

The consultation runs from 23 September 2021 to 22 December 2021.

All those wishing to respond to the consultation are strongly encouraged to enter their responses electronically through this survey. This makes collation of responses much simpler and quicker. However, the option also exists of sending in a separate response (in hard copy or by other electronic means such as e-mail), and details of how to do so are included in the member's consultation document.

Questions marked with an asterisk (*) require an answer.

All responses must include a name and contact details. Names will only be published if you give us permission, and contact details are never published – but we may use them to contact you if there is a query about your response. If you do not include a name and/or contact details, we may have to disregard your response.

Please note that you must complete the survey in order for your response to be accepted. If you don't wish to complete the survey in a single session, you can choose "Save and Continue later" at any point. Whilst you have the option to skip particular questions, you must continue to the end of the survey and press "Submit" to have your response fully recorded.

Please ensure you have read the consultation document before responding to any of the questions that follow. In particular, you should read the information contained in the document about how your response will be handled. The consultation document is available here:

[Consultation Document](#)

[Privacy Notice](#)

I confirm that I have read and understood the Privacy Notice attached to this consultation which explains how my personal data will be used.

If you are under 12 years old and making a submission, we will need to contact you to ask your parent or guardian to confirm to us that they are happy for you to send us your views. Please **ONLY** tick this box if you are **UNDER** 12 years of age.

On the previous page we asked you if you are **UNDER 12 YEARS** old, and you responded **Yes** to this question.

If this is the case, we will have to contact your parent or guardian for consent.

If you are under 12 years of age, please put your contact details into the textbox. This can be your email address or phone number. We will then contact you and your parents to receive consent.

Otherwise please confirm that you are or are not under 12 years old.

No, I am over 12 years old and I have read and agree the Privacy Notice

About you

Please choose whether you are responding as an individual or on behalf of an organisation.
Note: If you choose "individual" and consent to have the response published, it will appear under your own name. If you choose "on behalf of an organisation" and consent to have the response published, it will be published under the organisation's name.

on behalf of an organisation

Which of the following best describes you? (If you are a professional or academic, but not in a subject relevant to the consultation, please choose "Member of the public".)

No Response

Please select the category which best describes your organisation

Representative organisation (trade union, professional association)

Please choose one of the following:

I am content for this response to be published and attributed to me or my organisation

Please provide your Full Name or the name of your organisation. (Note: the name will not be published if you have asked for the response to be anonymous or "not for publication". Otherwise this is the name that will be published with your response).

Scottish Care

Please provide details of a way in which we can contact you if there are queries regarding your response. Email is preferred but you can also provide a postal address or phone number.

We will not publish these details.

Aim and Approach - Note: All answers to the questions in this section may be published (unless your response is "not for publication").

Q1. Which of the following best expresses your view of the proposed Bill?

Neutral (neither support nor oppose)

Please explain the reasons for your response.

As the representative body for the independent care sector, Scottish Care has members that provide many

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different types of care and support services – for older individuals, people with disabilities and other adults with life-limiting conditions. Many of the services we represent have strongly held philosophical and religious traditions and perspectives, and the vast majority of our members are engaged in palliative and end of life care of residents in residential and nursing homes and those who live independently with support in the community. We have therefore determined to seek to be neutral in our response to reflect a diversity of views on what is a highly contentious and often emotive issue. In doing so, however, we want to be clear that should legislation be considered and implemented that we believe that there needs to be a robust system of safeguards and a transparent operational framework established to ensure the safety and dignity of those who are supported and cared for now and into the future. We also believe that consideration of any change in the law should be accompanied by, and ideally preceded by, a rigorous examination of the current state of palliative and end of life care in Scotland as a whole but in particular as that care is delivered by the social care workforce.

In examining the nature of the debate on assisted dying in Scotland we are concerned that the discussion has often become polarised, has used language emotively and on occasion has lacked a robust evidential grounding, from whatever perspective the argument might have been made.

There are very obvious sensitivities around the issues under discussion and the careless use of language can exacerbate unhelpful stereotypes and debate. It is incumbent upon us all, therefore to be cautious and careful in our use of language and sensitive to the inevitably partisan nature of the debate, and we regret that at times this is not evident in the consultation document, even in the first words of the Bill sponsor in his foreword:

"I have long believed that the people of Scotland should be able to access safe and compassionate assisted dying if they choose, rather than face the potential of a prolonged and painful death."

Or when the consultation document states that:

"...an end to the current blanket ban on the right to a compassionate death is long overdue..."

The choices open to those who consider the consultation, and who may be required to vote on the introduction of any new legislation, should not be articulated as one between an excruciating and painful death on the one hand and being assisted to die on the other. We would contend as the consultation document itself does that at the centre of choices around support in dying should be a robust and adequate palliative and end of life care provision and an end-of-life experience which enhances individual control, embeds human dignity and which is enshrined as a legislative right.

