Introduction

Parkinson’s UK welcomes the opportunity to respond to this consultation.

We have held a neutral position on end of life decisions for some years, taking the view that wherever possible, and within the framework of the law, the decisions and wishes of people with Parkinson's should be respected.

We are working with people who are affected by Parkinson's to make sure our position reflects the current context and the full range of views in this area.

Opinion polls show that people in the UK have differing views about end of life decisions, informed by personal, social and cultural factors. Parkinson's affects individuals from all backgrounds. We believe that it is important that we support everyone affected by Parkinson's, whatever their standpoint.

Our response is framed around the questions asked by the Committee, and highlights the issues that are of particular relevance to people with Parkinson’s, their families and carers. It should not be read as implying either support for, or opposition to, the Bill.

About Parkinson’s

About 10,000 people in Scotland people have Parkinson's.

Parkinson's is a progressive, neurological disorder, with no known cure. The three main physical symptoms associated with Parkinson’s are tremor, muscle rigidity and slowness of movement. However not everyone will experience all three. Non-motor symptoms and medication side effects can also cause sleep disturbance, difficulties with balance, incontinence, problems with altered posture, speech and swallowing difficulties, pain and mental health problems such as dementia, hallucination and depression. Parkinson’s UK, believes that with the right care and support many people with Parkinson’s can have a good quality of life for years after diagnosis. However, the later stages of Parkinson’s can be challenging to live with, as symptoms progress and medication side effects become harder to manage.

Parkinson’s affects people from all social and ethnic backgrounds and age groups. The average age of onset of Parkinson’s is between 50-60 years of age, though one in seven will be diagnosed before the age of 50 and one in twenty will be diagnosed before the age of 40.
Are you satisfied with the two categories of people who would qualify to be assisted under the terms of the Bill?

It is possible that people with advanced Parkinson’s could be included in both of the categories defined in the draft Bill, yet there are requirements which might rule them out. It can be very hard to predict what will happen to a person with Parkinson’s, because the condition affects all individuals in different ways. This would make it difficult to say whether someone would be expected to survive for six months or more. It is similarly difficult to define a fluctuating condition such as Parkinson’s as a “permanent” incapacitation.

In addition, many people with Parkinson’s need ongoing support in their daily activities for a long time before their condition progresses to the advanced stages. People with Parkinson’s commonly experience significant mental health symptoms. These can include depression, which affects about half of all people with Parkinson’s,¹ as well as compulsive behaviours and psychotic symptoms. Parkinson’s UK is concerned that people with Parkinson’s who experience mental health symptoms could decide to opt for assisted suicide or voluntary euthanasia as a result of these mental health issues. If the Bill were to proceed, this underlines the importance of strong safeguards and expert knowledge when capacity is assessed.

It might be helpful to consider whether these definitions would need to be changed to reflect these issues, which are likely to be shared with other progressive neurological conditions.

The Bill outlines a several stage consent and verification process that would be required to be followed for an eligible person to receive end of life assistance. Are you satisfied with this process?

Parkinson’s UK is concerned that the limit of 28 days after receipt of the second request may put undue pressure on the requesting person to act to end their life. We recognise the need to ensure that a person retains capacity between making a request and taking action, but feel that there are risks in stipulating such a tight timescale.

We have specific concerns about the provisions for residents of care homes, and specifically the requirement for one witness to be a member of care home staff. Although we recognise that many care workers have a good relationship with and knowledge of residents, and that some care home residents may lack a circle of friends or acquaintances who could act as disinterested witnesses, we are concerned about the minority of care homes which provide poor care. In the Care Commission’s recent rankings one in ten care homes for older people were ranked poor or inadequate,² and we are concerned that it staff in those homes may not have a sufficiently high quality relationship with residents for this to provide an adequate safeguard against abuse.

We are also concerned that there is potential for conflict of interest, for example if care home managers wished to offer a place to another resident for any reason.
Do you consider the level and nature of safeguards as set out in the Bill to be appropriate?

Parkinson’s is a complex condition. The recent NHS QIS Clinical Standards for Neurological Health Services\(^3\) make clear that people should have access to support from a specialist multi-disciplinary team. We believe that the attending physician should also be required to consult with the person’s Parkinson’s specialist clinical team. This additional safeguard would ensure that the attending physician would be aware of alternative treatment options which might offer symptomatic relief and of medication side effects that could be addressed by altering the timing, dosage or composition of an individual’s medication regime.

