Parkinson’s UK policy statement
End-of-life decisions, including assisted suicide

“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 should be able to exercise their right to access effective health and social care services at every stage of the condition, including at the end of life. This should always involve timely provision of good quality information so people know what support is available at every stage and how they can get it.

Parkinson’s UK recognises that everyone affected by Parkinson’s experiences the condition differently, and acknowledges that individuals affected by Parkinson’s hold a wide range of personal beliefs about end-of-life decisions. 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 suicide

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, support and information until 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.

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, continence issues, frailty, falls, immobility 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. 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.

National guidelines say that people with Parkinson’s should have access to palliative care and support from the point of diagnosis onwards.

Factors that may affect capacity
Mental capacity refers to whether a person is able to make decisions for themselves. People with advanced Parkinson’s commonly experience communication difficulties, making it harder to make their wishes known. Mental health issues including depression and dementia are also very common. Research suggests that depression affects up to half of all people with Parkinson’s and up to 80% of people who have lived with Parkinson’s 10 years or more may develop dementia. This may mean that the person with Parkinson’s is not defined as legally competent to make decisions, although a diagnosis of dementia or depression does not automatically mean that a person does not have mental capacity. It is particularly important that mental capacity is accurately assessed in Parkinson’s in light of these issues.

Advance care planning and “living wills”
Advance care planning is when someone talks about their future care options with the people providing care and support. Carers, friends and family members are often included in these discussions if the person wishes.

Advance care planning enables people to make their preferences and decisions known in advance about how they want to be treated at the end of life. The conversation might include topics like 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 to speak on their behalf if they aren’t able to do so. This may be a carer, family member or friend, or an independent advocate.

It is not essential for decisions to be in writing, but professionals need to be aware of them, so writing them down or including them in medical notes is helpful. More formal measures, such as making a so-called “living will” (known as an ‘advance decision’ in England and Wales, and ‘advance directive’ in Scotland) or appointing a welfare 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.

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.

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 are designated as next of kin (which has no legal status), or have legal responsibility through appointment as a welfare attorney.

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.
- All carers and family members should be given access to the information and emotional support they need to ensure that the person’s wishes are enacted.
- Where carers and family members are not in agreement with the wishes or decisions of the person with Parkinson’s, the wishes of the person with Parkinson’s have priority.
- People with Parkinson’s, carers and families have a right to information that enables them to make informed choices, and that there should be clarity about the law so that all parties know where they stand.

**Reflecting people’s beliefs**
People in the UK have a range of views about end-of-life decisions, informed by various factors including personal experience, social attitudes and personal traits, as well as religious and cultural background. As Parkinson’s affects individuals from all backgrounds, it is important that Parkinson’s UK supports everyone affected by Parkinson’s, whatever their belief.

**Current debate on assisted suicide and euthanasia**
There is ongoing public debate about assisted suicide and euthanasia throughout the UK, following high-profile court cases, interventions in Parliaments and Assemblies, and media stories.

Some cases have involved Parkinson’s. In Scotland in particular, the issue of assisted suicide is linked to Parkinson’s because the late Margo MacDonald MSP, who had Parkinson’s, lodged three Members’ Bills in the Scottish Parliament on this topic. Her latest proposal, for legislation to allow assisted suicide for adults with terminal or degenerative conditions, is currently being considered by the Scottish Parliament.

Lord Falconer is pursuing a Private Members’ Bill to legalise physician-assisted suicide in England and Wales.

**What’s the evidence?**
People with neurological conditions including Parkinson’s are 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. 6 7 8 9 10

Work undertaken by Parkinson’s UK has identified that the needs of people with Parkinson’s at the end of life are not always identified or satisfied, and that problems include a widespread failure to offer advance care planning.11
What Parkinson’s UK is doing

Parkinson’s UK continues to work with local and national governments and health and social care providers to ensure that people with Parkinson’s have access to information and support to make decisions in good time about end-of-life care.

We will also continue to campaign for improvements in the provision of palliative care services, including end-of-life care, for people with Parkinson’s.

We will also work with hospices to ensure that people with Parkinson’s and their families making decisions about end-of-life issues receive the information and support they need.

