

Policy statement: Employment

"... you can still have potential, even though you've got Parkinson's. I mean, I don't think you're gonna be an asset in a cocktail bar, but there are certain things that you can excel at."

Focus group participant with Parkinson's

What we believe

Parkinson's UK believes that people with Parkinson's should be able to live full, independent lives and should be supported to remain in employment for as long as they are able to work.

Why we believe this

1. While the majority of people develop Parkinson's symptoms after the age of 65, thousands of working age people are also affected.¹ People with Parkinson's can and do contribute to a variety of workplaces in a variety of roles and should be enabled to continue doing so even as their condition progresses. Both the UK government and employers have critical parts to play in ensuring that this happens. At the same time, when people with Parkinson's are no longer able to work, they should be supported to continue to live well.
2. Parkinson's is a progressive condition, for which no cure currently exists. Parkinson's UK is concerned that lack of understanding about the condition by both employers and the UK government results in the skills, knowledge and experience of employees with Parkinson's being wasted.
3. Paid work not only provides an income, it is also a source of identity and purpose for many. Good work^{2 3} also has health benefits.^{4 5} However, where job, workplace or organisational culture design are inadequate, work can and does compromise health.^{6 7}
4. We believe that jobs should be redesigned as far as possible to fit people's changing capacity and capability. This is not only good for people with Parkinson's who can remain in work for longer, but is also good for employers. The flexibility of smart working - removing time and place constraints of work - increases the productivity of workers.^{8 9 10}
5. In this paper, we set out what people with Parkinson's have told us about their employment experiences. We then identify what we think needs to change to better support people with Parkinson's to gain and retain work.

¹ Pringsheim T, Jette N, Frolkis A, Steeves T D L. The prevalence of Parkinson's disease. *Movement Disorders*. 2014.

² Brinkley I. CIPD Good Work Index 2023: Survey report. Chartered Institute of Personnel and Development. 2023.

³ Dobbins T. Good work: policy and research on the quality of work in the UK. House of Commons Library. 2022.

⁴ Waddell G, Burton A K. *Is Work Good for Your Health and Well-being?* TSO. 2006.

⁵ Marmot M. *Fair Society, Healthy Lives*. The Marmot Review. 2010.

⁶ Shaw J. New polling: crisis in working conditions making Brits ill. *Workwhile*. 2023.

⁷ Morgan D. 'Too ill to Work': A deeper look at what the figures show. ONS. 2023.

⁸ Marta Angelici M, Paola Profeta P. Smart Working: Work Flexibility Without Constraints. *Management Science*. 2023.

⁹ Choudhury R P, Foroughi C, Larson B. Work-From-Anywhere: The Productivity Effects of Geographic Flexibility. *Strategic Management Journal*. 2020.

¹⁰ Giovanis E. The relationship between flexible employment arrangements and workplace performance in Great Britain. *International Journal of Manpower*. 2018.

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Employment policy context

6. People with long-term conditions were a key group driving the rise in economic inactivity in recent years.¹¹ The number of working age adults not working due to long-term ill health reached a new record of 2.55 million in the first quarter of 2023.¹²
7. In March 2023, the UK government published its health and disability white paper.¹³ In that paper, the UK government acknowledged that many people with long-term conditions like Parkinson's, could gain and retain paid work, if they had the right support. The paper identified three ways to provide that support:
 - investing to step up our employment support for disabled people and people with health conditions
 - ensuring people can access the right support at the right time and have a better overall experience when applying for and receiving health and disability benefits
 - reforming the benefits system for the future so it focuses on what people can do rather than on what they cannot

What our community says

8. We wanted to find out, in more detail, what our community experiences in relation to employment. In June and September 2019, we asked people with Parkinson's about their experiences of employment when living with the condition. Then, in Autumn 2021, we ran a number of focus groups with people with Parkinson's to discuss their employment experiences. Based on that research, this paper looks at challenges that people with Parkinson's have told us they experienced throughout the employee life cycle, from gaining work through to leaving work.

"... you can still have potential, even though you've got Parkinson's. I mean, I don't think you're gonna be an asset in a cocktail bar, but there are certain things that you can excel at."

