

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.

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 Response

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

Third sector (charitable, campaigning, social enterprise, voluntary, non-profit)

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).

Parkinson's UK Scotland

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.

Parkinson's UK Scotland neither supports nor opposes a change in the law to allow assisted dying, although we monitor proposed changes in legislation and policy to make sure that the specific issues might affect people with Parkinson's and those closest to them are addressed. Our position is neutral because we recognise that people with Parkinson's and their partners, families and friends have a wide range of

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

personal beliefs on this issue.

Parkinson's UK Scotland believes that with the right care and support, many people with Parkinson's can have a good quality of life for many years after diagnosis. We believe that people with Parkinson's, their carers and families have a right to effective health and social care services at every stage of the condition, including at the end of life.

This includes timely provision of good quality information so people know what support is available at every stage and how they can access it.

We recognise that everyone with Parkinson's experiences the condition differently, and acknowledge that individuals hold a wide range of personal beliefs about end of life decision making, including assisted dying.

We believe that people with Parkinson's should be given the opportunity to exercise their right to make decisions about end of life care in good time, and that the decisions and wishes of people with Parkinson's should be at the centre of their care.

Parkinson's UK Scotland would like to highlight some issues around the use of "terminal illness" in the bill. Conditions like Parkinson's which are progressive and incurable are often not considered to be "terminal" – possibly because people can live for many years after diagnosis and can often live with very advanced illness for a period of many months or years. Many people with Parkinson's would not identify themselves as terminally ill.

The pattern of progression with Parkinson's is different from that typically seen in conditions like cancer and organ failure. On average, people live with the most advanced stages of Parkinson's for around two years, but this is highly variable and needs may change towards the end of life.

Prognostication is very difficult for people with a condition like Parkinson's, and the uncertainty involved in assessing someone on a protracted trajectory of frailty makes doctors more reluctant to identify that someone may be reaching the end of their life.

People with advanced Parkinson's have quality of life as bad as – and in some cases worse than – those with terminal cancer and motor neurone disease (MND). Yet People with Parkinson's are much less likely to have been involved in advance care planning, or to have received specialist palliative care input than those with other types of condition. This reflects wider work showing that people with non-malignant conditions are very unlikely to receive specialist palliative care input at all, such as work by Audit Scotland and Marie Curie.

Recently, YouGov was commissioned by the campaigning organisation Dignity In Dying to assess attitudes to assisted dying. From 502 participants, 207 had a diagnosis of Parkinson's. Of those with Parkinson's, the overwhelming majority (89%) reported that their doctor had not discussed end of life care with them.

The consultation document proposes that the definition of terminal illness used to define access to disability assistance under special rules in Scotland should be used. Parkinson's UK Scotland believes that using this definition would make it more likely that people with progressive neurological conditions like Parkinson's would identify themselves - and be identified by clinicians - as being terminally ill than if a prognosis-based definition was used.

We believe that if the Bill were to proceed, it would be absolutely essential to create guidance for clinicians about the factors to consider in reaching a clinical judgment that the person was reaching the end of their life. The process for determining terminal illness in respect of special rules in Scotland is underpinned by extensive guidance from the Chief Medical Officer for clinicians, and we would suggest that similar guidance must be developed for this purpose. It may be necessary to include some aspects of the guidance on the face of the bill. We believe that both legislation and guidance would have to make clear that having a diagnosis of a condition like Parkinson's - which typically progresses over many years - would not be the only factor to be considered.

It is also important to consider public messaging and debate around any legislation, which could have unintended consequences. Specifically, Parkinson's UK Scotland is concerned about the risk that people

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

with a new diagnosis of Parkinson's could get the message that they could - or should - consider assisted dying solely on the basis of their diagnosis.

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.

Parkinson's UK Scotland does not have a view about whether or not legislation to "enable mentally competent adults who are terminally ill to be provided with assistance to end their life at their request" is required in Scotland.

However, it is clear that the aim of the proposed bill cannot be realised in Scotland without legislative change. When MSPs have considered previous proposals for similar legislation, witnesses from all sides of the debate have agreed that there is a lack of clarity about the current law in Scotland. Disagreement has arisen around whether or not the current legal ambiguity may be helpful, as well as how the law could - or should - be changed to clarify this.

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. Please see commentary on section 4.

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

Neutral (neither support nor oppose)

Please explain the reasons for your response.