If changes to the law on assisted suicide or euthanasia are proposed or introduced, Parkinson’s UK will campaign to ensure that the legislation provides effective safeguards in order to protect the interests of people with Parkinson’s.

If Parkinson’s UK receives a request for information about assisted suicide or euthanasia from someone affected by Parkinson’s, we will deal with this in according to policies and guidelines on safeguarding and protection of vulnerable adults that we develop in consultation with people with Parkinson’s and their carers.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on end-of-life decisions and assisted suicide. The Policy Panel consists of over a dozen 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

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Appendix

1. Definitions

**Assisted suicide** A process by which a person receives help from someone else to end their life. This includes both the administration of treatment, and assistance to the person to self-administer treatment.

**Carer** A person who provides unpaid, informal support or care to a relative, partner, friend, colleague or neighbour who has Parkinson’s.

**Euthanasia** A process by which one person intentionally facilitates the death of another person. Euthanasia is an umbrella term which can refer to assisted suicide (also known as voluntary euthanasia), as well as forms of involuntary euthanasia, where consent is not given.

**Living will** An advance statement outlining a person’s wishes, requests for treatment and specific refusals of treatment. Only statements that refuse treatment are legally binding, and they have a different legal status in different parts of the UK.

**Next of kin** This is usually defined as the individual closest to the person through marriage or blood, but a person can designate anyone as their next of kin. The term has no legal status in any UK jurisdiction, but the next of kin is treated by care providers as the key individual to be informed about the person’s condition, and to be consulted in relation to treatment decisions. The individual designated as next of kin has no legal right to consent to or refuse treatment on behalf of another adult.

**Welfare attorney** A person legally designated to represent a person and take decisions relating to their care on their behalf if they become incapable.

2. Legal framework

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

**Mental Welfare 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.
The Act
- 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 Incapacity Bill Northern Ireland
There is currently no legislation relating to end-of-life decisions or capacity in Northern Ireland. The Northern Ireland Executive is currently consulting on a draft Mental Capacity Bill. This would introduce similar provisions to England and Wales in respect of lasting power of attorney, but would not include new legislation relating to Advance Decisions.

Legal status of “living wills”
These are also known as ‘Advance Decisions’ or ‘Advance Directives’.

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 lose capacity. Other aspects of advance care planning, such as values, wishes, priorities or preferences must be considered but are not legally binding.

To be legally binding, an Advance Decision must be in writing, and be signed and witnessed. It must state clearly that the decision applies even if life is at risk. Healthcare professionals must also take steps to ensure that the Advance Decision remains valid.

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

In Northern Ireland there is currently no legislation covering the use of advance decisions to refuse treatment or living wills.

Legal status of euthanasia and assisted suicide in the UK
All forms of euthanasia, including assisted suicide are unlawful in all UK jurisdictions, and anybody who assists someone to take their life may be prosecuted.

In England and Wales, the Crown Prosecution Service (CPS) has issued guidance to help prosecutors to decide whether or not to prosecute in cases of assisted suicide. The Policy for Prosecutors in respect of Cases of Encouraging or Assisting Suicide lists 16 public interest factors that are considered in favour of prosecution and six public interest factors against prosecution. The guidance makes clear that each case should be treated individually, and that factors may be weighted differently in different cases.

In Northern Ireland, the Public Prosecution Service (PPS) has issued similar guidance, the Policy on Prosecuting the Offence of Assisted Suicide.

In Scotland, the Lord Advocate has declined to develop guidance relating to Scots law, stating that “any change in the current law related to homicide is properly a matter for the Scottish Parliament.”
3. What do other organisations think about assisted suicide?

**Royal College of Nursing – Neutral**

"Assisted suicide is a complicated issue and this was reflected in the range and variety of responses that we received to our consultation. The split in responses shows that there is no overwhelming support among nurses for either opposing or supporting a change in the law on assisted suicide. We fully support the common themes that came through the consultation, namely maintaining the nurse-patient relationship, protecting vulnerable patients and making sure there is adequate investment in end-of-life care.

