

Written evidence submitted by Parkinson's UK (RTR0067)

About Parkinson's UK

1. Every hour, two people in the UK are told they have Parkinson's - a brain condition that turns lives upside down, leaving a future full of uncertainty.
2. Parkinson's UK is here to make sure people have whatever they need to take back control – from information to inspiration.
3. We want everyone to get the best health and social care. So, we bring professionals together in the UK Parkinson's Excellence Network,¹ to drive improvements that enable people to live life to the full.

About Parkinson's

4. There are over 40 symptoms of Parkinson's and these can include freezing, tremor, painful muscle cramps, difficulties speaking and swallowing, anxiety, depression, dementia and hallucinations.
5. Currently 145,000 people in the UK are living with the condition.² It is the fastest growing neurodegenerative condition in the world³. With population growth and ageing, we estimate this will increase by nearly a fifth to 172,000 by 2030. Parkinson's not only affects those with the condition but also has a significant impact on family, friends and carers.
6. While the majority of people develop symptoms after the age of 65, thousands of working age people are also affected.⁴

Context of response

7. We welcome the committee's inquiry into recruitment, training and retention in the health and social care workforce.
8. People with Parkinson's continue to be negatively impacted by the paucity of health and social care provision across the country, as well as the variable understanding of condition-specific needs.
9. The unmet needs of our community have grown more acute due to the COVID-19 pandemic, worsened by cancellations and delays to the delivery of care and treatment they need to live well with the condition.

To what extent is there an adequate system for determining how many doctors, nurses and allied health professionals should be trained to meet long-term needs?

10. At present, the systems in place for ascertaining the full picture of health and social care provision for people with Parkinson's, and neurological conditions more broadly, are disparate and sporadic.

¹ Parkinson's UK - <https://www.parkinsons.org.uk/professionals/your-network>, accessed 17 January 2022

² Parkinson's UK. 2018. 'The incidence and prevalence of Parkinson's in the UK.' <https://bit.ly/3ntTYJK>, accessed 14 January 2022

³ Bloem, Bastiaan, et al. "Parkinson's disease" The Lancet Vol 397, issue 10291, P2284-2303, June, 2021. [https://www.thelancet.com/journals/lancet/article/PIIS0140-6736\(21\)00218-X/fulltext](https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)00218-X/fulltext)

⁴ Pringsheim, Tamara, et al. 2014. 'The prevalence of Parkinson's disease' *Movement Disorders* 29.13: 1583-1590

11. What we do know for certain is that our community faces a shortage of health and social care professionals to cater to their needs.⁵ The country-wide lack of neurological professionals is especially worrying, given the increasing incidence of neurological disorders with age, combined with the UK's increasingly ageing population.
12. Recent data published by the Association of British Neurologists revealed that the UK's workforce of consultant neurologists is considerably lower than anticipated. They found that the number of full-time equivalent neurology consultants is 1.1 per 100,000 people. This is considerably lower than European countries with a similar economic status, such as France and Germany, both of which have a ratio of over 1 per 25,000 people - more than three times smaller than the UK's.⁶
13. While neurological staff shortages have been a longstanding area of concern,⁷ the COVID-19 pandemic has further exacerbated the situation. The Neurological Alliance obtained hospital episode statistics data that compared hospital-based appointments for neurology, physiotherapy, speech and language therapy, occupational therapy and hospital admissions for people with neurological conditions for the first lockdown (March - June 2020) to the same period in 2019. The majority of people in this dataset, 58%, had a Parkinson's diagnosis. The findings revealed that:
 - a. Face-to-face neurology appointments fell by 31%.
 - b. Physiotherapy appointments fell by 44% for people with neurological conditions.
 - c. Speech and language therapy appointments fell by 23% overall.
 - d. Occupational therapy appointments saw a 37% drop compared to the same period in 2019.
 - e. Hospital admissions declined nationally by a third. Emergency admissions were reduced by 20% and planned admissions fell by 55%.
14. Workforce planning serves the important purpose of identifying present and future gaps in staffing, allowing interventions to be made before staff shortages seriously impede the care received by our community. It is doubtless that the current shortage of trained health and social care professionals specialising in, or adequately trained to care for those with, neurological conditions such as Parkinson's will cause avoidable suffering. It is evident that without a clear picture of the current level of provision of care, it will not be possible to determine the number of doctors, nurses and allied health professionals that should be trained to meet long-term needs.