Capacity

Parkinson's UK Scotland would particularly highlight the need for appropriate assessment around capacity for people with Parkinson's. We believe that additional provisions may be needed around expert assessment and communication support.

As Parkinson's progresses, people may lose mental capacity. About 3 in 10 people with Parkinson's have dementia, and people with Parkinson's are around 6 times more likely to develop dementia than people of the same age without the condition. A diagnosis of dementia does not automatically mean that a person lacks mental capacity, and in Parkinson's-related dementia, it is very common for capacity to fluctuate. In addition, mental health symptoms and medication side effects can also affect capacity - depression, psychosis and impulse control disorders are common. In light of these condition-specific complexities, Parkinson's UK Scotland believes that doctors assessing capacity in a person with Parkinson's should have specific expertise in the mental health and cognitive aspects of the condition to ensure that capacity is accurately assessed.

Capacity is also affected when a person is unable to make themselves understood. People with advanced Parkinson's commonly experience communication difficulties, making it much harder to make their wishes known. When a person's speech is affected, we believe that communication support via technology or speech therapy must be provided and that it will be important to make sure that communication support needs are considered if the bill proceeds.

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

Informed decision-making and coercion

Parkinson's UK Scotland believes that any legislation would need extremely robust safeguards around assessing whether or not someone is making an informed decision or is being coerced. The consultation paper lacks detail about how two doctors would assess this in practice, and we believe professional guidance would be needed to underpin any legislation. Parkinson's UK Scotland believes that other types of professionals such as social workers or counsellors might be better placed than doctors to investigate the wider context in which a decision is being made.

Information about care options

We have outlined the evidence that people with Parkinson's are often not informed about care options at the end of life, and that it can be difficult for people with progressive neurological conditions, including Parkinson's, to access specialist palliative care services offered by the NHS and third sector.

Most people with Parkinson's receive end of life care from generalist health and social care workers, including GPs, district nurses, ward and care home staff and home care workers. People with Parkinson's who are dying with advanced Parkinson's can have very complex needs spanning major physical and cognitive impairments, bladder and bowel issues, communication problems, pain, swallowing issues and autonomic system problems. Parkinson's medication may need to be withdrawn as side effects can begin to outweigh any benefits. Typically, a multi-disciplinary team approach to care is needed including speech therapy, physiotherapy, occupational therapy and dietetics as well as hands-on nursing care, support with activities of daily living and expert advice on medication. We know that this is often not available to people with Parkinson's - and especially to those who are resident in care homes, people who are in hospital, and those who can no longer leave their home.

For people with Parkinson's it is important that services are provided to meet current unmet need - and this means that information about available support is not enough. Whether or not legislation on assisted dying proceeds, there is a need for additional investment in support for people living and dying with advanced Parkinson's.

Signing a written declaration

People with Parkinson's often experience issues with handwriting from an early stage with the condition and can have particular difficulties with signatures. If the legislation were to proceed, consideration would need to be given to whether other kinds of signature (eg a simplified signature, mark, initials, stamp or electronic signature) could be accepted from people whose ability to manage a pen and paper is impaired.

Reflection period

If the bill were to proceed, Parkinson's UK Scotland is uncertain about how people expected to die within 30 days would be identified, given studies that show that prognostication is very difficult and doctors' estimates of life expectancy can be very inaccurate. We also note that there is no suggestion about a minimum waiting period for people whose death is expected within 30 days. We would suggest that one would be needed if the bill were to go ahead.

Self-administration

Parkinson's UK Scotland notes that the requirement to self-administer the life ending medication may mean that people with advanced neurological conditions like Parkinson's which affect gross and fine movement and swallowing may be excluded from the legislation. If the bill were to proceed, we recommend that consideration be given to this.

Recording

Parkinson's UK Scotland believes that if the bill were to proceed, robust independent monitoring would be absolutely essential with a presumption of access to relevant information for relatives and friends of individuals where that can be provided.

The Covid-19 pandemic exposed some very concerning practices around existing end of life decision-making, including blanket imposition of so-called "do not resuscitate" (do not attempt CPR) orders on groups of patients without consultation. This caused significant anxiety amongst people with Parkinson's in Scotland and rUK. Age Scotland has called for a Parliamentary Inquiry into the extent of this practice in Scotland. Doubts about whether individual consent processes were bypassed by some clinicians persist. Many disabled people and older people - including people with Parkinson's and their families - would require a very high level of scrutiny to be in place to make sure that the system was not abused.

