

Parkinson's UK policy statement

Mental capacity

"I was told I would only be able to access the confidential information in his care assessment if I was registered as his Lasting Power of Attorney. I was astounded that as his closest relative I had no right to that information, although he lacked capacity and I needed the information to fight his corner."

Son of a person with Parkinson's

What we believe

We believe that people with Parkinson's should make decisions for themselves wherever possible. Assumptions should not be made about people's ability to make decisions just because of their diagnosis, or the way their condition fluctuates.

If people are not able to make decisions ("lack mental capacity"), we believe that they should be supported to take part in the decision-making process and that any decisions taken on their behalf should be based on their known wishes. The systems and bodies that safeguard the affairs of people who lack capacity should be as open and simple to deal with as possible.

We also believe that people with Parkinson's should have the opportunity to make their wishes clear at the earliest possible stage in their illness, if they would like to do so.¹

Why we believe this

Mental capacity refers to whether a person is able to make decisions for themselves. People with Parkinson's can experience problems making decisions as the condition can affect memory, concentration, planning, judgment and mental agility. They can also experience mental health symptoms such as depression, which can also cause problems in making decisions. However, none of these symptoms in themselves mean someone lacks mental capacity. We believe that every adult:

- should be presumed to have capacity unless proven otherwise
- has a right to make their own decisions, even unwise decisions
- should be supported to make their own decisions, if this is necessary
- where capacity is lacking have decisions made in their best interests

These principles are vitally important for people with Parkinson's and in providing support for their carers. However applying these principles in practice can cause problems.

¹ There is an overlap between these issues and those relating to assisted dying and a right to die which are discussed in the forthcoming Parkinson's UK policy position on *End of Life Decisions*. More information on the mental health issues that people with Parkinson's can experience are also discussed in the Parkinson's UK policy position on *Mental Health*.

Professional awareness of Parkinson's

The lack of awareness of Parkinson's generally amongst health and social care professionals² causes concern: even more so when professionals come to assess mental capacity. It is very important that they do not make assumptions based on some of the symptoms of Parkinson's, such as slowness of speech, low volume, masked facial expression and limited body language, as these may present a very misleading picture of someone's mental capacity.

People may need adequate time to answer questions, or help from a speech and language therapist in order to make their wishes clear. Side effects of medication can also cause confusion, and immobility, all within a very brief period of time, which need to be taken into account.

As well as being given independent support to assist in making or communicating decisions if they need it, it is important that assessments are thorough, to ensure that capacity is assessed accurately. This might include postponing an assessment until the circumstances are right, and ensuring that re-assessments take place regularly.

Planning ahead

It can be a lengthy and expensive process to gain access to someone's finances to pay for someone's care and support needs if they have lost capacity and not designated someone with power of attorney over their financial affairs. Similarly, where people have not appointed a welfare attorney, carers, families and friends have no legal right to make decisions relating to care on behalf of the person.

Making preferences and decisions known in advance, by making a so-called 'living will' (known as an Advance Decision in England and Wales, and Advance Directive in Scotland) can help to ensure that people's wishes are known and respected. Some have legal status, while others are advisory, with a presumption that they will be taken into account where possible.

The professional responsible for the person with Parkinson's care plan could provide information and advice on these issues. However putting plans in place for this sort of eventuality is not restricted just to people with Parkinson's. There should be much more public information and education on how to make plans in advance amongst the wider population, and the benefits this can bring.

Ensuring safeguards are in place

There may be disagreements between carers, family members, professionals or others concerned with the welfare of someone who lacks mental capacity. Balancing these concerns and deciding between them may be difficult, but it is vital that everyone acts to protect and safeguard those who lack capacity.

This can be helped by ensuring processes are open and clear to all, and there is regular scrutiny of the systems and bodies that have been created to aid people who lack capacity. People should not be deterred from adopting legal protection for people who lack capacity because of high costs.

² Parkinson's UK *Life with Parkinson's today – room for improvement* (2007)

Independent advocates aim to work with individuals to make sure that the person is actively involved and decisions are taken in their best interests, and availability of these services is essential.

Everyone involved in the day to day care and support of a person lacking capacity should be vigilant as the person may be more vulnerable to abuse and also less able to tell people when it is happening. Information should be clear on the obligations on professionals involved in care and treatment of people who may lack capacity.

Mental capacity and research

We believe it is important not to exclude people who lack capacity from taking part in research, in the same way that they should not be excluded from services and medical treatment. Research involving people with Parkinson's at all stages of the condition is important because it can help us to understand more about the condition, its causes and possible treatments, as well as people's experiences of living with Parkinson's.

There are a number of difficult ethical issues that require the most stringent safeguards to be in place, however, there is some evidence that ethics committees are not allowing research involving people who lack capacity to proceed, despite safeguards being in place.

We support the use of legally recognised measures (such as Statements of Wishes and Preferences, Advance Decisions in England and Wales and Advance Directives in Scotland³) to allow people with Parkinson's to express their wishes regarding research participation in the future when they may be unable to give consent.

More information on the legislation relating to mental capacity can be found in **Appendix 1**.

Monitoring

All governments should monitor the impact and implementation of legislation to ensure that people with Parkinson's are being supported. As the only UK nation not to have mental capacity laws on statute, the Northern Ireland Assembly should introduce equivalent legislation as soon as possible

What's the evidence?

