

Parkinson's UK policy statement

End of life care

"This is a subject which nobody likes to talk about, but I think it has to be brought out into the open, so that all families affected by Parkinson's are able to make the right decisions if they need to. My wife and I are glad we've had the opportunity to discuss these issues, because we now have a clearer understanding of each other's thoughts and feelings. We think it's really helpful to have a prompt for such conversations while the person with Parkinson's is relatively well. It's certainly been positive for us."

Carer, whose wife has Parkinson's.

What we believe

Parkinson's UK believes that with appropriate 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.

Parkinson's UK recognises that everyone with experiences the condition differently, and acknowledges that individuals hold a wide range of personal beliefs about end of life care. 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.

On assisted dying

Parkinson's UK neither supports nor opposes a change in the law to allow assisted dying, although we monitor changes in legislation to ensure that people with Parkinson's are appropriately safeguarded. Our position is neutral because we recognise that people affected by Parkinson's have a wide range of personal beliefs on this issue.

Why we believe this

Parkinson's is a progressive, fluctuating neurological disorder which is degenerative. Despite advances in treatment, there is no known cure. The advanced stages of Parkinson's can be very difficult to cope with^{1 2}.

The symptoms of advanced Parkinson's can include pain, fatigue, problems with swallowing, breathlessness, weight loss, frailty, and other issues. It is also very common for people with advanced Parkinson's to have other serious health conditions. Both Parkinson's and other conditions increase the risk of infections, and other life-threatening situations, developing.

¹ 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

² Goy ER et al (2008) 'Neurologic disease at the end of life: caregiver descriptions of Parkinson disease and amyotrophic lateral sclerosis' *Palliative Medicine*; 11(4):548-554

This may mean that people need to make decisions about life-sustaining treatment, such as resuscitation, respiratory support, medication, artificial nutrition and hydration. Some people with Parkinson's may wish to refuse certain interventions, while others may request them.

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 2.2 years³, but as this is variable services must be flexible enough to provide appropriate support to people with Parkinson's, their carers and others close to them throughout the course of the condition as their needs may fluctuate and change towards end of life.

Advance planning for end of life

People with Parkinson's should be involved in decisions about end of life care wherever possible. As Parkinson's progresses people may lose mental capacity to make decisions. For example, people with Parkinson's have an increased risk of developing dementia. While a diagnosis of dementia does not automatically mean that a person lacks mental capacity, many people with dementia do not have mental capacity.

People with advanced Parkinson's commonly experience communication difficulties, making it harder to make their wishes known. It is particularly important that mental capacity is accurately assessed in Parkinson's in light of these issues. For more information see [our policy statement on Mental Capacity](#).

As there are factors which may affect people's mental capacity, it is important that there are opportunities to plan ahead at an earlier stage and that people with Parkinson's are supported to use their rights. Advance care planning is when someone talks about their future care options with the people providing care and support. It enables people to make their preferences and decisions about how they want to be treated at the end of life known in advance.

Carers, friends and family members are often included in these discussions if the person wishes. The conversation might include topics such as a person's preferred place of treatment or their choice about where they want to die, how to accommodate religious or other beliefs, refusing certain types of treatment or intervention, or specifying someone (for example a carer, family member, or friend) to speak on their behalf if they aren't able to do so.

Information must be shared across multi-disciplinary teams so that all professionals have access to it and people should have an opportunity to regularly review their plans or to make them if they haven't. More formal measures, such as an 'advance decision' in England, Northern Ireland and Wales, and 'advance directive' in Scotland or appointing someone to act as an Attorney can help to ensure that people's wishes are known and respected. Some mechanisms have binding legal status while others are advisory, however there is a presumption that they will be considered and applied where possible. See the appendix for more details.

³ Richfield et al (2013) 'Palliative care for Parkinson's disease: A summary of the evidence and future directions' *Palliative Medicine*; 27(9):805-10.

It is also important to recognise that not everybody will want to take up the option of advance care planning, and it is essential that nobody is compelled to do so.

Education and training for health and social care professionals

Talking to people about end of life care early is important to give people the opportunity to make choices and plan their care. However, health and social care professionals can find it difficult to broach issues related to end of life wishes, particularly when a patient's future is uncertain. A Care Quality Commission (CQC) report highlighted that people with conditions including Parkinson's felt that their healthcare professional was reluctant to talk about end of life care. This was echoed by many of the health and care staff CQC spoke to who said they found conversations difficult to start⁴.

