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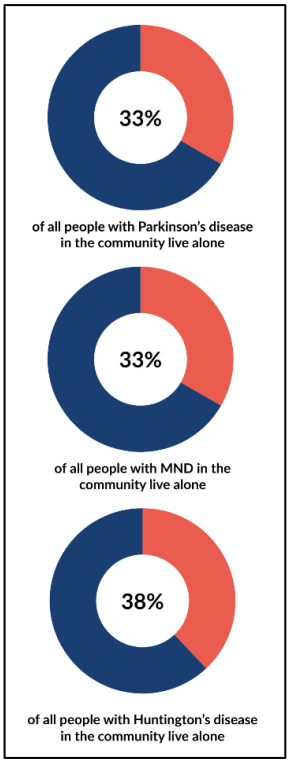
Living alone with a progressive neurological condition:

Focus on Parkinson's disease, motor neurone disease and Huntington's disease



Overview

'When you haven't got that network, what's going to happen…?' (Consultee)

At least one-third of people with one of these progressive neurological conditions residing in the community live alone. There is still a widespread assumption that people have a carer available, and neither health and social care services nor community provision are designed to accommodate the needs of people living alone. This is unhelpful and costly for individuals and services. The result is that living alone is a neglected source of inequality.

Eight Key Areas for Policy Innovation

1. Knowing the numbers to plan better support

- Estimate the number of people with a progressive neurological condition living alone.
- Design systems and processes to ensure living situation is recorded, updated and shared.

2. Reducing inequalities in access to services

- Provide people living alone with a specialist nurse, key worker or care co-ordinator.

3. Providing flexible, personalised, co-ordinated care

- Commission services with flexibility to meet the needs of people living alone.

4. Educating the health and care workforce and the public

- Ensure all relevant professionals have the necessary knowledge.

5. Facilitating access to financial support

- Streamline the process of applying for Continuing Health Care funding.

6. Strengthening community responses

- Work with community organisations to strengthen resources for providing practical support.
- Promote integration of disability-friendly design into new housing stock.

7. Supporting informal carers including those at a distance

- Encourage health and social care professionals to engage with and involve informal carers.

8. Reviewing research priorities and inclusion

- Identify living situation as a required dimension of research inclusion.
- Allocate funding to research which can benefit patients in the short term.

Background

In this project we:

- Analysed publicly-available primary care data to explore the number and proportion of people with Parkinson's disease, motor neurone disease or Huntington's disease recorded as living alone in England in 2023.
- Reviewed research to identify what is known about people with these conditions who are living alone and how best to support them.
- Consulted people with lived experience, practitioners, and other stakeholders about how to meet the support needs of people living alone with these conditions in England.
- Identified policy implications and recommendations for policy and practice.

Key Findings

Living alone with a progressive neurological condition is more common than is realised

- Of those residing in the community in 2023, 33% with Parkinson's disease and motor neurone disease, and 38% with Huntington's disease lived alone. Compared to 2009 figures, there has been no change for Parkinson's disease, a slight decline for motor neurone disease and an increase for Huntington's disease from 33.07% to 38.10% (see Figure 1).
- This means a significant proportion of those diagnosed are likely to need additional care and support due to living alone.

Living alone is more common among some groups than others (see Table 1)

- People living in deprived areas or registered at urban GP practices are more likely to live alone.
- People of black ethnicity are more likely to live alone than people of white ethnicity and those of Asian ethnicity are least likely to live alone.
- Addressing specific challenges of disadvantaged groups – such as access to care, social isolation, and financial hardship – could significantly improve their experience.

Not enough is known about living alone with a progressive neurological condition

- There is very little research on the needs of people with progressive neurological conditions who are living alone.
- We found only 18 research studies for Parkinson's disease, 2 for Huntington's disease and none about living alone with motor neurone disease.
- We gained more understanding through consulting people with lived experience and practitioners.