Do the curriculums for training doctors, nurses, and allied health professionals need updating to ensure that staff have the right mix of skills?

15. We have heard countless times from people with Parkinson's that the provision and quality of care that they receive is unacceptably variable, leading to poor outcomes.
16. They have highlighted multiple areas in which the health and social care staff that support them would benefit from dedicated training on Parkinson's:
 - a. **Parkinson's and mental health:** We know that for the majority of people living with Parkinson's, their symptoms of anxiety or depression are the most distressing aspect of their condition. At any given time, up to 40% will have depression⁸ and up to 31%

⁵ British Medical Association. 2021. 'Medical staffing in England: a defining moment for doctors and patients.'

⁶ The Association of British Neurologists. 2020. 'Neurology Workforce Survey.' <https://bit.ly/3Gv2EH7>, accessed 13 January 2022

⁷ Royal College of Physicians. 2011. 'Neurology services not meeting patients' needs'

⁸ Aarsland D et al. 2012. 'Depression in Parkinson's disease – epidemiology, mechanisms and management.' *Nature*

will experience anxiety.⁹ This is considerably higher than the 17% of the general population who will experience a common mental health problem.¹⁰

In our research into the mental health of our community, Parkinson's UK found that while three quarters of people with Parkinson's surveyed felt that their mental health problems impacted their quality of life, 65% were not confident that their needs were being met by healthcare professionals.¹¹

This is compounded by a persistent attitude among health professionals that mental health problems are "just part of Parkinson's." This prevents people from receiving proper support, and sometimes referrals are not accepted for this reason.¹²

As one person with Parkinson's told us, *"The healthcare professionals in the psychiatric unit and social services had little or no understanding of the link between Parkinson's and mental health."*

- b. **Parkinson's-related dementia:** In our research into Parkinson's-related dementia, which affects 3 in 10 people with Parkinson's at any given time, only 14% of health professionals we surveyed said their training had prepared them well to provide high-quality care for people with Parkinson's-related dementia.¹³

Worryingly, almost half of carers of people with Parkinson's-related dementia thought that hospital staff did not have sufficient knowledge to provide the care their loved one required.¹⁴ We see the effects of a lack of training among the social care workforce too.

A common theme from the interviews with people with Parkinson's-related dementia and their families was a lack of understanding among social care workers of either Parkinson's or dementia.

When asked if paid care staff at home understood the needs of the person relating to their Parkinson's, only 29% of carers said yes, while 38% said it could be improved. Similarly, for dementia, just 25% said the paid carer understood their needs.¹⁵

- c. **Parkinson's and medication:** The average person living with Parkinson's may find themselves on nine doses of medication a day.¹⁶ The timing of these medications alters from person to person and often doesn't correspond with typical medication rounds on hospital wards. This is because everyone's Parkinson's symptoms are different and therefore need different medication management regimes. As a result,

Reviews Neurology; 8: 35–47

⁹ Broen MPG et al. 2016. 'Prevalence of anxiety in Parkinson's disease: a systematic review and metaanalysis' *Movement Disorders*; 31: 1125–1133

¹⁰ Mind. 'Mental health facts and statistics', <https://bit.ly/3JSzweP>, accessed 4 January 2022

¹¹ Parkinson's UK. 2018. 'Mental health matters too.' p. 9

¹² (Ibid), p. 19

¹³ Parkinson's UK. 2021. 'Nobody really knows us: The state of health and social care for people with Parkinson's-related dementia.' p. 19

¹⁴ (Ibid), p. 23

¹⁵ (Ibid) p. 32

¹⁶ Grosset D et al. 2009. 'Adherence to antiparkinson medication in a multicenter European study.' <https://bit.ly/3rsajQ4>, accessed 14 January 2022

people with Parkinson's often miss out on their vital medication while staying in hospital for reasons unrelated to Parkinson's. This happens because someone with Parkinson's will often be treated on a general medical ward – rather than a specialist neurological ward – for ill health unrelated to their condition. This makes missed medication more likely as staff on these wards do not have an in-depth knowledge of Parkinson's.

In real terms, we know that at the time of publication of our report on the issue, 63% of people living with Parkinson's did not always receive their medication on time when staying in hospital and less than half (44%) of trusts and health boards offer ward staff mandatory training on Parkinson's.¹⁷ Not only does this have hugely adverse effects on people's health – keeping them in hospital longer – it also costs the NHS extra money. Data in 2019¹⁸ showed that people with Parkinson's faced 28,860 excess bed days in hospital every year in England alone, costing the NHS £10m a year.