It's essential that staff across health and social care are given appropriate training in order to be proactive in advance care planning and provide high-quality, person-centred care and communicate sensitively to people affected by Parkinson's. Professional associations and healthcare training bodies should provide guidance and support for their staff in helping people to make choices and assert control even in situations of uncertainty.

Access to specialist care

It is important that people with Parkinson's at the end of life receive specialist input. As Parkinson's is a complex condition, it is important that services are commissioned and managed in a multidisciplinary way. Knowledge from neurology, mental health, palliative care as well as speech and language therapy, physiotherapy, and other necessary specialist and therapy areas should be brought together to provide holistic support across all settings to ensure high quality care at the end of life. Services must be coordinated in order to enable people's priorities to be consistently addressed and care provided must support the personal, social, psychological and spiritual needs of the person with Parkinson's and their friends and family.

Cardiopulmonary Resuscitation (CPR)

Conversations about CPR at the end of life can be extremely difficult. Many people's perceptions of CPR are influenced by modern day television, where it is almost always successful and people recover swiftly. However, in reality it can be traumatic and invasive and may not always be in the best interests of the person with Parkinson's. People may consider making a Do Not Attempt CPR (DNACPR) decision. This is a clinical decision based on the person's best interests.

Having a diagnosis of Parkinson's is not in itself grounds to make a DNACPR decision. We believe that people with Parkinson's should be supported to consider the circumstances in which they may or may not wish to receive CPR as part of their advance care planning, and in light of their personal circumstances. It's important that professionals discuss fully with the person what DNACPR entails so that people can exercise control over their care.

DNACPR decisions must be communicated to every professional involved in the person's care to ensure that no inappropriate or unwanted CPR attempts are made. The person and/or their carers should also be aware that they should keep their DNACPR form with them so that

⁴ Care Quality Commission (2016) 'People with conditions other than cancer' *A different ending: addressing inequalities in end of life care*

their information can be shared with health professionals. When a person has not made their views known on CPR in advance, a clinical decision may have to be made by a health professional.

We believe that decisions should always be made with input from a person with Parkinson's multidisciplinary team, and with the involvement of the person and their carers. Where this is not possible the reasons for this must be recorded.

Support for families and carers

Parkinson's UK recognises that carers and families are often closely involved in making sure that the wishes of the person with Parkinson's are enacted at the end of life. This is especially the case when individuals have legal responsibility through mechanisms such as lasting power of attorney in England and Wales, power of attorney in Scotland, and Enduring Power of Attorney in Northern Ireland.

We believe that health and care professionals should treat carers and family members as 'expert partners', fully including them in decisions wherever this is possible and is in the best interests of the person with Parkinson's. Furthermore, all carers and family members should be given access to good quality advice, information and support that they need to ensure that the person's wishes are enacted. This should include out of hours support, to provide people with assistance and guidance if the person they are caring for experiences changes in their symptoms.

What's the evidence?

People with neurological conditions including Parkinson's are currently much less likely to have opportunities to take part in advance care planning, or to receive specialist palliative care and end of life support than people with cancer^{5 6 7 8 9}. More research and action is required to ensure that people with Parkinson's receive quality care in the place they choose at the end of life.

Findings of the 2017 Parkinson's audit highlighted that of those people with markers of advanced Parkinson's (21.0%), discussions about end of life care issues were only recorded in 36.8% of cases. In only 16.9% of cases (at all stages of Parkinson's) was there evidence that the patient and/or carer had been offered information about, or had set up, a Lasting Power of Attorney (Power of Attorney in Scotland). Just 56.1% of patients in the palliative phase had been offered information about, or had set up, a Lasting power of Attorney. As a result, people with Parkinson's can be left in a position where their families and health and social care professionals cannot fulfill their care choices.

⁵ Harrison N et al (2012) 'Are UK primary care teams formally identifying patients for palliative care before they die?' *British Journal of General Practice* 62(598):e344-52.

