Proposed Right to Palliative Care (Scotland) Bill Consultation Response from Parkinson's UK Scotland

Respondent Information

This is an organisational response and can be published in full.

Contact: Tanith Muller, Parliamentary and Campaigns Manager, Parkinson's UK Scotland
Email: tmuller@parkinsons.org.uk
Phone: 0344 225 3726 / 07899 064 087

X I confirm that I have read and understood the privacy notice to this consultation which explains how my personal data will be used.

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About Parkinson's and Parkinson's UK Scotland

Parkinson's is the fastest growing neurological condition in the world. Nearly 13,000 in Scotland have Parkinson's, and over 30 people are told they have the condition each week.

Parkinson's is what happens when the brain cells that make dopamine start to die. There are more than 40 symptoms which impact on all aspects of daily living including walking, speaking and eating, mood and thinking. Parkinson's gets worse over time and no existing treatment can slow down, stop or reverse its progress. Every year, hundreds of people in Scotland die with Parkinon's recorded on their death certificates as a cause of death or a contributor to it.

Parkinson's UK Scotland is here for everyone affected by Parkinson's. We are part of Parkinson's UK, which funds research into the most promising treatments, taking us closer to a cure every day. We fight for fair treatment and better services.

Our small staff team works alongside our volunteers and supporters in Scotland. We have over 40 volunteer-led local groups and other activities based in every community in Scotland and are developing more. We offer free and confidential information and support to people with Parkinson's and their partners, family members and friends via our team of community-based Parkinson's local advisers. We support individuals at every stage from Parkinson's diagnosis to the end of life and post-bereavement.

Parkinson's UK Scotland also works closely with health and care professionals who support people with Parkinson's, through the UK Parkinson's Excellence Network.

The range of our work means that we have both direct and indirect insight into many of the issues that people with Parkinson's face when dealing with deteriorating health and death.

Aim and approach

1. Do you agree that terminally ill adults and children and young people with life shortening conditions residing in Scotland should have a right to palliative care?

Strongly agree
Partially agree X
Neutral (neither support nor oppose)
Partially disagree
Fully disagree
Unsure

Please explain the reasons for your response, including what you think a right to palliative care should deliver.
Parkinson's UK Scotland supports the principle that everyone who can benefit from palliative care should be able to access it. We believe that this support can be offered at any point from diagnosis, in line with current NICE Guideline 72 on Parkinson's Disease in Adults.[1]

[1] NICE (2017) NICE Guideline 72: Parkinson's Disease in Adults, recommendation 1.9 Palliative Care

Our specific area of interest, however, is in the provision of support for people diagnosed with Parkinson's. We believe that a legal right to palliative care has potential to address inequalities in access for those who are currently largely excluded from this support, including people with Parkinson's and those supporting them.

We are concerned that people with Parkinson's and their partners, family members and friends often miss out on specialist palliative care services, and that both Parkinson's specific services and more general care and support services could do much more to support people living with deteriorating health and at the end of life. People with Parkinson's and their families may have experiences in common with those with other progressive neurological conditions, including dementia, multiple sclerosis (MS), Huntington's, motor neuron disease (MND), progressive supranuclear palsy (PSP) and multiple system atrophy (MSA).

We have clear ideas about what a right to palliative care should look like, but we'd like to raise some issues around the use of the word "terminal" which could have unintended consequences in terms of entrenching existing inequalities.

We believe that it is important to make sure that any legal right to palliative care is accompanied by resourcing to enable people to access this right. The evidence shows that there is currently a very wide gap between the services and support that people with Parkinson's can currently access and high quality person-centred and multidisciplinary palliative care.

What should be included

NICE 72 outlines the need for people with Parkinson's and their partners, family members and friends to be given support based on their personal preferences and shared decision making, covering:

- Information about prognosis
- Future planning
- Options and support for people whose Parkinson's has progressed
- Referral to specialist palliative care teams

We believe that it is important that unpaid carers are explicitly included in the provision of care, along with the person that they support.

To the areas above, we would add explicit identification of the social care and community-based supports in addition to NHS / healthcare facilities.