"We will continue to play an active role in any discussion around assisted suicide to ensure that the nurse voice is heard. It is vital that we now commission further work to make sure that nurses receive much-needed guidance around the legal, ethical, regulatory and clinical issues of assisted suicide."

The RCN published [detailed guidance for nurses](#) in 2011.

**BMA – Against**

**Current BMA policy**

- opposes all forms of assisted dying
- supports the current legal framework, which allows compassionate and ethical care for the dying and
- supports the establishment of a comprehensive, high-quality palliative care service available to all, to enable patients to die with dignity

The BMA represents doctors throughout the UK who hold a wide range of views on the issue of assisted dying.

While the BMA fully acknowledges this broad spectrum of opinion within its membership, the consensus since 2006 has remained that the law should not be changed to permit assisted dying or doctors’ involvement in assisted dying.

The Association has clear policy on the issue, agreed in 2006.

The BMA:

- believes that the ongoing improvement in palliative care allows patients to die with dignity
- insists that physician-assisted suicide should not be made legal in the UK
- insists that voluntary euthanasia should not be made legal in the UK
- insists that non-voluntary euthanasia should not be made legal in the UK
- insists that if euthanasia were legalised there should be a clear demarcation between those doctors who would be involved in it and those who would not.

**Royal College of GPs – Against**
‘The RCGP believes that with current improvements in palliative care, good clinical care can be provided within existing legislation and that patients can die with dignity. A change in legislation is not needed.’

The RCGP confirmed its position in 2011, following consultation with its membership.

**Alzheimer’s Society – Against**
The Society’s position remains that it does not support a change in the law on assisted dying, assisted suicide or euthanasia. The Society supports quality palliative care that is available to all people.

**Motor Neurone Disease Association – Neutral**
“The Motor Neurone Disease (MND) Association supports all people with MND, their families and carers. We are a membership organisation and our members hold a wide range of views on assisted suicide.

“We take a position of neutrality toward any change in the law on assisted suicide. We always work within the law and do not provide encouragement or assistance to people wishing to pursue an assisted suicide.

“Surveys of people living with MND show that the end of a person’s life is something that they often want to discuss with both their family and healthcare professionals. We provide information and support to help people have these difficult conversations. We also campaign for access to appropriate, high-quality end-of-life care for everyone with MND.”

**People with MND and their families and friends can call the MND Association national helpline, MND Connect on 08457 626262**

**Macmillan Cancer Support – Neutral**
“Macmillan has taken the position that, given our present state of knowledge and the existing legal situation, we will not take a stance on assisted suicide. Our decision is influenced by a number of key principles which we believe should govern an end-of-life policies and services:

— Patients should be enabled to exercise choice and make personal decisions.
— To exercise choice, patients and families need access to information about options.
— Health and social care professionals need to be sensitive to patients’ personal circumstances and beliefs.
— Healthcare professionals need to be supported and trained to openly discuss end of life issues with colleagues, patients and their families.
— There should be access to supportive and palliative care for all to enable people to die in the place of their choice, including their home, if they so wish.
— There is a need for research into patient and carer views at end of life.”

**Multiple Sclerosis Society - Neutral**
The MS Society maintains that there is good evidence that the right palliative care can make a big difference to quality of life for people with severe MS and the focus must therefore be to provide everyone with the palliative care they need. However, assisted suicide is sometimes
explored both by those with severe MS and by those who have few symptoms but who wish to consider the choices available to them should they become seriously disabled.

Across British society there exists a huge variety of views around death, dying and assisted suicide, dependent on personal experience, choice and religious or spiritual views relating to the sanctity of life and the concept of a ‘good death’. Because MS can affect anyone regardless of ethnicity, religion or belief, this diversity of views is also reflected in the MS Society’s membership. The MS Society seeks to support all its members, and all those with MS, as far as possible in making their own personal choices surrounding the end of life. The Society neither supports nor opposes any attempt to change current legislation on assisted suicide.

- MS Society is calling for a high-level inquiry such as a Royal Commission on assisted suicide.

RADAR – Against
“RADAR is campaigning against the introduction of assisted dying on the grounds that it would be a step back in achieving equality for all disabled people.”

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