Focus group participant with Parkinson's

Getting a job

9. Research shows that interviewers recall less information about interviewees with visible disabilities.¹⁴ This chimes with what we heard from many people with Parkinson's, who told us that they are concerned that physical manifestations of their Parkinson's - such as a visible tremor - in an interview will be off putting for interviewers.

"I knew damn well that if I went anywhere and sat down in an interview with a shake, they would say, what's the matter with you and I'd say, Parkinson's. They wouldn't employ me. They wouldn't say that they couldn't employ me because of Parkinson's. They'd just say that there was another candidate that was much better so I knew that I'd hit a brick wall, so to speak."

Focus group participant with Parkinson's

"I have a tremor that's quite dominant. And when I'm stressed it definitely is. And so I just kind of

¹¹ Murphy R. Dennes M. White E. Vizard T. Reasons for workers aged over 50 years leaving employment since the start of the coronavirus pandemic: wave 2: ONS. 2022.

¹² Cominetti N. Growing, but for how long. Resolution Foundation. 2023.

¹³ Transforming Support: The Health and Disability White Paper. DWP. 2023.

¹⁴ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

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think, would anybody actually want to employ me? I mean, you sort of said it. They wouldn't necessarily say it's back because you've got Parkinson's, but it would be an underlying thing"

Focus group participant with Parkinson's

"...getting into the interview, but they might just be doing it because they're obliged to rather than anything else."

Focus group participant with Parkinson's

10. And, while employers may express positive attitudes towards disability employment policies, they often show negative hiring practices, which means that positive attitudes are not translated into actual hiring.¹⁵ For example, even if disabled people do make it into applicant pools, hiring managers might incorrectly assume that these applicants do not want challenging careers or assignments.¹⁶

"I was shortlisted for the job, and then, when I got the criteria about what was going to happen at the interview, obviously it was a practical exercise and I thought, oh no. This is really where I'm gonna fall down because I'm going to be slow. I'm not going to get done in time. So you know I rang the manager and I explained the situation, I said look this is where I'm at, I can complete the task, I probably just need longer to do it. And we negotiated how that task was going to run for me."

Focus group participant with Parkinson's

11. One way that employers could be proactive in addressing this unconscious bias is by working with agencies and community-based organisations that specialise in supporting the employment needs of disabled people.¹⁷

Diagnosis disclosure

12. People with Parkinson's have told us they are often reluctant to disclose their diagnosis. In our 2019 survey, we found that:

- A quarter of (25%) of survey respondents with Parkinson's either did not disclose or delayed disclosure of their diagnosis to their employer.
- A quarter (25%) did not feel supported by their employer.
- Over half (56%) said their employer did not attempt to find out more about Parkinson's.
- Of the 56% of respondents in work, half stated they would want to retire early on health grounds, as they felt unable to continue working *at the same level*.

13. This reluctance is born of a fear of actual or perceived stigma. And research suggests that this fear is well-founded, particularly given managers' concerns about the performance

¹⁵ Østerud K L. Vedeler J S. Disability and Regulatory Approaches to Employer Engagement: Cross-National Challenges in Bridging the Gap between Motivation and Hiring Practice. Social Policy and Society. 2022.

¹⁶ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

¹⁷ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

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and productivity of disabled employees.¹⁸

"I had Parkinson's for five years before anybody knew about it."

Focus group participant with Parkinson's

"I was very concerned at the outset. I didn't want people to know, I was a bit sensitive about it."

Focus group participant with Parkinson's

14. Many of the people with Parkinson's we spoke to described line managers who were understanding, flexible and supportive. But workers with Parkinson's don't just have working relationships with their line managers. They will also have relationships with colleagues. People with Parkinson's have told us of obstructive responses from colleagues responsible for organisational infrastructure, such as IT hardware and software.

"... but I still had problems with IT ... you shouldn't have two [laptops] and I'm like, I've got a disability and they're oh oh, sorry. Sorry we didn't realise that, and then they back off."

Focus group participant with Parkinson's

"The IT section was terrible... I'd go to them with technical problems using the mouse with a shake, as you can see, and stuff like that, and they were hopeless, didn't have a clue."

Focus group participant with Parkinson's

15. Even when someone has disclosed their diagnosis to a line manager or human resources department, the people with Parkinson's we spoke to told us of having to repeatedly disclose their condition to colleagues and justify adaptations.