In potentially introducing such a significant change, as that envisaged by the proposed legislation, to the maintenance of individual life and the exercising of personal autonomy, we want to be assured that the legislators making these decisions are as informed as they require to be. To that end the following is offered as a constructive support.

Scottish Care has long advocated for a recognition that social care services and its workforce are a primary agency in delivering effective and local 'generalist' palliative care support and end of life care. The vast majority of care support delivered in care homes and in the community by homecare staff enables individuals who are on a palliative care and end of life pathway to live as full, meaningful and independent lives as possible. You cannot understand social care without understanding palliative and end of life care especially for an older population group. In particular, the extensive skill based developed by social care staff especially but not exclusively in care homes, in supporting people in advanced stage dementia and other neurological conditions is of real societal benefit and significance and we would argue, itself specialist in nature.

We have therefore argued that palliative and end of life care should be seen as an essential continuum and as part of the delivery of dignity-infused, person-led and rights-based support and care. Such care support will be an intrinsic part of the soon to be developed National Care Service. It is therefore important that we understand the extent of palliative care provision in Scotland and whether or not citizens have been enabled to access palliative care and end of life care which properly meets their needs. We would consider such an assessment to be a primary first step in considering any legislation on assisted dying. In relation to which we simply do not recognise the Consultation's assertion that Scotland has one of the best palliative care systems in the world. This is without evidence and foundation.

In this regard we would concur with the robust findings and recommendations of the report 'Every Story's Ending' published earlier this year by the Scottish Partnership for Palliative Care. This extensive and robust report resonates with our own research and analysis, not least in our report 'The Trees that bend in the Wind' and subsequent work. The experience of the social care sector in Scotland whether that be in care home or homecare is of a fractured, inconsistent, and significantly under-resourced delivery of palliative and end of life care support. In particular we have long expressed concern that there has been a failure to properly resource and prioritise the palliative care of those living with advanced dementia. It is our view that many of the laudable aims of the Strategic Framework for Palliative Care have not been fully realised or achieved, although the lack of any formal and independent analysis of this former strategy, makes such a statement hard to substantiate beyond anecdote and practitioner experience. If we were to be asked whether as a society we have achieved all that we could in terms of palliative and end of life care, the response from social care services and practitioners in Scotland would be a resounding no. In considering the Consultation we would want to underline our support of enabling people who want to die

Q1. Which of the following best expresses your view of the proposed Bill?

at home or in a homely setting to achieve their wishes without unnecessary and unscheduled admission to hospital in the last months and year(s) of life and without interventions which they do not wish or do not believe will add to the quality of their life. The ability to have a person-led death in so far as it is possible necessitates real change in supporting the social care sector to deliver effective palliative and end of life care which enables individual citizens to exercise real choice and live their last days with dignity. Significant change to current delivery requires the need to reform commissioning, increase financial investment in specialist services, and to better train and support the social care workforce.

Q2. Do you think legislation is required, or are there other ways in which the Bill's aims could be achieved more effectively? Please explain the reasons for your response.

We have indicated a neutral position on the requirement of a Bill and remain to be convinced that there is sufficient support for it. Public opinion has been much mentioned in the consultation but the experience of the social care sector, not least during pandemic response, points to the fickle and transitory nature of such 'opinion.' Further we are concerned that critical decisions risk being made, as noted above, on a lack of real understanding of what choices are available to citizens. There is at least a debate to be heard around whether the tragic cases which have been mentioned in the Consultation are in part as a result of inadequacies in treatment and care, and also more independent evidence required as to the actual extent of demand for assisted dying within the Scottish population. To the end that such debate and discussion, including a more societal conversation around death and dying per se, can only add value, then the desire to debate the Bill is one we welcome. The aim of ensuring that individuals have a 'good death' should be a priority of all, and in part we would contend that this would be substantially and significantly achieved were there to be a refocus upon the potential to deliver a well-resourced and extensive palliative and end of life care provision across Scotland.

In September 2021, we saw commitment in the Programme for Government to the creation of a new Palliative and End of Life Care Strategy as well as further work in the development of a new Human Rights Act for Scotland. With all these changes and initiatives, we are at a point of real potential and opportunity. For those of us who have worked in palliative and end of life care for many years there has been a desire to create systems and models, supports and structures, relationships and freedoms, which enable people to end their life in a way which upholds their choice and dignity, supports them and their families and friends, and ensures that we become the best nation in which to end one's life such is the quality of palliative and end of life care support.