Current access to this for people with Parkinson's

Parkinson's is progressive and there is no current medical treatment that can slow down, stop or reverse the progress of Parkinson's. Over time, symptoms change and worsen, and medications become less effective. People with advanced Parkinson's have quality of life as bad as – and in some cases worse than - those with terminal cancer[2] and motor neurone disease (MND).[3]

Early future planning discussions are particularly important because people with Parkinson's are 6 times more likely to develop dementia than people of the same age without the condition.[4] About 3 in 10 people with Parkinson's at any given time have dementia.[5] In light of the risk that people may not retain consistent capacity, it is important for people to be given the opportunity to make sure that their wishes and preferences are known as soon as possible. Of course, these discussions should also be revisited regularly, and even when someone lacks capacity they are often still able to express their preferences and needs.

Despite clear clinical guidance promoting access to future planning for people with Parkinson's, evidence from NHS Scotland Parkinson's services shows that many people are not receiving this.

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[2] 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.

[3] 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

[4] Giuntoli C, et al. Incidence of dementia in Parkinson's disease: The PINE study. Journal of Neurology, Neurosurgery and Psychiatry 2014:85e4.

[5] Aarsland D, Kurz MW. The epidemiology of dementia associated with Parkinson's disease, Neurol Sci. 2010 Feb 15;289(1-2): 18-22

The UK Parkinson's Audit takes place every 2 - 3 years as a service improvement tool for NHS Parkinson's services that opt in. In 2022, the Audit covered 47 NHS Scotland services in 11 NHS Boards, and examined 859 patient records. Separately, some 666 people with Parkinson's and unpaid carers completed the Audit Patient Reported Experience Measure survey in Scotland.

The 2022 Audit shows that about 1 in 5 (21%) of people with Parkinson's in Scotland had signs that their condition was advanced - such as dementia, swallowing issues or frailty. Yet even for this group of people, fewer than half (41%) had a discussion about end of life care in the previous 12 months. And across the whole group of people with Parkinson's in Scotland in the Audit, fewer than 2 in 5 (38%) had a record of any discussion around setting up Power of Attorney.[6]

This does mark an improvement from previous Audits, and services in Scotland are performing better than their peers in the rest of the UK, but there is still a long way to go. It also reflects published research in this area, which shows that 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.[7] [8] [9] In general, people with non-malignant conditions are very unlikely to receive specialist palliative care.[10] [11]

Recent analysis of place of death data in England and Wales showed that people with Parkinson's were less than half as likely as the general population to die in a hospice - about 2% of people with Parkinson's died in this setting. In contrast, 39% of people with Parkinson's died in a hospital and 39% in a care home.[12]

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[6] UK Parkinson's Audit 2022 - unpublished data.

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

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

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

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

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

[12] Wilson E et al. Place of death in Parkinson's disease and related disorders in England and Wales: post-pandemic trends and implications for care planning. Age Ageing. 2024;53(3):afae048. doi:10.1093/ageing/afae048

Issues around "terminal illness" terminology

Parkinson's UK Scotland would like to highlight some issues around the framing of entitlement to palliative care around terminal illness. It is for this reason that we can only "Partially agree" with the proposal.

Although Parkinson's is progressive and incurable, it is rarely described as "terminal" – possibly because people can live for many years after diagnosis - and with very advanced illness for months or years. Prognostication is particularly challenging for people with Parkinson's which can make it very hard to identify when someone has reached the end of their life.

Many people with Parkinson's would not identify themselves as terminally ill - indeed, many have been told that their condition is not terminal, and that they will die with, rather than of, Parkinson's.

There are great sensitivities around understanding of the word terminal. Some people with progressive and incurable conditions would consider the use of terminal to suggest that they are reaching the end of their life imminently. They may not consider this to be the case and still benefit from general and / or specialist palliative care.

For this reason, we believe that eligibility of the legal right to palliative care should be based on the wording used in the WHO definition of palliative care - of life threatening conditions, rather than terminal illness. Another option may be to consider using "life limiting" conditions, or conditions causing deteriorating health.

2. What is your view on the World Health Organisation definition of palliative care, that is the basis of statutory guidance in England on palliative care provision, being the basis for a legal right to palliative care?

Please explain the reasons for your response, and whether you think a different definition of palliative care should be considered for health and social care legislation, human rights legislation, and other forthcoming legislation that is relevant to how people may experience end of life.

Parkinson's UK Scotland supports this broad definition. We particularly welcome the use of "life threatening" conditions in this definition which may make it easier for those with non-malignant conditions to access the support they need.

However, it is important to consider how this definition is likely to need to be supplemented by more detailed guidance about how services will know that someone is eligible for palliative care support, so that they can provide it.