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

If the bill were to go ahead, Parkinson's UK Scotland believes that it will be important that family members and friends are able to access the records around a person's decision, although this may need to be balanced by respecting the deceased person's confidentiality where they have requested this.

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.

Please see comments in Section 4.

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

Parkinson's UK Scotland does not have a view on this.

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:

don't know

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.

Parkinson's UK Scotland does not believe that it is helpful to frame this legislation in terms of costs to the NHS, social care, individuals, families or businesses.

We recognise that much of the public discourse around people with long term health conditions, disabled people and older people is framed in terms of the financial costs of accessibility, care and social security rather than the huge contribution that people from all kinds of backgrounds make in an inclusive society. We know that many people with conditions like Parkinson's fear being perceived as a burden, and are acutely aware of the financial impacts that their condition has on their income and that of other members of their household or family.

An average household in Scotland affected by Parkinson's loses £13,375 per year because of the condition, which explains why people are concerned.

Just one example of high costs for some people with Parkinson's is care home costs. Parkinson's is so complex that people with the condition are much more likely to need support in a care home setting than people of the same age without the condition. According to the Scottish Care Homes Census, in 2018-19 (last figures available) the average weekly fees for a self funded care home resident were £995 per week with nursing care, and £894 per week without nursing care.

Self-funding care home fees are far in excess of what most people would understand as reasonable accommodation costs, and bear no comparison with a typical rent or mortgage payment. The average private sector rent for a 1 bedroom property in Scotland in 2019 was £519 per calendar month. A typical

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:

self-funded care home place with nursing care in Scotland would have cost more than 8 times that amount in 2019.

There is significant unmet need in terms of health and care support for people with advanced Parkinson's, which means that more investment will be needed regardless of the outcome of this legislation.

Living with advanced Parkinson's can be very challenging, and depression and anxiety caused by Parkinson's can make it much harder. Nobody should make a decision about their end of life care on the basis of cost or perceived cost to them, their family or to society as a whole.

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?

Neutral (neither positive nor 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.

Parkinson's UK Scotland does not have a position on this.

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

Please explain the reasons for your response.

Parkinson's UK Scotland does not have a position on this.

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)?

Please see list of references below. These can be provided in a word document if preferred:

Higginson IJ, et al. (2012) Symptoms and Quality of Life in Late Stage Parkinson Syndromes: A Longitudinal Community Study of Predictive Factors. PLoS ONE 7(11): e46327.

Goy ER, Carter J, Ganzini L (2008) Neurologic disease at the end of life: caregiver descriptions of Parkinson disease and amyotrophic lateral sclerosis. J Palliat Med. 11(4):548-54

Walker RW (2013) Palliative care and end-of-life planning in Parkinson's disease J Neural Transm 2013 120:635–638

Richfield EW et al (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions Palliat Med 2013 27: 805

Ghoche R (2012) The conceptual framework of palliative care applied to advanced Parkinson's disease Parkinsonism and Related Disorders 18 S2eS5

Audit Scotland. (2008) Review of palliative care services in Scotland.

Dixon J et al (2015). Equity in Provision of Palliative Care in the UK. LSE, PSSRU, Marie Curie.

Dignity in Dying (2019) What Matters to me <https://cdn.dignityindying.org.uk/wp-content/uploads/What-matters-to-me-Dignity-in-Dying-Nov-2019.pdf>

Social Security Scotland Disability Benefits Policy Terminal Illness CMO guidance V1.0 <https://www.socialsecurity.gov.scot/guidance-resources/guidance/chief-medical-officers-guidance-for-clinicians-completing-a-basis-form-for-terminal-illness>

Age Scotland (2021) Age Scotland Calls for Scottish DNACPR Inquiry <https://www.ageuk.org.uk/scotland/latest-news/2021/march/age-scotland-calls-for-scottish-dnacpr-inquiry/>

Public Health Scotland Care Home Census 2009 - 2019 <https://publichealthscotland.scot/publications/care-home-census-for-adults-in-scotland/care-home-census-for-adults-in-scotland-statistics-for-2009-to-2019/>

Scottish Government Private sector rent statistics 2010-2019 <https://www.gov.scot/publications/private-sector-rent-statistics-2010-2019/documents/>