"So I had an experience where a colleague of mine came out to me and said, 'how come you got a parking space?' I just turned around pointblank and said, 'Well, I've got myself a life-changing condition', and they didn't know."

Focus group participant with Parkinson's

"You need to go to the toilet more frequently, and things like that. People see you walking around the or just basically, walking around the office just to get some mobility going. Sometimes you get some funny looks, and then so if they understand why you're doing it. It makes it a lot easier."

Focus group participant with Parkinson's

16. Yet in a truly flexible, inclusive and responsive workplace, the person with Parkinson's would not bear the responsibility of educating colleagues. The onus should lie with the employer, in conjunction with the employee living with Parkinson's, to take action needed to ensure all staff are sufficiently aware of the fact that colleagues will have differing needs and how those needs might be commonly met.

"I want people to know, but I don't want to have to keep telling people and I don't want to have to keep going over everything, I don't want to keep harking on about it, going on about it, for want of a better phrase."

Focus group participant with Parkinson's

¹⁸ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

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17. And in a truly flexible and inclusive workplace, someone with Parkinson's would not be expected to know what the best form of support might be available to them.

"[My line manager] wanted me to try and identify something [dictation software]. And that's where we seem to have stalled. Yeah, she was kind of like saying to me, you know ... is there something out there? But I'm not IT literate. I don't know. I even emailed our IT people ... all got back was there's a dictation function on your laptop ... and you can dictate to it. But it's not very good."

Focus group participant with Parkinson's

The problem of perception

18. Negative perceptions of disabled people persist^{19 20} and those negative attitudes are often considered a major barrier for disabled people to gain and maintain employment.²¹ People with the condition told us that there is a stereotypical view of what Parkinson's is, which revolves around the physical symptoms associated with the condition and with older age.

"...when you say you've got Parkinson's, everybody immediately defaults to an old stooped person with lots of tremors."

Focus group participant with Parkinson's

19. And yet, our community tells us that the reality is that the most significant symptoms of Parkinson's that determine whether or not they will succeed in the workplace are the mental health symptoms.

"It's not so much the physical adaptations we need, it's more about the mental, anxiety and stress, and ... about parking the car and ... getting there on time, you worry about that. I mean, if you make it more flexible and that helps a lot more on the mental side."

Focus group participant with Parkinson's

20. This is perhaps unsurprising, given that 40%²² of people with Parkinson's will have depression and up to 31%²³ will experience anxiety at any given time. More specifically, research has found that mental health in early onset Parkinson's has a greater influence on the likelihood of people leaving the workforce than physical symptoms.²⁴

21. We also heard from members of our community that they felt subject to seemingly benign discrimination.

"My colleagues overcompensated for me in as far as they would flag up when I made a mistake, and when I actually said to my neurologist, when I had a meeting with him. I said, is this a

¹⁹ Moss C. Frounks A. Attitudes and disability: the experiences of disabled people in 2022. Scope. 2022.

²⁰ Beatty J E. Baldrige D C. Boehm S A. Kulkarni M. Colella A J. On the treatment of persons with disabilities in organizations: A review and research agenda. Human Resource Management. 2018.

²¹ Grze'skowiak A. Zaluska U. Kozyra C. Kwiatkowska-Ciotucha D. Perception and Acceptance of People with Disabilities by Employers and Co-Workers International. Journal of Environmental Research and Public Health. 2021.

²² Aarsland D. Pålhlagen S. Ballard C G. Ehrt U. Svenningsson P. Depression in Parkinson's disease – epidemiology, mechanisms and management. Nature Reviews Neurology. 2012.

²³ Broen M P G. Nadia E Narayen N E. Kuijf M L. Nadeeka N W. Dissanayaka N N W. Albert F G. Leentjens A F G. Prevalence of anxiety in Parkinson's disease: a systematic review and metaanalysis. Movement Disorders. 2016.

²⁴ Armstrong M J. Gruber-Baldini A L. Reich S G. Fishman P S. Lachner C. Shulman L M. Which features of Parkinson's disease predict earlier exit from the workforce? Parkinsonism and Related Disorders. 2014.

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problem? He said. Well, did you make mistakes before? And I said, well, probably because everybody makes mistakes. And he said, well, they're just overcompensating. They're just looking at you more closely because they're worried about you. So, out of the kindness of their heart, they were bullying me. I was starting to feel a bit bullied."