At Scottish Care, we have previously spoken about the human right to palliative and end of life support and believe strongly that the creation of a Scottish Human Rights Act should underpin this particular human right. We have called for such new legislation to fully incorporate the International Covenant on Economic, Social and Cultural Rights including a 'right to health', part of which we have argued should be a holistic human right to palliative and end of life care. Scotland has the legislative, policy and practical opportunity to become the first nation to enshrine such a right within our society and community – an opportunity which should not be lost. It would be deeply regrettable that at a time when there is a potential to enshrine in law a right to assisted dying that there was not at the same time enshrined in Scottish law a right to palliative and end of life care.

In addition, we believe that it is important that there is significant focus upon, including a renewed resource and capacity building of the social care workforce, to anticipatory care planning. We support every opportunity for people to adequately prepare for their own death; it is through this process we engage upon the most person-centred activity we will ever undertake. The current proposals do not, we believe, develop the potential of this area of work, and the associated risks, sufficiently.

Q3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 in the consultation document (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Neutral (neither support nor oppose)

Please explain the reasons for your response, including if you think there should be any additional measures, or if any of the existing proposed measures should be removed. In particular, we are keen to hear views on Step 2 - Reflection period, and the length of time that is most appropriate.
Step 1 – No comment

Q3. Which of the following best expresses your view of the proposed process for assisted dying as set out at section 3.1 in the consultation document (Step 1 - Declaration, Step 2 - Reflection period, Step 3 - Prescribing/delivering)?

Step 2 – The experience of many practitioners in social care is that individuals consistently and continually change their minds in a palliative and end of life context. We therefore strongly support a reflection period.
Step 3 – No comment

Q4. Which of the following best expresses your views of the safeguards proposed in section 1.1 of the consultation document?

Fully supportive

Please explain the reasons for your response.

We strongly agree that safeguards require to be robust and 'owned.' In order for them to give the adequate and necessary protections. We would have liked to have seen some further evidence in the Consultation paper on the evidence basis for the safeguards which have been described, regardless of our agreement with them.

As stated above we believe that planning is a critical safeguard. It helps safeguard an individual's ability to make informed choices and have control over their care and support. This in turn will help in enabling them to live and die well, on their own terms, where possible at home or in a homely setting, and make the best use of their communities and their individual assets. This is especially if individuals become incapacitated and unable to make decisions about life-sustaining treatments later in their care.

Whilst we fully recognise that the current proposed Bill is solely related to those who have capacity and are able to consent, experience from elsewhere suggests that these lines are not always as robust and clearly defined as they might be, and as a whole society we require assurances especially for those living with latter stage neurological conditions, that there is robust clarity around issues of capacity, especially if fluctuating in nature.

When thinking about advanced care planning and consent in Scotland, extensive safeguards must be in place: requiring clinicians familiar with the patient's prognosis and treatment options to participate in the formulation of directives; assuring regular review of decisions; allowing physicians to err on the side of preserving life when uncertain about the application of an advance care directive; specifying the role of the health care proxy in interpreting or even overriding directives; requiring specialised counselling for non-emergent choices to limit life-sustaining treatment; training and certification of clinicians for conducting such conversations; and use of structured formats, clinical guidelines, and system support aides that promote quality and safety. Finally, associated research needs should also be outlined.

As the consultation highlights other locations where assisted suicide procedures are available, we believe that similar safeguards to these locations would need to exist in Scotland. We believe that those noted in the consultation take us partially along that road.

Evidence suggests that people provided with early and effective palliative care and support in all settings had better outcomes, with a better quality of life, fewer depressive symptoms, and on average that they live longer, even when opting for less for curative (and often futile) treatment. All of these elements enabling a robust palliative and end of life care provision would, we would argue, need to be guaranteed as considered and/or in place in preceding the ultimate decision that an individual would like to choose an assisted dying pathway. There needs to be independent evidence that the best available palliative care provision was accessible by the individual.

Q5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

Neutral (neither support nor oppose)

Please explain the reasons for your response, including whether you think this should be a new or existing body (and if so, which body) and what data you think should be collected.

Scottish Care has spoken extensively about data, highlighting the potential for data in social care if it is approached using the co-produced principles for data as outlined in the report 'Seeing the Diamond in Social Care Data'. By adopting the principles (such as citizen activated and citizen controlled, people should only have to tell their story once, among others), we can build trust, improve strategy and policy,

Q5. Which of the following best expresses your view of a body being responsible for reporting and collecting data?

and ultimately, quality of care and support.

A new body to be responsible for the data collection and reporting would need to make clear:

- Who would this body be?
- Who would be required to enter all the information?
- How would it work in relation to data collected for people that are in hospices, care homes and those who are receiving palliative care?
- How would it work/look for people who receive care and support more generally?
- How would it integrate with existing systems (Care Inspectorate, Turas, etc.)?
- How would this integrate with NHS-held data?

