

Parkinson's UK policy statement Employment and Parkinson's

"My first thought when I found out I had Parkinson's was: 'can I go on working?'"

Richard, person with Parkinson's

"I'm determined to carry on working for as long as possible. I used to work seven days a week. That's just not feasible any more so I have reduced my hours and work from home. When I first told my business partner that I'd been diagnosed with Parkinson's, he was devastated. He knew less about the condition than I had done. But he has been really supportive and business is still going well."

William, person with Parkinson's

What we believe

People with Parkinson's should have the support and opportunity to work if they wish and are able to do so. Being able to remain in, or return to, work can have clear benefits to someone's wellbeing, as well as the wider economy. Support from employers can make a huge difference to the experience of a person with Parkinson's in the workplace. However, people also need to feel valued and respected if they can't work, as work is not always beneficial or possible when living with Parkinson's.

Why we believe this

There are many people with Parkinson's of working age. One estimate is that there are more than 17,000 people living with the condition aged between 20 and 64 across the UK. The average age of diagnosis of Parkinson's is between 50 and 60 years of age, although one in seven people will be diagnosed before the age of 50 and one in 20 before the age of 40.¹ A diagnosis of Parkinson's is not the end of someone's working life. It is a long-term condition and many people have full and independent working lives for many years.

However, Parkinson's can impact on many aspects of daily life as the condition progresses. Many people with Parkinson's fall under the legal definition² of having a disability and should be protected from disability discrimination and unfair treatment. This means employers need to make sure that no one is directly or indirectly discriminated against in terms of the recruitment process or failure to make reasonable adjustments to help someone with a disability to stay in work.³

¹ Parkinson's prevalence in the United Kingdom (2009) Parkinson's UK. Estimate of over 17,000 of working age people extracted by Parkinson's UK research department. <http://www.parkinsons.org.uk/pdf/parkinsonsprevalenceuk.pdf>

² For example, the Equality Act 2010 in Great Britain sets out that a person has a disability if: "they have a physical or mental impairment, the impairment has a substantial and long-term adverse effect on their ability to perform normal day-to-day activities." An equivalent definition exists in the Disability Discrimination Act 1995 provisions in Northern Ireland.

³ The Equality Act 2010 (Great Britain) states that an employer should not discriminate - directly or indirectly - against a person with disabilities. It also says that the employer should make reasonable adjustments. In Northern Ireland equality provisions of the 1998 Northern Ireland Act, include the requirement to "promote equality opportunity between persons with a disability and persons without".

Research shows that someone with a disability is less likely to be in employment⁴ and more likely to experience unfair treatment at work than someone without a disability.⁵ People with Parkinson's tell us that their employment experiences mirror that of the wider population of disabled people and that they want to see disability discrimination challenged.⁶

It is easier to support disabled people to stay in work than to have to retrain and rebuild skills and confidence after they have lost their job.⁷ Also, if people are unemployed or don't earn enough money they are at more risk of being socially excluded. Disabled people are twice as likely to live in poverty as non-disabled people.⁸

As people live longer, long-term conditions will become more common. And as the pension age increases, a larger proportion of the workforce will experience disability. Actions by governments to help people stay and get into work will become even more of a priority.

We believe the following actions should be taken to support people with Parkinson's:

Make the workplace more equal

All governments should raise awareness of equalities legislation. Everyone with Parkinson's should know their rights and all employers need to understand their obligations not to discriminate and to make reasonable adjustments.

Such adjustments do not need to be expensive or difficult, and can be made at any time from recruitment onwards. They can include flexible working, working from home or simple physical adjustments to the work environment.

Each person with Parkinson's is unique and the condition affects everyone differently. If someone has informed their workplace about their diagnosis, then managers must talk to their employee and get an understanding of the condition rather than making assumptions about what a diagnosis means. This includes, for example, appreciating that the challenges of Parkinson's are not confined to just movement.

Promote awareness of support

There are a number of schemes that exist to help disabled people and employers meet the extra costs of support while in employment. The Access to Work scheme is a UK-wide scheme⁹ open to disabled people and employers. This scheme can, for example, provide support with transport costs (when public transport is not an option), aids and adaptations at work, and making premises more accessible. Specialist advisory services locally¹⁰ can also help support people into work and give advice to employers on reasonable adjustments and good recruitment practice.

⁴ The employment rate of disabled people is 48.8 per cent, compared with 77.5 per cent of non-disabled people (Office for Disability Issues, 2011).

⁵ The Fair Treatment at Work Survey (Office for National Statistics, 2008) found that 19 per cent of disabled people experienced unfair treatment at work compared to 13 per cent of non-disabled people.

⁶ See Parkinson's UK Disability Discrimination and Equalities policy statement (2012) www.parkinsons.org.uk/policy. This has more information on the broader issues and actions for society to take.

⁷ For example, see the Sayce Review of Disability Employment Schemes, on behalf of the Department for Work and Pensions (2011).

⁸ Parckar G, 2008, *Disability Poverty in the UK*, Leonard Cheshire Disability.

⁹ For more information see the Access to Work scheme factsheet by Disability Rights UK www.disabilityrightsuk.org/f27.htm

¹⁰ Local Disability Employment Advisers in Great Britain based at Job Centres/ Job Centre Plus and in Northern Ireland Disability Employment Service Advisers based at Department for Employment and Learning offices

However, many disabled people and small and medium-sized employers do not realise this support exists.¹¹ All governments should do much more to promote the support available and encourage uptake so places of work become much more accessible.

Governments need to encourage uptake of benefits that help people stay in work. For example, government research shows that Disability Living Allowance is widely but wrongly thought to be an out-of-work benefit.¹² The research also found disabled people in work feeling 'guilty' about claiming it, despite its vital role in helping them.