Focus group participant with Parkinson's

"The company has been good, but the one thing I'm feeling is that I think they're over compensating for me. So I feel I'm not getting a lot of the stuff I used to manage is being taken away from me now I think about it. I'm hoping that it's my line manager and my other managers think they're doing me a favour by easing off my tasks. But it's then making me feel like insecure. Are they just trying to work me out [of the organisation]?"

Focus group participant with Parkinson's

"I think they're almost frightened that they might not do what I need and they're sort of ahead of the game in offering to do stuff, which sometimes feels as though they're rushing me through the process of reducing my hours."

Focus group participant with Parkinson's

22. These experiences are reflected in research. Non-disabled colleagues can behave in a way that suggests they view their working relationships with disabled people, such as those with Parkinson's, as a parent–child dependency relationship.²⁵ Other research suggests that disabled people are viewed as having high warmth (e.g., friendly, good-natured) but low competence (e.g., incapable, unskilled).²⁶ These perceptions can lead to managers having lower expectations of disabled workers, the negative impact of which can include compromised self-confidence and self-esteem and, consequently, an increased risk of anxiety.

"...the lack of education for other people. That's definitely the case. It kind of feels like it, even though they've [participant's employers] known about it for a while. Nobody's actually kind of looked into what could be the difficulties or anything"

Focus group participant with Parkinson's

Numbers count

23. Many employers will sign up to corporate social responsibility goals and promote inclusivity and diversity. Yet this may reflect a commitment to reputation management rather than to tangibly inclusive workplaces and cultures.²⁷ The effect can be to keep disabled people at a distance, instead of integrating them into a workplace and work culture. And employers cannot begin to know whether they have genuinely succeeded in developing a truly inclusive workplace and work culture, as data on employers' disabled workers are not collected.

- Just 12 of the FTSE 100 report on the total number of their employees who have disclosed as disabled.

²⁵ Beatty J E. Baldrige D C. Boehm S A. Kulkarni M. Colella A J. On the treatment of persons with disabilities in organizations: A review and research agenda. Human Resource Management. 2018.

²⁶ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

²⁷ Segovia A I. Saavedra-Robledo I. Fernández de Tejada V. Analyzing Disability in Socially Responsible Companies. Social Indicators Research. 2017.

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- Only 5 of 100 have issued board level statements on disability as part of their leadership agenda.
- No more than 16 of 100 companies set credible targets related to the representation of disabled people.²⁸

Focus on the possible

24. Without a supportive work environment, disabled workers, including those with Parkinson's, have difficulty maintaining their jobs in an open market.²⁹ If employers are to meaningfully commit to providing the flexible, responsive workplace needed to support people with Parkinson's to gain and remain in employment, they will need to commit to ensuring all staff are familiar with Parkinson's, its common features and how that impacts upon those with the condition.

"I just feel useless. My employer never encouraged me to stay or help reduce my hours. I assumed once you had Parkinson's that was it."

Person with Parkinson's

25. It is the positive attitude of employers and non-disabled co-workers that is essential for people with Parkinson's and others with long-term conditions to successfully adapt in the workplace.³⁰ Explicitly including disability in formal diversity statements and policies, and day-to-day practices that implement those policies, can help organisations move beyond adopting a limited legal compliance perspective, that just seeks to meet minimum legislative requirements.³¹ Communicating about and normalising these practices to internal and external stakeholders is critical to employers changing workplace culture and becoming truly inclusive.³²

26. To bring about such a cultural shift, the government must proactively enable employers to gain accurate insight into working with disabled people and consistently share this insight with their staff. Critical to this is collecting accurate information on the number of disabled people in the workforce. Research suggests that estimates of the proportion of the workforce with a disabling long-term condition are, in fact, underestimates. If employers do not have an accurate idea of how many working age disabled people there are in the workforce, they cannot know whether the number of disabled people they employ reflects the norm.³³

Reasonable adjustments

27. A key barrier for the recruitment of people with health conditions is employers' limited understanding of the cost of reasonable adjustments and how the government could

²⁸ Gbedemah L. Disability 100 Findings Report. Tortoise. 2021.

²⁹ Kwan C K. Socially responsible human resource practices to improve the employability of people with disabilities. Corporate Social Responsibility and Environmental Management. 2019.

