

Parkinson's UK policy statement

Promoting equality for people with Parkinson's

"Trying to use the disabled parking bays in supermarkets and cities can be a nightmare ... The times when I need to use a wheelchair means that I often can't use the underground. If I'm travelling on the underground on foot, I can rarely get to the special seats, people don't give them up and as I'm a slow walker, I get shoved and knocked about getting to platforms."

"I've been out at times and complete strangers have accused me of being drunk or admonished me for being slow to pay at a checkout. I've tried not to let it knock my confidence – instead I use the opportunity to tell people to read up about Parkinson's!"

Comments from people with Parkinson's

What we believe

Everyone with Parkinson's has the right to full and equal participation in society and to live a life free of harassment or discrimination related to their condition. Negative attitudes and the physical barriers that exist towards people with Parkinson's, and other disabilities or long-term conditions, need to be challenged and public understanding of Parkinson's must be improved. The law needs to be used and strengthened where necessary to protect people with Parkinson's from discrimination.

Why we believe this

People affected by Parkinson's report that the attitudes of other people and society at large can create significant difficulties in living with the condition. People report that the more visible symptoms of Parkinson's, such as tremor, slowness, uncontrolled movements, speech problems and a lack of facial expression, can give rise to negative comments and harassment. In extreme cases, lack of understanding and suspicion about the behaviour of someone affected has prompted police involvement.

Social attitudes and the way that services are organised can mean physical barriers and stigma get in the way of everyday activities for people affected and have a major impact on quality of life. It's crucial that people are treated equally and with dignity and respect¹. Legislation in the UK exists to make it unlawful to discriminate against someone on the basis of age, disability, race, religious belief, sex and sexual orientation. The key legislation is set out in the appendix.

Many people with Parkinson's fall under the legal definition of having a disability and should be protected from discrimination and unfair treatment on the grounds of disability.

People with Parkinson's have other characteristics that are covered by anti-discrimination legislation, including age, race, religious belief, sex and sexual orientation.

People who are at risk of being discriminated against on multiple counts can find life even more challenging. With Parkinson's being most common among older people, many people

¹ Parkinson's UK's *Equal opportunities and diversity policy* sets out the charity's own commitment to promoting equality and valuing diversity

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with Parkinson's say age discrimination, as well as disability discrimination, is an issue for them.

As well as problems with attitudes in public, common areas of complaint from people with Parkinson's include:

Employment

People with Parkinson's report many challenges in the world of work. These can include encountering prejudice in recruitment or the day-to-day working environment and difficulty getting suitable adjustments. Our policy statement on employment has more detailed recommendations on what employers and governments can do to improve the situation.²

Facilities, services and goods

Gaining physical access to shops, transport and other services can be challenging. Telephone conversations can become increasingly difficult for those with speech problems. Assumptions are often made about people's ability to access the internet or undertake financial transactions, despite a significant number of people having no internet access or finding it difficult to use a computer for dexterity reasons.³

Health and social care

Some accepted practice in health and social care can be discriminatory. For example, residents with Parkinson's in care homes are entitled to appropriate healthcare from the health service but evidence shows their rights are often overlooked.⁴ In homecare, a report has identified a number of issues with the way care is delivered that infringe upon human rights.⁵ This has added to the calls to ensure all those in receipt of care – whether privately or publicly funded – are covered by human rights legislation.⁶

There may be a lack of understanding about Parkinson's among health and social care staff. This can include assumptions that people are uncooperative at certain times of day when this is related to the fluctuating nature of their Parkinson's.

The examples above show society has a long way to go before adopting a 'social model of disability', based on the principle that disability is caused by the way society is organised, rather than by a person's condition or impairment.

In order to improve matters for people with Parkinson's we believe that:

- service providers, employers and the public must reflect the spirit of anti-discrimination and disability rights legislation in their attitudes and actions
- people with Parkinson's need clear information about their rights and the confidence to challenge discrimination when it happens
- there must be improved compliance with anti-discrimination and disability legislation. We believe that governments, public bodies and other groups must take proactive

² For more information see the Parkinson's UK policy statement on Employment (2014).

https://www.parkinsons.org.uk/sites/default/files/policystatement_employmentandparkinsons.pdf

³ The latest statistical analysis from the Office of National Statistics suggests 23% of households have no internet access.

<http://www.ons.gov.uk/ons/rel/rdit2/internet-access--households-and-individuals/2011/stb-internet-access-2011.html>

⁴ *Please mind the gap – Parkinson's disease services today* (All Party Parliamentary Group for Parkinson's Disease, 2009)

⁵ Equality and Human Rights Commission (2011) www.equalityhumanrights.com/news/2011/june/inquiry-reveals-failure-to-protect-the-rights-of-older-people-receiving-care-at-home/

⁶ See Appendix. The Human Rights Act, allows individuals to enforce convention rights directly against "public authorities", but not private companies, unless the care company operates under a contract to the public authority. This leaves those who individually fund their own care unprotected by human rights legislation.

steps to address these issues via national policy, enforcement of the law, measures to increase awareness and spread good practice

- current gaps in legislation need to be addressed. This includes the application of human rights legislation to those who pay for their own care in care homes or from homecare agencies, and adopting a freestanding right to independent living for disabled people in legislation that applies across the UK (rather than as reference to a UN convention where complaints have to be addressed at that level)

What's the evidence?

Research shows that people with Parkinson's find a number of barriers⁷ when they are going about their daily lives, some of which relates to the way society is organised.

- Two out of five people with Parkinson's found it difficult to access key public transport services.
- Nearly half of people with Parkinson's wanted to do activities outside of their home such as socialising, visiting relatives or pursuing hobbies, but could not in the three months before being surveyed. Common reasons why not were: lack of public toilets (30% of respondents), problems getting around the streets (30%), difficulties with transport (29%) and problems with access to buildings (25%).