We have asked for the adoption of systems which interact with the existing reporting tools that people, and providers already use to capture data, and which would give ownership of data to the citizen in a method which is not dissimilar in conception to a simplified Blockchain technology, and which already exists in the marketplace.

Data generated from care planning is a significant and developing source of information for supporting commissioning decisions. The strategic commissioning of palliative and end of life care should take account of these other related areas of policy and delivery. We would ask that any new system and body take all of this into consideration as there is a real risk of duplication and overreporting.

Q6. Please provide comment on how a conscientious objection (or other avenue to ensure voluntary participation by healthcare professionals) might best be facilitated.

No comment.

Financial Implications

Q7. Taking into account all those likely to be affected (including public sector bodies, businesses and individuals etc), is the proposed Bill likely to lead to:

a significant increase in costs

Please indicate where you would expect the impact identified to fall (including public sector bodies, businesses and individuals etc). You may also wish to suggest ways in which the aims of the Bill could be delivered more cost-effectively.

As we have stated throughout this response, we believe that there is a requirement for substantial and significant investment in palliative and end of life care. We would contend that such a financial investment needs to be across the whole of palliative care delivery but most especially in social care supports. We note that the consultation evidence (pages 15-16) numerous instances where following the adoption of assisted dying legislation in other administrations that this resulted in significantly increased resource being made available to palliative and end of life care. Whilst this on its own is useful evidence we would have hoped that the valuing of effective and quality palliative care was not subject to or dependent upon any new legislation, however related it is. Palliative care and end of life care should be, as we have stated, be seen as a human right in its own terms, deserving of appropriate financial resourcing and priority. If equivalent figures were to be extrapolated to a Scottish context this would result in a required investment of tens of millions of pounds.

The mere assertion of evidence of financial investment in palliative care from other jurisdictions is not sufficient guarantee that this will occur in Scotland. There are many financial constrictions facing our nation at the present time and the creation of a new National Care Service alone will result in massive financial investment. We are therefore deeply concerned that not only will the new legislation result in specific new expenditure in its own right but that the required investment in palliative and end of life care will not be forthcoming.

Equalities

Q8. What overall impact is the proposed Bill likely to have on equality, taking account of the following protected characteristics (under the Equality Act 2010): age, disability, gender re-assignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, sex, sexual orientation?

Slightly negative

Please explain the reasons for your response. Where any negative impacts are identified, you may also wish to suggest ways in which these could be minimised or avoided.

As iterated in the Bill proposal, there is likely to be more significant impact on certain protected characteristic groups, many of whom access care and support - whether due to age, ailment or disability (among others). It is essential that health and social care standards be upheld and that human rights principles maximise the dignity of people so any potential for discrimination is avoided. Regrettably we live in an ageist society in which decisions are not infrequently made which disadvantage and discriminate against older persons solely on the grounds of their age and where those of older age are considered to be of less worth than others. The experience of the response to the pandemic has been one which many older people organisations believe to have been one of discrimination, including highly questionable clinical ethical frameworks which potentially used age as a proxy for hard decisions in the context of resource restriction. Scottish Care is concerned that in the context of a national emergency such as a pandemic that the existence of any legislation can be undermined, and that due priority is not given to human rights-based legislation and protections. This general concern is especially heightened when we might have in statute the ability of the State to support an individual to end their own life.

Sustainability

Q9. In terms of assessing the proposed Bill's potential impact on sustainable development, you may wish to consider how it relates to the following principles:

- living within environmental limits
- ensuring a strong, healthy and just society
- achieving a sustainable economy
- promoting effective, participative systems of governance
- ensuring policy is developed on the basis of strong scientific evidence.

With these principles in mind, do you consider that the Bill can be delivered sustainably?

Unsure

General

Q10. Do you have any other additional comments or suggestions on the proposed Bill (which have not already been covered in any of your responses to earlier questions)?

If the proposed legislation were to be enacted there would be inevitably some instances where an individual who makes such a request is being cared for and supported in a residential or nursing home. As the representative body of care home providers Scottish Care is concerned, as has been the experience elsewhere in the world, that this negatively impacts on the experience and wellbeing of other residents who live in such shared environments and communities. In addition, there are also associates risks upon staff who may have conscientious objection to the proposed practice, as although they may

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have no direct involvement they are inevitably engaged by association and direct care. There are also very real risks of a negative damage to the care home per se in terms of public confidence, reputation and messaging around older person care. We call upon those considering the Bill to give serious thought to how these practical issues can be minimised, to consider what workforce development, support and capacity building may be required, and the risks of any wider societal messaging which may result from any proposed interventions.