Our findings suggest that the issue of living alone with a progressive neurological condition is one of inequality. People living alone have specific needs that are different to those living with others and are likely to experience inequalities across the care pathway. This is especially the case where there is pre-existing social disadvantage.

Table 1: Who is most likely to be living alone?

	Parkinson's disease	Motor neurone disease	Huntington's disease
Sex	Women	Men	No sex difference
Age	Older people	People with onset after age 45	No age difference
Ethnicity	Black people	Black people	Too few to assess
Urban/rural	Registered with an urban GP practice	Registered with an urban GP practice	Registered with an urban GP practice
Area	Living in a more deprived area	Living in a more deprived area	Living in a more deprived area
Region	Living in London, the Midlands, or the North	Living in London or the Midlands	Too few to assess

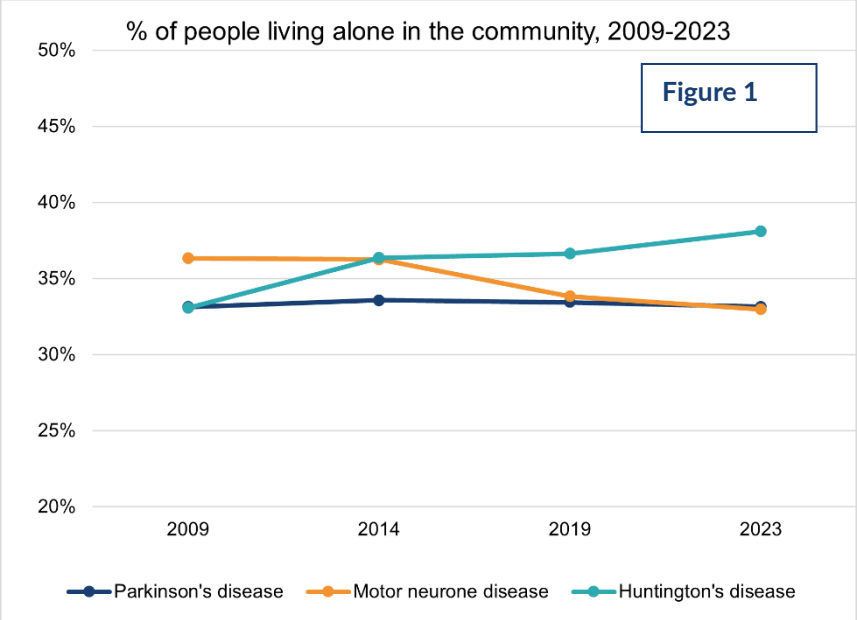
Policy Implications

Our findings suggest that the issue of living alone with a progressive neurological condition is one of inequality. This can be exacerbated by any pre-existing social disadvantage.

People living alone have specific needs that are different to those living with others, but this is rarely considered.

They are likely to experience inequalities across the care pathway. They '*don't receive the same level of care because they don't have that advocacy*' that a co-resident partner or family member provides. This is even more likely where there is little or no family support of any kind.

Our research suggests the need to find new and better ways of meeting the needs of people living alone with progressive neurological conditions.



Conclusion

Our research suggests the need to find new and better ways of meeting the needs of people living alone with progressive neurological conditions, for example by:

- acknowledging the scale of the issue
- adapting pathways and services to provide more responsive personalised care
- facilitating practical and financial support for those diagnosed
- enhancing support for community agencies and for distant carers
- making research more inclusive and practically relevant
- educating professionals and promoting public understanding

Providing more proactive support and preventing crises will benefit NHS and social care services as well as transforming the experience of people who are coping with progressive neurological conditions alone at home and increasing their capability to live well.

Contact details and where to find out more

Read the full policy report at
Clare, L., Martyr, A., Gamble, L., Caulfield, M., Charlwood, C., Hulme C., Prina M., Oyebode, J. (2025). *Living alone with a progressive neurological condition: a neglected inequality.* NIHR Policy Research Unit in Dementia and Neurodegeneration, University of Exeter. **http://hdl.handle.net/10871/140651**.

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