We believe that the requirement for a psychiatrist to assess capacity would be an essential safeguard. Issues of capacity are of particular importance for people with Parkinson’s, and for those with other neurological conditions. Accurate and sensitive assessment of capacity is particularly important for people with advanced Parkinson’s, who are likely to experience communication difficulties in addition to mental health symptoms and medication side effects. These may include depression, dementia, compulsive behaviours and psychotic symptoms.

Parkinson’s UK agrees with the Bill’s specification that communication difficulties should not be considered to indicate a lack of capacity, where human or mechanical aids can be used to overcome difficulties. If the Bill proceeds, we would like to see a duty to involve a speech therapist where people have significant communication difficulties.

Depression affects up to half of all people with Parkinson’s,\(^4\) and psychotic symptoms and compulsive behaviours frequently occur caused both by the condition itself and as side effects of the medications used to manage it. The latest evidence suggests that cognitive decline and dementia are very common in Parkinson’s, and become more common as the condition progresses.\(^5\)\(^\,\)\(^6\) However, there is also evidence that these symptoms are under-diagnosed and under-managed, and there is a danger that capacity may not be assessed accurately as a result. In a recent training needs analysis, some seven in ten health and social care professionals said that they needed training on Parkinson’s Disease dementia.\(^7\)

In view of the complex communication and psychiatric issues in late Parkinson’s, Parkinson’s UK believes that a general psychiatrist without knowledge of Parkinson’s may not be able to assess capacity accurately without input from the Parkinson’s specialist team, especially in cases where medication side effects may be involved. We also question whether the legislation might also provide for assessment by a clinical neuro-psychologist, in line with recommendations made in guidance accompanying the Adults with Incapacity (Scotland) Act.
Do you have any other considerations on the Bill not included in answers to the above questions?

The Bill lacks detail explaining the ways in which the requesting person might receive assistance, and both assisted suicide (where the requesting person administers the treatment designed to end their life) and voluntary euthanasia (including instances where a third party administers the treatment) are permitted. Parkinson’s UK believes that the Committee and the Parliament should explore the implications of such a broad definition of action when considering the legislation. In particular, the reasons for allowing any person to administer life-ending methods to a requesting person, requiring the designated practitioner to act as witness should be carefully considered, as the potential for administration errors increases if the person is not trained.

Parkinson’s UK believes that any discussion of assisted dying legislation should be supported by a framework of high quality and accessible palliative care. There are very serious areas of unmet need in Parkinson’s care at the end of life, particularly with regard to the management of non-motor symptoms such as pain, depression and incontinence.

Clinicians’ awareness of the non-motor symptoms of Parkinson’s remains lower than the motor symptoms, yet many people find that the non-motor symptoms have a greater impact on their quality of life. If such symptoms remain untreated, it means that people are more likely to find their lives intolerable.

There is also good evidence that there is a lack of palliative care support for people with Parkinson’s: Parkinson’s UK has identified that that the needs of people with Parkinson’s at the end of life are not always identified or satisfied. Problems include:

- fragmented services characterised by a poor knowledge and understanding of Parkinson’s
- diminished access to services as Parkinson’s progresses, and treatment becomes less effective
- lack of information about the condition, medications, financial and other available support
- lack of face-to-face personal support
- providers focusing on the age of the person, rather than the stage of the condition
- failure to address fears about the future, or offer future planning.

The recent Audit Scotland Review of palliative care services in Scotland showed that there are particularly significant gaps in the provision of appropriate end of life support for people with neurological conditions like Parkinson’s compared with conditions like cancer and organ failure. In addition, the finding that people aged over 75 may be less able to access specialist palliative care is also of concern, as the incidence of Parkinson’s increases with age.
Whether or not this Bill proceeds, it is essential to address these gaps in services.

About Parkinson’s UK

For more information, please contact the Scotland Parliamentary and Campaigns Officer, Tanith Muller, email: tmuller@parkinsons.org.uk, telephone 0844 225 3726.

Every hour, someone in the UK is told they have Parkinson’s. Because we’re here, no one has to face Parkinson’s alone. We bring people with Parkinson’s, their carers and families together via our network of local groups, our website and free confidential helpline. Specialist nurses, our supporters and staff provide information and training on every aspect of Parkinson’s. As the UK’s Parkinson’s support and research charity we’re leading the work to find a cure, and we’re closer than ever. We also campaign to change attitudes and demand better services. Our work is totally dependent on donations.

Find out more about us at parkinsons.org.uk

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12 May 2010

1 Goetz CG, Koller WC, Poewe W et al. (2002) Treatment of depression in idiopathic Parkinson’s disease. Movement Disorders. 17(s4):s112–s119
7 Parkinson’s Disease Society (unpublished) results of training needs analysis.