Our research in 2005⁴ found a widespread failure to offer advance planning for end of life care. These findings were supported by evidence to a parliamentary inquiry on Parkinson's services which found poor access to information, advice and specific services that can help people express their wishes, such as speech and language therapy.⁵

³ In England and Wales, a Statement of Wishes and Preferences is a summary term that allows people to make a written or oral record in relation to future treatment or care. It is not legally binding but can be taken into account by professionals. Advance Decisions are legally binding and come into effect when individual has lost capacity to give or refuse consent. Where they relate to refusal of life sustaining treatment they need to be made in writing and witnessed. Advance Directives in Scotland are not legally binding, but there is a presumption that they will be met.

⁴ Parkinson's UK *Just invisible: a summary* (2005)

⁵ All Party Parliamentary Group on Parkinson's Disease *Please mind the gap: Parkinson's disease services today* (2009)

Coupled with a Parkinson's UK members survey which pointed to an overall picture of poor knowledge of Parkinson's amongst health and social care professionals⁶, the evidence points to a strong likelihood that people with Parkinson's are not being made aware of their rights to access support, and plan in advance, should their capacity begin to fluctuate or wane as the condition advances. The recent changes to the law may also mean they aren't being given up to date information.

In 2010 the Mental Health Foundation surveyed the way in which professionals were implementing the Mental Capacity Act in England and Wales, and found 52% of professionals were assuming that service users did not have capacity before conducting an assessment, and 38% were conducting an assessment purely because of a service user's disability or illness. Both are contrary to the principles in the Act.⁷ The survey indicates the need for much closer monitoring of how the law protects people who may lack capacity.

Parkinson's disease dementia can also cause problems with decision making, however many health and care professionals have limited awareness of the condition. Seven in ten UK health and social care professionals recently said that they needed training on Parkinson's disease dementia.⁸

What Parkinson's UK is doing

We are working to ensure that people are aware of their rights under the Mental Capacity Act through our information resources, advisory services and regional teams. We also train professionals working with people with Parkinson's so they are better educated about the condition. We campaign for improvements to the law where these are needed.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on mental capacity. 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 Social Policy and Campaigns team. Tel: 020 7963 9307 or email: campaigns@parkinsons.org.uk

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⁶ Parkinson's UK *Life with Parkinson's today – room for improvement* (2007)

⁷ Mental Health Foundation *Initial findings from the Mental Health Foundation's Assessment of Mental Capacity Audit Tool* (2010)

⁸ Parkinson's UK (unpublished) results of training needs analysis

Appendix 1: Legislation

Scotland

The Adults with Incapacity (Scotland) Act 2000 (and later the Adult Support and Protection (Scotland) Act 2007) sets out the framework on mental capacity. It set out major principles that presume adults are capable of making decisions for themselves, and have the right to make “unwise decisions”. Where they cannot make decisions there are principles that ensure their wishes are taken into account, carers are consulted and the decisions will be beneficial to them and not restrict their freedoms. The Act also contains a criminal offence of ill treatment and wilful neglect of a person who lacks capacity. It also contains:

- the ability of a person to grant someone they trust the powers to act as a continuing (financial) Power of Attorney or Welfare Power of Attorney
- an access to funds scheme that allows a person’s main carer to access the adult’s account/s in order to meet his/her living costs
- Intervention and Guardianship Orders that allow an individual or the local authority (where the person has no-one) to safeguard or promote the adults interest as a single action or in the long term
- Rules on decision making and consent for medical treatment and research, including the use of Advance Directives.

The main bodies involved in implementing the Act are the Office of the Public Guardian (Scotland) which registers and supervises those authorised to manage property and financial affairs of the person, and the Mental Welfare Commission which has a role in protecting the welfare of the person, and making special investigations and reviews. Legal cases are decided in the Sherriff Courts.

England and Wales

The Mental Capacity Act 2005 introduced principles for helping people who may have difficulties making decisions, and procedures for assessing mental capacity. It also set out major principles, that presume adults are capable of making decisions for themselves, even unwise decisions. Where they cannot make decisions, these will be taken in their best interests and not restrict their rights and freedoms, taking account of their wishes. The Act also contains a criminal offence of ill treatment and willful neglect of a person who lacks capacity.

It also introduced organisations and systems to support the Act including:

- the ability to appoint two types of Lasting Powers of Attorney. One for property and affairs and one for personal welfare, to help act for that person if they subsequently lose capacity
- Statements of Wishes and Preferences, and Advance Decisions, the former a term to embrace a range of written/oral records which are not legally binding with Advanced Decisions a more formal and legal binding statement on what forms of treatment someone would or would not like, including the refusal of life-sustaining treatment
- Deprivation of Liberty Safeguards, introduced in April 2009, as a legal framework for restricting someone’s freedom so that treatment or care can be provided in a care

home or hospital when they lack mental capacity. This is irrespective of whether they are placed there under public or private arrangements

The main bodies involved in implementing the Act are the Office of the Public Guardian which registers and supervises Lasting Powers of Attorney, among other duties. The Court of Protection will take decisions on serious issues where there are complex or disputed cases. The court can appoint 'Deputies' who will deal with property, affairs and personal welfare decisions on behalf of that person.

In addition, there are some people who lack capacity who have no family or friends and no one to support them with potentially life-changing situations. To assist, the Independent Mental Capacity Advocate service (IMCA) is a specific advocate (not a decision maker) and one should be located in each local authority area.

Northern Ireland

Although there is no equivalent legislation in Northern Ireland, the Bamford Action Plan 2009-2011 (named after an earlier comprehensive review) has proposed a single Act encompassing mental capacity and mental health to be introduced in the Assembly after 2011. In the meantime, cases in Northern Ireland are decided under common law.