Fair treatment in back-to-work schemes

Back-to-work schemes in Great Britain and in Northern Ireland operate via local job centres and offices for people who are long-term unemployed.¹³ Providers of these schemes, who are paid to help someone find employment, need to understand the complexities of Parkinson's when identifying suitable work for someone. As there is always a temptation for providers to focus on those easiest to place into work, it is essential people with Parkinson's are not overlooked.

There is an increasing number of sanctions for people who repeatedly fail to meet back-to-work obligations. It is not acceptable for anyone with Parkinson's to be sanctioned due to the effects of their condition. Governments should do more to ensure regional job centre and office structures in the UK have access to good information on Parkinson's, so that advisors are properly informed.

Supporting people who cannot work

It must be recognised that some people with Parkinson's cannot work, and in fact work could make their condition much worse. If they rely on benefits to help them, this should be respected. People have contributed to the welfare system with their taxes throughout their lives.

Some people with Parkinson's say they have been told by people in the benefits system that they are 'fit to work' when they know their Parkinson's makes this impossible, even dangerous. The Work Capability Assessment tests that assess fitness for work must be overhauled to recognise the complexities of Parkinson's.¹⁴

What's the evidence?

Parkinson's UK members' survey¹⁵

Parkinson's UK received more than 13,000 responses to this survey. Key findings were:

- a third of working age people with Parkinson's responding were in employment. 12% of women were in full-time work and 20% part-time, with 25% of men in full-time work and 7.5% part-time

¹¹ For example, see the Sayce Review of Disability Employment Schemes, on behalf of the Department of Work and Pensions (2011). This described the Access to Work scheme as "Government's best kept secret".

¹² Impact of Disability Living Allowance and Attendance Allowance: Findings from exploratory qualitative research. University of York report 649 (2010) <http://research.dwp.gov.uk/asd/asd5/rrs-index.asp>

¹³ In Great Britain this is the Work Programme, see: <https://www.gov.uk/government/policies/helping-people-to-find-and-stay-in-work/supporting-pages/managing-the-work-programme> and in Northern Ireland this is the Steps to Work/Pathways to Work Programme see: <http://www.nidirect.gov.uk/stepstowork>

¹⁴ See the Parkinson's UK policy statement "Income replacement benefits" (2011) www.parkinsons.org.uk/policy for more information on the actions needed to improve these tests.

¹⁵ *Life with Parkinson's today – room for improvement* (Parkinson's UK, 2008)

- less than 0.5% of respondents to the survey were involved in any training
- 98% of respondents were in or had undertaken paid work. The most likely type of work that respondents were in or had done was in professional or technical grades (29%), managers/administrators (19%), clerical workers (18%) or artisans (11%)

Parkinson's UK employment study¹⁶

A UK-wide survey investigated the effect of Parkinson's on employment and the critical factors that would help people with Parkinson's remain in or re-enter employment. 327 people with Parkinson's took part in a survey and a smaller number in one-to-one interviews. The study's findings showed that:

- four out of five reported that Parkinson's made work difficult for them
- six out of 10 respondents reported leaving work because of these difficulties
- minor adjustments could make work life easier, including flexible working hours, specialist equipment and occupational therapy
- four out of 10 felt that they were supported by their employer
- respondents had worked an average of 4.7 years after diagnosis
- there was a variety of experiences with Access to Work, but a lack of awareness of the scheme

Some smaller studies have also found people retire earlier when they have Parkinson's. For example in one study the average retirement age was 55.8 years, compared to the then UK average of 62 years.¹⁷

Parkinson's UK YouGov survey¹⁸

For Parkinson's Awareness week in 2013, Parkinson's UK published findings of a major survey of people affected by Parkinson's. Of nearly 3,000 people with Parkinson's who responded to questions on employment and the experience of problems in the workplace people with Parkinson's have faced, it found:

- 86% of respondents have been in paid employment at some point in their lives
- 76% of respondents who have been in paid employment have never had any problems from other colleagues or their employer when they needed reasonable adjustments after their diagnosis
- 5% of those questioned felt their colleagues were unsupportive
- 14% of respondents under 50 years old found that their colleagues were unsupportive and 17% said their employer did not make suitable arrangements or adjustments
- 20% of those diagnosed with Parkinson's over 10 years ago took early retirement but didn't want to, whereas 25% retired early but did so willingly

What Parkinson's UK is doing

Parkinson's UK is committed to supporting people with Parkinson's and ensuring that they can access appropriate employment opportunities. A freephone UK-wide helpline is available to provide expert information on employment, along with written information resources. We

¹⁶ *What are the key factors which enable people with Parkinson's to remain in or re-enter Employment?* P Banks, M Lawrence (University of Glasgow, supported by a Parkinson's UK research grant, 2003)

¹⁷ *Time of loss of employment in Parkinson's disease.* Schrag A, Banks P. *Mov Disord.* 2006 21(11): 1839-43

¹⁸ Survey of people with Parkinson's and their friends, family and carers, YouGov. April 2013.

also provide free and confidential one-to-one support at local level through our Information and Support Workers.

We lobby for a fair deal for people with Parkinson's in terms of employment rights and government action. We also work to change attitudes about Parkinson's.

As the leading UK charity for people with Parkinson's, we're keen to have a workforce that is representative of the people we support. We therefore actively encourage people with Parkinson's to apply for roles where they have the necessary skills, knowledge and experience. We are working with people affected to develop models of good practice in employing people with the condition.

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 on a regular basis to help guide the charity's position on a range of policy issues.

Further information

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

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