³⁰ Grze'skowiak A. Zaluska U. Kozyra C. Kwiatkowska-Ciotucha D. Perception and Acceptance of People with Disabilities by Employers and Co-Workers International. Journal of Environmental Research and Public Health. 2021.

³¹ Lengnick-Hall M L. Gaunt P M. Kulkarni M. Overlooked and underutilized: People with disabilities are an untapped human resource. Human Resource Management. 2008.

³² Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

³³ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

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support these.³⁴ Not only were employers unaware of the support available to facilitate continued employment, our 2019 survey found that less than a third (31%) of respondents were aware of the key government support scheme, [Access to Work](#). Just over one in ten (13%) had used the scheme. And although the UK government acknowledged a need to expand Access to Work provision, funding for the scheme has not met that ambition. Rather, rationalising of the scheme led to effective cuts to service.^{35 36}

28. In another study, over two thirds (67%) of those who had become unemployed or who had retired as a result of Parkinson's believed that adjustments such as changes in work schedule, type of work or having a longer time to complete tasks could have helped them to stay employed longer at work.³⁷

"I approached the SENDCO and he said it was the only job left for me to do ... he told me I was inadequate. I went and saw the head and he said there's no room for negotiation. They had no education about Parkinson's at all."

Focus group participant with Parkinson's

"flexibility ... is the most important thing for me, where I can get to work at 9 or 10 or 8.30 or whenever, because some days you're worse than others."

Focus group participant with Parkinson's

29. Fewer than half (43%) of respondents to our survey requested changes or adaptations at work, either through Access to Work or as a reasonable adjustment, many of which would have incurred little to no cost. Adjustments requested included:

- Different role.
- Reduced or flexible hours, more rest breaks or working from home.
- Time off for medical appointments.
- Different chair and/or equipment.
- New software.
- Less travel.
- Change of working environment - no working at height.
- Use of taxis to get around.
- Reduction in performance targets.
- Parking space.
- Ramps.
- Accessible toilet facilities.

30. Some employers recognise that their staff are valuable assets and take action to ensure that the skills, knowledge and expertise accumulated by those staff are not lost. There is a range of changes that employers can make to continue to reap the benefits of retaining experienced staff. At one end of the spectrum, it could be as simple as allocating a parking

³⁴ Institute for Employment Studie. Health-led Trials: Evaluation Synthesis Report. DWP. 2023.

³⁵ Hale C. Barriers to Work: a survey of Deaf and Disabled people's experiences of the Access to Work programme in 2015/2016. Inclusion London. 2017.

³⁶ Parliamentary and Health Ombudsman. A report of investigations into complaints about Access to Work. Parliamentary and Health Ombudsman. 2017.

³⁷ Mehanna R. Jankovic J. Young-onset Parkinson's disease: Its unique features and their impact on quality of life. Parkinsonism and Related Disorders. 2019.

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space.

"I get a lot of anxiety about trying to park the car. Got a parking space now, so I don't have to rush into work. I can take my time."

Focus group participant with Parkinson's

"It's about being able to open the car door, or you don't get that in parking spaces usually, so it makes it much easier."

Focus group participant with Parkinson's

31. For many with Parkinson's, fatigue is particularly problematic. Yet full time work can still be viable - with adaptations to accommodate fatigue and work completed to a more flexible schedule.

"If I can't sleep at night, I don't stress over it. I'm like okay. I can get up in the morning and I can log on. I can do a few hours and go back and have a kip. So, having that flexibility to be in the office, work from home, do whatever I need to do is a life saver. It takes all that stress out of the situation, and I just go with the flow rather than feeling I've got to be somewhere and do something at a certain time. So yeah, for me, it would just be having that flexibility I think is really key."

Focus group participant with Parkinson's

"I was feeling tiredness in the middle of the day, at the time. At the time I was quite exhausted. I think it was down to the ropinirole I was on at the time, a side-effect, I think so she [the line manager] organised a room with a bed in where I could have a sleep when I needed to"

Focus group participant with Parkinson's

32. For those people with Parkinson's with desk-based jobs, the normalisation of working from home has meant that many of the stressors which compromise symptom control are no longer an issue: difficulties with travel; car parking; having to be at a specific location outside the home, at a specific time; meeting people in person; verbal communication.

"... my managers are very relaxed about their attitude towards my work. They are very supportive about what I can do, when."