⁶ 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*

⁷ Walker RW (2013) 'Palliative care and end-of-life planning in Parkinson's disease' *Journal of Neural Transmission*; 120:635–638

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

⁹ Ghoche R (2012) 'The conceptual framework of palliative care applied to advanced Parkinson's disease' *Parkinsonism and Related Disorders*; 18:S2-S5

What Parkinson's UK is doing

Parkinson's UK provides evidence-based information and has a network of local advisers and a dedicated helpline to enable people with Parkinson's, their carers and their families to make informed choices about their care options.

We also work with local and national governments, health and social care providers, and decision makers to ensure that people with Parkinson's can access high quality information, support, and care at the end of life. This includes campaigning to ensure that people with Parkinson's have the opportunity to plan ahead if they wish to do so.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on end of life care. The Policy Panel consists of people with experience of Parkinson's who meet on a regular basis to help guide the charity's position on a range of policy issues.

Further information

Please contact the policy and campaigns team on **020 7963 9349** or email campaigns@parkinsons.org.uk.

Parkinson's UK June 2018
Review date June 2021

Appendix

Different legislation about end of life care applies in different parts of the UK. Important legislation includes:

Mental Capacity Act 2005 (England, Wales)

This legislation came into force in 2007, and provides a framework which presumes that all adults have capacity to make decisions about their property and affairs, care and treatment, and living arrangements, unless it is proven otherwise.

Key provisions include:

- Definitions of capacity
- Ability to nominate a welfare attorney through a lasting power of attorney
- Clarification of legal status of advance decisions for when a person may lack capacity. For example, advance decisions to refuse treatment are legally binding, but requests for positive treatment are advisory.

Adults with Incapacity Act 2000 (Scotland)

This legislation came into force in 2002, and provides a framework for safeguarding the welfare and managing the finances of adults who lack capacity. The presumption is that all adults have capacity unless proven otherwise.

Key provisions include:

- explains what is meant by 'incapacity'
- enables people to nominate a welfare attorney, through lodging a welfare power of attorney
- makes clear that advance directives for when a person may lack capacity do not have legally binding status, but must be considered.

Mental Capacity Act 2016 (Northern Ireland)

This is Northern Ireland's first independent legislation to cover the legalities surrounding a lack of mental capacity.

Key provisions include:

- explains terms such as 'lacking capacity' and 'best interest's decision making'
- sets out Lasting Powers of Attorney and Advance Decisions to Refuse Treatment

Legal status of Powers of Attorney

In England and Wales Lasting Powers of Attorney are registered and recognised by the Office of the Public Guardian. There are two types:

1. Lasting Power of Attorney for property and affairs, which covers decisions such as running your bank and savings accounts, making or selling investments, paying bills and making other purchases on your behalf.
2. Lasting Power of Attorney for health and welfare, which covers decisions such as the type of social care, health care and medical treatment you receive, including life sustaining treatment, where you live, and day to day matters including your diet and daily routine.

In Scotland, Powers of Attorney are registered and recognised by the Office of the Public Guardian. There are three types:

1. General Power of Attorney (GPA) allows you to appoint someone to make decisions on your behalf for a set amount of time or for a specific issue
2. Continuing Power of Attorney (CPA) allows you to appoint someone to look after your property and financial affairs
3. Welfare Power of Attorney (WPA) allows you to appoint someone to make decisions about your health and welfare.

In Northern Ireland, an Enduring Power of Attorney is registered and recognised with the Office of Care and Protection. This deals with the control of finance and property.

Legal status of advance decisions

In England and Wales, adults over the age of 18 who have capacity can make legally binding Advance Decisions to Refuse Treatment in the future if they lost capacity. It is also sometimes called a Living Will or Advance Directive. The Mental Capacity Act says that an Advance Decision is legally binding if it's valid and applicable. It must also be in writing, and signed and witnessed.

Other aspects of advance care planning, such as values, wishes, priorities or preferences must be considered but are not legally binding. An Advance Statement allows people to record their wishes, feelings, beliefs and values. An Advance Decision only covers refusals of medical treatment, whereas an Advance Statement can include any information the person feels is important in relation to their health or care.

In Scotland, Advance Directives to refuse treatment are not legally binding, although healthcare professionals must take them into account.

In Northern Ireland, there is provision for adults with capacity to make an Advance Decision to Refuse treatment and they can be legally binding, but only in common law providing certain criteria are met.