Parkinson's and other neurological conditions associated with frailty are often characterised by considerable uncertainty about prognosis. People with Parkinson's often experience sudden deterioration in their health in response to a crisis like an infection or a fracture, which are - by their nature - unpredictable. And one of the things that makes conditions like Parkinson's so challenging for individuals and families to live with is that the future is often so unpredictable.

For these reasons we would oppose guidance restricting access to support in terms of estimated prognostic timescales. In terms of existing legal guidance, we would refer to the Chief Medical Officer's Guidance to determine when a person can access to Social Security Scotland disability benefits under special rules for people with terminal illness:

"An individual is to be regarded as having a terminal illness for the purpose of determining entitlement to disability assistance if, having had regard to the (Chief Medical Officer's (CMO)) guidance, it is the clinical judgement of an appropriate healthcare professional that the individual has a progressive disease that can reasonably be expected to cause the individual's death."

3. Any new law can have an impact on different individuals in society, for example as a result of their age, disability, gender re-assignment, marriage and civil partnership status, pregnancy and maternity, race, religion or belief, sex or sexual orientation, caring responsibility, or location (urban or rural and island community settings).

What is your view on the different impacts that a right to palliative care would have and the different considerations there would be in implementing that right for different groups and people in Scotland living with terminal illness(es)?

Strongly agree
Partially agree
Neutral (neither support nor oppose)
Partially disagree
Fully disagree
Unsure

Please explain the reasons for your answer, including the impact this proposal could have on particular people if it became law, and if there are any ways you think the proposal could avoid negative impacts on particular people.

Parkinson's UK Scotland cannot agree or disagree with the question as it is framed.

However, in our response to Q1, we highlighted the evidence that people with non-malignant conditions including Parkinson's experience considerable inequalities in terms of access to palliative care. We believe that this proposal could help to address these.

Parkinson's UK Scotland strongly agrees that there are issues around disparities in access to care for people with the characteristics listed in Q3. We believe that this bill has an important role to play in levelling the playing field for groups who have historically had less access to palliative care and support, although we think that specific guidance may be needed to realise this.

We would like to highlight the following in particular:

Age

Although adults of all ages are living with Parkinson's, it is more common in older people. While about 1 in 7 people with Parkinson's is aged under 65, the average age for someone to get a new Parkinson's diagnosis is over 70, and 1 in 3 people with Parkinson's are aged over 80.

There are clear differences in the pathway to palliative care based on age as well as diagnosis. Deterioriating health and death are expected outcomes for older people, so the need for specialist services and support is not as apparent as for younger people who are facing situations which are uncommon in their cohort.

Major barriers to palliative care amongst older people have been established in the research.[13] [14]

Older people needing support with complex and deteriorating health typically have fewer options for support than their younger counterparts. For example, very few older people feel that they actively choose to move to a care home. For many, this enormous change comes as a result of a crisis which exposes an inability to remain at home.The high levels of home care support which would enable them to remain in their own home is likely to be deemed unaffordable for statutory funders and beyond the resources of all but the most wealthy to buy in themselves.

Those who do remain at home are usually supported by considerable informal care, provided by partners, family members and friends. A recent study of carers for people with more advanced Parkinson's in North East England, showed that unpaid carers – with an average age of 70 - were typically providing care for 16 hours every day, ie through all their waking hours. Yet around four in every five of the people with Parkinson's that they supported did not receive any formal social care support.[15] We have no reason to suppose that the picture is significantly different in Scotland.

The reality of care provision for people with Parkinson's and carers is that they are often left to get on with it, with very little support. We recognise that palliative care is not the sole preserve of specialist health services, and we recognise that social care workers often provide high quality care in line with the WHO definition.

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[13] Pal LM, Manning L. Palliative care for frail older people. Clin Med (Lond). 2014 Jun;14(3):292-5.
[14] Nicholson CJ, et al.. Addressing inequity in palliative care provision for older people living with multimorbidity. Perspectives of community-dwelling older people on their palliative care needs: A scoping review. Palliat Med. 2023 Apr;37(4):475-497.
[15] Hand, A. et al. The role and profile of the informal carer in meeting the needs of people with advancing Parkinson's disease. Aging & Mental Health, 2018. 23(3), 337–344.

However, the gap between the best and the worst is wide. And we fear that under a system where older people struggle to access even basic, task-orientated social care, how a new legal right to palliative care will be resourced and implemented.