- d. **Parkinson's and allied health professionals:** The UK Parkinson's Audit provides the largest ever dataset on the quality of care provided to people with Parkinson's across the UK. The 2019 iteration¹⁹ revealed significant training gaps across the allied health professional community supporting people with Parkinson's:
- i. **Occupational therapists:** 27% of occupational therapy services offer no Parkinson's induction training to their workforces.
 - ii. **Physiotherapists:** Documented Parkinson's inductions and support strategies are not available for new physiotherapists working with people with Parkinson's in 43% of physiotherapy services.
 - iii. **Speech and language therapists:** Only 19% of services provide specific Parkinson's induction and support strategies for staff new to working with people with Parkinson's.

Having Parkinson's specific induction strategies is essential in supporting therapists to offer high quality care. This is especially true given that most therapists see people with Parkinson's as part of a generalist caseload.

17. Given that over the past few years, the UK has seen an increase in demand for neurological services,²⁰ it is clear that now more than ever, the non-specialist health and social care workforce needs dedicated training on Parkinson's and neurological conditions more broadly. We therefore recommend that the committee urges NHS England and Health Education England to work with Parkinson's UK and other neurological organisations to develop a more relevant curriculum for health and social care professionals.

What are the principal factors driving staff to leave the health and social care sectors and what could be done to address them?

18. With around 100,000 vacancies among the NHS workforce,²¹ it is clear that the efflux of healthcare staff needs to urgently be addressed. Similarly, with some 120,000 vacancies²²

¹⁷ Parkinson's UK. 2019. 'Get It On Time – the case for improving medication management for Parkinson's.' pp. 4-6

¹⁸ Parkinson's UK. 2019. Excellence Network Data Dashboard. <https://bit.ly/3rlobM9>, accessed 14 January 2022

¹⁹ UK Parkinson's Excellence Network. 2019. '2019 UK Parkinson's Audit Summary report. <https://bit.ly/3GGUw6A>, accessed 19 January 2022

²⁰ GBD 2016 Neurology Collaborators. 2019. 'Global, regional, and national burden of neurological disorders, 1990-2016: a systematic analysis for the Global Burden of Disease Study 2016.' *The Lancet. Neurology*, 18(5), pp. 459-480

²¹ Nursing Times. 2021. 'A bleak picture': Nurse vacancies increase across English NHS.' <https://bit.ly/3IfW8Vh>, accessed

and a turnover rate of 30 per cent,²³ the social care workforce is in a comparably precarious position.

19. From consultation with our Parkinson's professional networks, a number of reasons have been identified as factors driving staff to leave the health and social care sectors:

Healthcare:

- Chronic excessive workloads, leading to an inability to achieve a work/life balance.
- Fragmented responsibilities, with a lack of clarity regarding particular duties.
- An incoherent approach to workforce planning and inadequate funding for education, training and professional development.
- Work-related stress and burnout in the wake of the COVID-19 pandemic.

Social care:

- The widespread perception that the profession is not valued or respected.
- Notably low pay when compared to levels of responsibility.
- Work-related stress and burnout in the wake of the COVID-19 pandemic.
- A distinct lack of pathways for career progression.

20. These factors are reflected in the wider health and social care staff environment:

- a. Evidence indicates that NHS staff are 50% more likely to experience high levels of work-related stress compared with the general working population,²⁴ damaging both their health as well as care quality and organisational performance.
- b. The NHS Staff Survey paints an alarming picture of high and increasing proportions of staff reporting feeling unwell as a result of work stress (44%) and coming to work despite not feeling well enough to perform their duties (46%).²⁵
- c. While the same national data does not exist for social care workers, research suggests significant numbers are on the brink of burnout.²⁶
- d. It is also important to note that discrimination has a substantial influence on workplace stress, but year after year racialised staff in the NHS report worse (and often shocking) experiences when compared with white staff and continue to be underrepresented in senior posts.²⁷ Unfortunately, equivalent data for social care does not exist in the public domain.
- e. Worryingly, a recent BMA survey revealed that one in five doctors, across all specialties, have indicated that they intend to leave their profession once the COVID-19 pandemic is over.²⁸

21. In terms of what can be done to address these factors, our Parkinson's professional networks have highlighted the following:

17 January 2022

²² Bottery S, Babalola G. 2020. 'Social care 360.' <https://bit.ly/3rngswY>, accessed 17 January 2022

²³ Skills for Care. 2019. 'The state of the adult social care sector and workforce in England.'

