

**Assisted Suicide (Scotland) Bill****Parkinson's UK**

- 1. Do you agree with the general purpose of the Bill to make it permissible, in the circumstances provided for, to assist another to commit suicide?**

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

Parkinson's UK neither supports nor opposes a change in the law to allow assisted suicide. Our position is neutral because we recognise that people affected by Parkinson's have a wide range of personal beliefs on this issue.

Whether or not the law is changed, Parkinson's UK will continue to provide evidence-based information to enable people with Parkinson's, their carers and their families to make informed choices. We will continue to campaign for access to high quality care and support until the at the end of life for people with Parkinson's, their carers and families, as well as post-bereavement support for carers and families after someone with Parkinson's dies.

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.

- 2. Do you have any views on how the provisions in this Bill compare with those from the previous End of Life Assistance (Scotland) Bill?**

No.

- 3. The Bill precludes any criminal and civil liability for those providing assistance, providing the processes and requirements set out in the Bill have been adhered to. Do you wish to make any comment on this?**

No.

- 4. The Bill outlines a three stage declaration and request process that would be required to be followed by an individual seeking assisted suicide. Do you have any comment on the process being proposed?**

Parkinson's UK has major concerns about the maximum 14 day time limit between the second request and the act of suicide, which is half the time that was proposed in the previous Bill. We believe that this timeframe may put undue pressure on the requesting person to act to end their life.

- 5. Do you have any comment on the provisions requiring that the person seeking assisted suicide must have a terminal or life-shortening illness, or a progressive condition which is either terminal or life-shortening?**

Parkinson's UK notes that there is some clinical debate about the extent to which Parkinson's can be seen as a life shortening condition. We have some concerns that the new criteria of "terminal", "life shortening", "progressive", "illness" and "condition" may be quite subjective and open to interpretation by individual practitioners.

**6. Are you satisfied with the eligibility requirements as regards age, capacity, and connection with Scotland as set out in the Bill?**

Parkinson's UK has serious concerns about the assessment of capacity for people with advanced Parkinson's and other neurological conditions as laid out in this bill, as the only requirement is for the person to be a registered medical practitioner.

A typical GP in Scotland will see only one new case of Parkinson's every 3.3 years.<sup>1</sup> It is a complex condition with a wide range of symptoms and medication side effects.

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.

Around 40% of people with Parkinson's have depression,<sup>2</sup> up to 50% experience anxiety<sup>3</sup> and around 25% experience mild psychotic symptoms.<sup>4</sup>

The latest evidence suggests that cognitive decline and dementia are very common in Parkinson's, and become more common as the condition progresses.<sup>5 6</sup> 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.

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.

In view of the complex communication and psychiatric issues in advanced Parkinson's, we are extremely concerned that GPs may not be able to assess capacity accurately. We believe that the legislation should specify that assessment of capacity should be made by a clinical neuro-psychologist, in line with recommendations made in guidance accompanying the Adults with Incapacity (Scotland) Act.

**7. Do you have any comment on the roles of medical practitioners and pharmacists as provided for in the Bill?**

As noted above, Parkinson's UK has concerns that non specialist doctors may lack knowledge about complex conditions like Parkinson's. In addition to the concerns about assessment of capacity, this is important because people with advanced Parkinson's can sometimes be offered changes in medication types, timings and doses that can offer significant symptomatic relief and improve elements in quality of life.

We recognise that the role of the registered medical practitioner is not to rule on the severity of the person's condition, as the legislation is framed to be driven by the perceptions of the individual about their quality of life. However, in light of the variability of people's symptoms and response to medication, and the fluctuating nature of Parkinson's, we believe that people with complex conditions like Parkinson's should be encouraged to seek input from their specialist team about potential changes and

improvements to their condition before making a decision based on their current or possible future quality of life.

**8. Do you have any comment on the means by which a person would be permitted to end his/her life under the Bill?**

No.

**9. Do you have any comment on the role of licensed facilitators as provided for in the Bill?**

No.

**10. Do you have any comment on the role of the police as provided for in the Bill?**

No.

**11. Do you have any comment to make about the Bill not already covered in your answers to the questions above?**

Parkinson's UK believes that any discussion of assisted suicide needs to happen alongside an awareness of the need for high quality and accessible palliative care for everyone, on the basis of need not diagnosis.