This is the reality that we hear about. We consistently hear from people who've been told they will have to wait months before a social worker will even be able to look at their situation, or that their existing homecare package is being withdrawn because there are not enough staff to provide the care. Many are told that they can't get care at all because there is no homecare to cover their area. This is an issue for people with Parkinson's of all ages - but the extent to which it shows a disregard for the actual health and care needs of those living with a condition that predominantly affects older people cannot be ignored.

One unpaid carer, who took part in a survey we undertook in Scotland in 2021 told us that he and his late wife only received any formal social care at all in the last year of her life, but that this was extremely limited. We would strongly question the extent to which the support provided here by a social care package, in any way met the aspirations of holistic palliative care "prevent[ing] and reliev[ing] suffering through the early identification, correct assessment and treatment of pain and other problems, whether physical, psychosocial or spiritual" for this individual and her husband at the end of her life.

> *"My late wife had Parkinson's…. As her condition deteriorated over the last few years of her life I became her full time carer. In the last year of her life she received a limited amount of morning care from the local … care team. This involved assistance with getting out of bed, bathing and dressing. The carers did not come every day and in some instances only three mornings per week. The limited amount of care was due to the fact that resources were limited and were thinly spread. For the rest of the time I undertook these tasks."*

Another former carer shared how their late husband died before care was put in place:

> "… we were exploring how *[care]* would be to our benefit, what we wanted, and who could provide this, when he died. It was obvious to our friends and family that it should have been in place earlier."

In our experience, these experiences are very far from uncommon. They illustrate the immense level of need and the gap to be filled. We would really welcome this legislation driving meaningful policy and practice change that would better meet the care needs of older people, and those with conditions that are associated with older age,

Disability

People with conditions like Parkinson's that cause a number of impairments may find it more challenging to access specialist palliative care services because they are not set up to deal with adults with complex care needs. Parkinson's has over 40 recognised symptoms that can cause significant impairments affecting movement, core bodily functions, mental health and cognition. As Parkinson's progresses care needs become more complex, and people can live with complex needs for several years. This compares with people dying with malignant conditions, who may be relatively able to access places with minimal support until they reach the last few days of life.

We often hear from individuals and families who cannot access a placement in a care home for long term care or a short break. Services sometimes say that they cannot provide care for people who cannot manage activities of daily living - including transfer from a bed to a chair, toileting or eating without assistance. Some services do not support people experiencing mental health symptoms like hallucinations and delusions or challenging behaviour caused by Parkinson's dementia. While this may reflect genuine issues around staffing and the support that service users with complex needs can have, it is essential that the new legal right is supported by resources that will enable people with the most complex needs to access palliative care support.

One of the very common challenges for people with advanced Parkinson's is that communication issues (such as quiet voice, slow speech and articulation problems) are very common. It is important that people with communication needs are supported to articulate their needs and access them.

Remote and rural

Parkinson's UK Scotland agrees with the analysis of the significant issues that people who live in remote and rural communities can face in terms of access to palliative care. We are especially interested in this because people with Parkinson's are over-represented in Scotland's remote communities. About 12% of people with Parkinson's - more than 1,500 people - live in communities defined as remote - compared with just 8% of the general Scottish population.[16] Improving palliative care provision in remote communities is very important for people with Parkinson's.

4. What is your view on how a right to palliative care should be implemented?
For example, you may wish to consider which bodies would be responsible for delivering palliative care and what their duties may be, and what data would need to be collected to assess how the right is being implemented. Please explain the reasons for your response.

Given that the health and care landscape is currently under review because of the proposed National Care Service Bill, it is difficult to be precise here. Parkinson's UK Scotland believes that the duty to provide palliative care should lie jointly with:

- NHS Boards
- Health and Social Care Partnerships (or their successors)
- Local authorities (where they retain relevant services after the creation of the National Care Service)

This should include a duty to supply / fund specialist palliative care services, including hospices, based on population need.

In terms of data collection, we would strongly welcome Scottish Government funding for a comprehensive survey of people who have been bereaved to enable people to report on their experiences of the care and support that the person that they supported received from health, social care and community-based resources, as well as their experiences as someone close to the person who died.

[16] Parkinson's UK Scotland (2024) Scotland Can't Wait report

Parkinson's UK Scotland believes that it is essential that condition-specific data is collected so that inequalities in access for people with certain conditions or groups of conditions can be identified and addressed.

5. Are there any other comments you wish to make on the proposed Bill, for example, on its financial implications, impact on equalities and sustainability? Please explain the reasons for your response.

Parkinson's UK Scotland has no comments to make.