This adds to the wider body of evidence relating to people with disabilities. For example, 57% of adults with disabilities say they experience barriers to employment (compared to 26% without) and 75% experienced barriers to using transport (compared to 60% without).⁸

In terms of attitudes and awareness, a recent opinion poll⁹ commissioned by Parkinson's UK also revealed that there is still a lack of public knowledge and understanding about Parkinson's.

- 77% of those surveyed had little or no knowledge of Parkinson's.
- 16% of those surveyed said they would feel annoyed, embarrassed or uncomfortable if they encountered someone with a tremor, which is one of the more visible signs of Parkinson's.

For Parkinson's Awareness Week in 2013, Parkinson's UK also published the findings of a major survey of people affected by Parkinson's. Of nearly 3,000 people with Parkinson's who responded to questions on attitudes they had experienced, it found:

- 67% felt the public had a poor understanding of the condition
- 47% had experienced discrimination, including being overlooked or receiving strange looks from the public
- 28% stated they had been treated differently by friends who didn't understand their condition
- 57% had been told they look 'too well' to have Parkinson's
- 27% said they avoided going out at busy times of the day because they were wary of the public's reaction to their Parkinson's
- 43% said their Parkinson's made them feel isolated when out in public
- 60% said their Parkinson's made them feel scared, uncomfortable or nervous in public

⁷ *Life with Parkinson's today – room for improvement* (Parkinson's UK, 2008)

⁸ Office of Disability Issues Life Opportunities Survey <http://www.ons.gov.uk/ons/rel/los/life-opportunities-survey/life-opportunities-survey/index.html>

⁹ ICM, *Low Awareness of Parkinson's, December 2012* <http://www.icmresearch.com/low-awareness-of-parkinson%E2%80%99s>

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- 21% said their Parkinson's had been mistaken for drunkenness
- 21% reported that incidents happened once a week or more, 16% reported it happened monthly and 24% stated they experienced this once or twice a year.

What Parkinson's UK is doing

As a charity, we are committed to changing attitudes around Parkinson's. We carry out research and campaigns to challenge discrimination and ensure goods, services and job opportunities are accessible to people with Parkinson's. Our annual Parkinson's Awareness Week is an important part of our work to raise awareness and increase understanding.

Parkinson's UK actively encourages people with Parkinson's to apply for roles at the charity. We are working with people affected to become a model employer of people with the condition.

We provide training for professionals and organisations via our network of Education and Training Officers and voluntary educators. Anyone who wishes their workforce to be more Parkinson's aware is welcome to contact us for training.

We also have a UK-wide network of information and support workers and a helpline. These services offer one-to-one information and emotional support to people with Parkinson's, their families and carers. They can also provide support and information if someone with Parkinson's experiences discrimination.

Acknowledgement

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

Further information

Please contact the Policy and Service Improvement team on 020 7963 9307 or email campaigns@parkinsons.org.uk

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Appendix

Government policy, relevant legislation and issues raised; definitions

The Equality Act 2010 replaced previous anti-discrimination legislation including disability and age discrimination legislation in England, Wales and Scotland. In Northern Ireland a variety of Acts exist to work in the same way.¹⁰

The legislation across the UK sets out different ways in which it is unlawful to treat someone, such as direct and indirect discrimination, harassment, victimisation and failing to make a reasonable adjustment for a disabled person. It prohibits unfair treatment in the workplace, when providing goods, facilities and services, when exercising public functions, in the disposal and management of premises, in education and by associations (such as private clubs). It means that a disabled person can raise a complaint, even take court action, should they feel that they have been treated in any one of the above ways.

The legislation in Great Britain and in Northern Ireland also contains a definition of a disabled person as someone who has a physical or mental impairment that has a substantial and long-term adverse effect on his or her ability to carry out normal day-to-day activities. It also recognises that for those with progressive conditions the law applies from when there is a noticeable effect on ability to carry out day-to-day activities, given the condition is likely to become more substantially disabling.

Human Rights Act (1998)

This Act incorporates the European Convention on Human Rights into domestic law, and applies across the countries of the UK. Three rights of particular relevance are:

- the right to life
- the right to be protected from inhuman or degrading treatment (under Article 3)
- the right to respect for their private and family life (under Article 8)

The Act places public sector bodies under an obligation not to breach people's human rights. Public sector organisations are therefore required to consider the impact on people's human rights when setting policies and making decisions. Human rights do not give individuals the right to demand services that cost a defined amount. However, a human rights approach can help to ensure that decisions are people-centred rather than solely made on the basis of cost.

The Human Rights Act allows individuals to enforce convention rights directly against "public authorities", but not private companies.

UN convention on the rights of those with disabilities

Article 19 recognises the equal right of disabled people to live in the community with choices equal to others. Britain has ratified the Optional Protocol of the UN Convention. This allows people to bring a petition to the UN Committee on the Rights of Persons with Disabilities if they believe that their Convention rights have been breached and they have exhausted means of redress via the UK or European Courts. However, there is no freestanding domestic legislation that gives concrete effect to this right, something which the parliamentary Joint Committee on Human Rights has recommended.¹¹

¹⁰ See Equality NI summary of legislation [http://www.equalityni.org/sections/default.asp?cms=Your Rights_Disability discrimination&cmsid=2_142&id=142&secid=2](http://www.equalityni.org/sections/default.asp?cms=Your_Rights_Disability_discrimination&cmsid=2_142&id=142&secid=2)

¹¹ See Joint Committee on Human Rights inquiry into disabled people's right to independent living (2012) <http://www.publications.parliament.uk/pa/jt201012/jtselect/jtrights/257/257.pdf>