There are very serious areas of unmet need in Parkinson's care at the end of life. People with advanced Parkinson's typically have very complex needs –dementia, immobility, pain, fatigue, problems with swallowing, communication problems, breathlessness, weight loss, continence issues, frailty, falls, and other issues. It is also very common for people with advanced Parkinson's to have other serious health conditions in addition to their Parkinson's.

People with the most severe forms of Parkinson's at the end of life report that their quality of life is as bad as – and in some cases is worse than - those with terminal cancer<sup>7</sup> and motor neurone disease (MND).<sup>8</sup>

Clinicians' awareness of the non-motor symptoms of Parkinson's remains lower than the motor symptoms,<sup>9</sup> yet many people find that the non-motor symptoms have a greater impact on their quality of life.<sup>10</sup> If such symptoms remain untreated, it means that people are more likely to find their lives intolerable.

People with neurological conditions including Parkinson's are much less likely to have opportunities to take part in advance care planning, or to receive palliative care and end of life support, than people with cancer. <sup>11 12 13 14 15</sup>

The Audit Scotland Review of palliative care services in Scotland<sup>16</sup> 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**

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

Parkinson's is a progressive, fluctuating neurological disorder, which affects all aspects of daily living including talking, walking, swallowing and writing. People with Parkinson's often find it hard to move freely. There are also other issues such as tiredness, pain, depression, dementia, compulsive behaviours and continence problems which can have a huge impact. The severity of symptoms can fluctuate, both from day to day and with rapid changes in functionality during the course of the day, including sudden 'freezing'. There is no cure.

The average age of onset of Parkinson's is between 50-60 years of age, and incidence increases with age. One in twenty people with Parkinson's is diagnosed before the age of 40.

**Parkinson's UK**


---

<sup>1</sup> SIGN (2010) SIGN Guideline 113, Diagnosis and Management of Parkinson's Disease. Edinburgh: SIGN.

<sup>2</sup> Reijnders J et al (2008), 'A systematic review of prevalence studies of depression in Parkinson's Disease', *Movement Disorders* (23, 2, pp 183-189)

<sup>3</sup> Prediger R et al (2012), 'Anxiety in Parkinson's disease: A critical review of experimental and clinical studies', *Neuropharmacology* (62, pp115-124)

<sup>4</sup> Mack J et al (2012), 'Prevalence of psychotic symptoms in a community-based Parkinson disease sample', *American Journal of Geriatric Psychiatry* (20, 2, pp123-132)

<sup>5</sup> Aarsland D, Zuccai J, Brayne C. (2005) A systematic review of prevalence studies of dementia in Parkinson's disease. *Movement Disorders* **20**(10):1255-63

<sup>6</sup> Aarsland D, Andersen K, Larsen JP et al. (2003) Prevalence and characteristics of dementia in Parkinson's disease: an 8 year prospective study. *Archives of Neurology*. 2003; 60:387–392.

<sup>7</sup> Higginson IJ, Gao W, Saleem TZ 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. doi:10.1371/journal.pone.0046327

<sup>8</sup> [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

<sup>9</sup> Shulman LM, et al. (2002) Non-recognition of depression and other non-motor symptoms in Parkinson's disease. *Parkinsonism and Related Disorders* **8**(3):193-7

<sup>10</sup> Karlsen KH, et al. (1999) Influence of clinical and demographic variables on quality of life I in patients with Parkinson's disease. *Journal of Neurology, Neurosurgery & Psychiatry* **66**(4):431–435.

<sup>11</sup> [Harrison N](#), [Cavers D](#), [Campbell C](#), [Murray SA](#). (2012) Are UK primary care teams formally identifying patients for palliative care before they die? *Br J Gen Pract*. **62**(598):e344-52.

<sup>12</sup> Royal College of Physicians, National Council for Palliative Care, British Society of Rehabilitation Medicine. (2008) *Long-term neurological conditions: management at the interface between neurology, rehabilitation and palliative care*. Concise Guidance to Good Practice series, No 10. London: RCP, 2008

<sup>13</sup> Walker RW (2013) Palliative care and end-of-life planning in Parkinson's disease *J Neural Transm* 2013 **120**:635–638

<sup>14</sup> Richfield EW, Jones EJS and Alty JE (2013) Palliative care for Parkinson's disease: A summary of the evidence and future directions *Palliat Med* 2013 **27**: 805

---

<sup>15</sup> Ghoche R (2012) The conceptual framework of palliative care applied to advanced Parkinson's disease *Parkinsonism and Related Disorders* **18** S2eS5

<sup>16</sup> Audit Scotland. Review of palliative care services in Scotland. Edinburgh August 2008