²⁴ Wall TD, Bolden RI, Borrill CS, Carter AJ (197). 'Minor psychiatric disorder in NHS trust staff: occupational and gender differences.' *The British Journal of Psychiatry*, vol 171, no 6, pp. 519-23

²⁵ NHS England. 2020. 'NHS Staff Survey results: questions 2020.' <https://bit.ly/3FBRizP>, accessed 14 January 2022.

²⁶ Peart L. 2020. 'Two-thirds of social care professionals on brink of burn out, research warns.' <https://bit.ly/3tzLmFi>, accessed 14 January 2022

²⁷ Ross S, Jabbal J, Chauhan K, Maguire D, Randhawa M, Dahir S. 2020. 'Workforce race inequalities and inclusion in NHS providers.' <https://bit.ly/3rqTiWp>, accessed 14 January 2022

²⁸ British Medical Association. 2019. 'Medical staffing in England: a defining moment for doctors and patients.'

- a. Facilitate working arrangements that enable part-time, flexible working, such as job-share models.
- b. Conduct adequate workforce modelling to ensure workloads do not become unmanageable due to persistent staff vacancies.
- c. Provide continuing professional development opportunities and training to facilitate career advancement and progression.
- d. Address the needs of young parents to make it easier to work more if they choose to do so.
- e. Incentivise consultants to not retire early, or retire and return, but to stay full-time for longer by removing the financial penalties of continuing to work full-time.
- f. Provide or meaningfully signpost to dedicated psychological support for staff to help them cope with emotionally demanding and distressing work.
- g. Commit to creating inclusive work environments: enforce zero tolerance policies when it comes to harassment, discrimination, and bullying.

What is the role of Integrated Care Systems in ensuring that local health and care organisations attract and retain staff with the right mix of skills?

- 22. It will be vital for Integrated Care Systems to proactively engage with local services and the voluntary, community and social enterprise sector in order to ensure health and care organisations attract and retain staff at the local level.
- 23. They will have specific expertise relating to their local context which will positively inform workforce and training arrangements. Their insights regarding gaps in provision, underserved communities, and local pressures will prove critical in addressing the factors behind training gaps as well as regional variation.

Conclusion

- 24. It is clear that people with Parkinson's, their carers and families continue to be negatively impacted by the paucity of health and social care provision across the country, as well as the variable understanding of condition-specific needs.
- 25. Additionally, a historic lack of workforce planning and opportunities for professional development, as well as variable working conditions and environments have taken their toll on the Parkinson's workforce, leading to a significant efflux of staff.
- 26. We make the following recommendations:
 - a. The Department of Health and Social Care should conduct a UK-wide mapping and modelling exercise of the neurological workforce to establish a clear picture of the current level of provision of care and to anticipate future demand.
 - b. A UK-wide audit of the training and professional development opportunities available to health and social care staff should be undertaken to identify gaps and remedy variable condition-specific understanding. The Department of Health and Social Care should work with Parkinson's UK to develop and roll-out dedicated training for the Parkinson's workforce.
 - i. In light of our recent findings on the unacceptably variable care that people with Parkinson's-related dementia face, the government must ensure that the recently announced £500 million of funding for training the social care workforce includes training on Parkinson's and Parkinson's-related dementia for social care staff directly providing care.
 - c. Regarding health and social care workforce retention, we recommend that workplaces should:

- i. Facilitate working arrangements that enable part-time, flexible working, such as job-share models.
- ii. Conduct adequate workforce modelling to ensure workloads do not become unmanageable due to persistent staff vacancies.
- iii. Provide continuing professional development opportunities and training to facilitate career advancement and progression.
- iv. Address the needs of young parents to make it easier to work more if they choose to do so.
- v. Incentivise consultants to not retire early, or retire and return, but to stay full-time for longer by removing the financial penalties of continuing to work full-time.
- vi. Provide or meaningfully signpost to dedicated psychological support for staff to help them cope with emotionally demanding and distressing work.
- vii. Commit to creating inclusive work environments: enforce zero tolerance policies when it comes to harassment, discrimination, and bullying.

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