Focus group participant with Parkinson's

33. The US government funded Job Accommodation Network (JAN) survey of 2020, suggests that not only are workplace adjustments low cost, they also positively impact the workplace more broadly.³⁸ Since inception of the JAN survey in 2002, results have consistently shown that the benefits gained from making workplace adjustments far outweigh the associated costs.

34. The JAN survey shows that making adjustments results in the retention of valuable staff, improved productivity and morale, reduced training costs and improved organisation diversity. Over half (56%) of workplace adjustments cost nothing, while the rest of the adjustments typically cost only \$500.³⁹ Often, the costs of accommodating a disabled

³⁸ Job Accommodation Network. Costs and Benefits of Accommodation. 2020.

³⁹ Job Accommodation Network. Costs and Benefits of Accommodation. 2020.

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employee are much lower than the alternative cost of recruiting a new worker.⁴⁰ The process of making adjustments also improves employers' awareness of how to support employees with long-term health conditions.⁴¹

35. As well as the direct benefits of making workplace adjustments, employers gain indirect benefits:

- 57% of respondents said adjustments led to improved interactions with colleague
- 55% of respondents said adjustments led to increased overall organisation morale
- 49% of respondents said adjustments led to increased overall organisation productivity⁴²

36. In contrast, not making adjustments can compromise the health of disabled people, including those with Parkinson's. In their 2022 research, the Work Foundation⁴³ found that:

- 70% of disabled workers said that if their employer did not allow them to work remotely, it would negatively impact their physical or mental health
- 85% of disabled workers surveyed felt more productive working from home

When work is no longer an option

37. However, the nature of Parkinson's is that it is a progressive, degenerative condition. And, while there are treatments and symptom control measures, there is, as yet, no cure. Our 2019 survey shows that as someone's condition progresses and the symptoms become more difficult to manage, people with Parkinson's increasingly drop out of the workforce.

- The vast majority (93%) were in employment when they were diagnosed
- Over two thirds (66%) who were still in employment were diagnosed with Parkinson's less than 5 years prior to our survey
- Over two thirds (69%) of those who said they were retired, were diagnosed with Parkinson's more than 7 years prior to our survey
- Two in five (41%) who said they were retired were diagnosed more than 10 years prior to our survey

38. These data are supported by research into people with Parkinson's diagnosed for a number of years. Of those who had been diagnosed for more than 5 years:

- 6–10% were working full time.
- 7% part-time.
- 46% were unable to work, with this percentage increasing to 82% after more than 10 years post-diagnosis.⁴⁴

⁴⁰ Bonaccio S. Connelly C E. Gellatly I R. Jetha A. Ginis K A M. The Participation of People with Disabilities in the Workplace Across the Employment Cycle: Employer Concerns and Research Evidence. Journal of Business and Psychology. 2020.

⁴¹ Institute for Employment Studie. Health-led Trials: Evaluation Synthesis Report. DWP. 2023.

⁴² Job Accommodation Network. Costs and Benefits of Accommodation. 2020.

⁴³ Taylor H. Wilkes M. Holland P. Florisson R. The Changing Workplace: enabling disability-inclusive hybrid working. Work Foundation. 2022.

⁴⁴ Gumber A. Ramaswamy B. Thongchundee O. Effects of Parkinson's on employment, cost of care, and quality of life of people with condition and family caregivers in the UK: a systematic literature review. Patient Related Outcome Measures. 2019.

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39. This means that, in the truly responsive, inclusive workplace, dialogue between employees with Parkinson's and those who employ them, must remain open.

"That's what I found, because, you know, when I was working full time and struggling to do full time, you're thinking you've got to keep going, you've got to keep going. So, you know, stress makes your symptoms worse. I found [it] made my symptoms worse."

Focus group participant with Parkinson's

"I think I've had that conversation with my employer, where, when I asked to reduce hours, I was like, I said, I still got a lot of stuff in me, and a lot of knowledge to share, but it's how you can do it."

Focus group participant with Parkinson's

40. As the condition progresses, the greater need for rest experienced by many people with Parkinson's, means that a traditional 9 to 5, five day a week work schedule isn't viable. And if people with the condition are not able to get sufficient rest and instead feel under pressure, that stress can often aggravate other Parkinson's symptoms, such as tremor, muscle rigidity or difficulties with speech.

"I think my symptoms made it difficult for me to carry on in that role, and I ended up going part-time, and reducing my hours, looking for ways to make it work."

Focus group participant with Parkinson's

41. Employers may decide job redesign is the best route to retain expertise. Job carving, also known as job customisation or customised employment, is used where a person can successfully undertake the majority of tasks in their job role, but there may be an element of their duties which they are not able to complete.

"...they invented a job for me partly, because, probably some of the projects that I'd had, only I knew how to run the projects ... my employer was saying to me, we'll invent a new job for you as compliance manager because I was doing the compliance for statutory bodies that we had to work with in the port, and I was the only one that knew how to do it, and they'd be up the proverbial creek without the proverbial paddle, if I suddenly stopped working."

Focus group participant with Parkinson's

"I used to lead investigations into multinational companies. It can be quite stressful and I was finding I was having panic attacks, anxiety attacks before meetings and so my job was redesigned, so I didn't have that role of supporting other people. The same with presentations at work. I found a couple of the times I had a bit of a meltdown, doing what would be regarded as very simple presentation, stuff I knew backwards. So I was taking off that kind of role. So a job was designed around what I can do, and that's worked that really well."

Focus group participant with Parkinson's

What needs to happen

42. If employers are to meaningfully commit to providing the flexible, responsive workplace needed to support people with Parkinson's to gain and remain in employment, they will need to commit to ensuring all staff are familiar with Parkinson's, its common features and how that impacts upon those with the condition. Recruiting and retaining staff with

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Parkinson's will result in a virtuous circle, as working alongside disabled people makes non-disabled people more aware of how to make the workplace more inclusive, so that inclusivity will deepen.^{45 46}

"It' be nice for them to have the confidence that they're supported by some government backed schemes or other, but you know that was there to support them, in their responsibilities, and how to handle people with disabilities A lot of the reluctance is just fear that they can upset people, and they don't want to say their own thing or want to put their foot in it."

Focus group participant with Parkinson's

Recommendations

1. Legislate for all employers to provide occupational health services to a standard set by Safe Effective Quality Occupational Health Service (SEQOHS)
2. Mandatory reporting for all organisations contracted by all levels of government and all medium-sized employers:⁴⁷
 - on policy and practice designed to include and support disabled people in the workplace
 - number of jobs redesigned to accommodate disabled employees' changing needs
 - number of Access to Work agreements in place
 - number of employees with long-term conditions who report being effectively and appropriately supported to stay in employment.
3. Reduce target waiting times for agreed Access to Work packages to a maximum of four weeks and reduce frequency of reassessments for people with Parkinson's.
4. Ensure every employer has the means to provide workplace adjustments in a timely manner.
5. Require all employers to provide relevant and appropriate disability awareness training to all staff.
6. Require medium-sized employers to provide workplace access to physical activity sessions and information and advice on diet.
7. Provide robust and sufficiently funded career training and advice for people who develop long term conditions, such as Parkinson's.⁴⁸

What will Parkinson's UK do?

- We will support the Disability Business Forum work to promote disability data monitoring.
- Work with employers' organisations to develop a standard adjustment passport.

⁴⁵ Workplace Initiative. Disability Employment and Inclusion: Your Guide to Success. Workplace Initiative. 2017.

⁴⁶ Grze'skowiak A. Zaluska U. Kozyra C. Kwiatkowska-Ciotucha D. Perception and Acceptance of People with Disabilities by Employers and Co-Workers International. Journal of Environmental Research and Public Health. 2021.

⁴⁷ Companies Act 2006 (s465(3))

⁴⁸ ILC. Health and place: How levelling up health can keep older workers working. ILC. 2023.

Policy statement: Employment

- We will call on the Department for Work and Pensions to improve Access to Work and make reassessments worker-led for people with Parkinson's.
- We will call on the Department for Education to ensure that The National Careers Service is able to provide appropriate advice for people with Parkinson's who want to change the type of job they do.
- We will call on the UK government to extend the Disabled Students' Allowance to those who need to retrain.

Acknowledgement

We are grateful for the advice and guidance of our Policy Panel in shaping this position paper on transport. 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 team. Tel: 020 7963 9349 or email: polycampaignsteam@parkinsons.org.uk

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