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Living alone with a progressive neurological condition: a neglected inequality

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Authors

Professor Linda Clare
Director, DeNPRU Exeter

Dr Anthony Martyr
Senior Research Fellow

Dr Laura Gamble
Research Fellow

Dr Maria Caulfield
Research Fellow

Dr Catherine Charlwood
Stakeholder Engagement and Impact Manager

Professor Claire Hulme
Leadership Team

Professor Jan Oyebode
Deputy Director, DeNPRU Exeter

Professor Matthew Prina
Leadership Team

Correspondence to: **denpru@exeter.ac.uk**

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Contents

Supplementary Appendix

- Codes used to identify people living alone with a progressive neurological condition in the CPRD dataset

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Summary

Living alone is increasingly common. Today almost 1 in 3 households are single-person households. A significant number of people living alone, especially in later life, are contending with health problems including dementia and progressive neurological conditions. There is still a widespread assumption that people with progressive neurological conditions 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.

We report on research exploring what can be done to provide appropriate services and support for people who live alone with a progressive neurological condition, taking Parkinson's disease, Huntington's disease and motor neurone disease (MND) as exemplars. The report outlines findings from a scoping review of research and grey literature, an exploration of primary care data to examine the recorded frequency of living alone with each of these conditions, and consultations with people with lived experience, practitioners and other stakeholders.

We found that one-third or more of people with these conditions residing in the community are living alone. Research evidence was limited but supported the understanding that this is an inequalities issue, which was echoed by contributors to the consultation exercise. Many of the points raised potentially affect everyone diagnosed with a progressive neurological condition, but living alone adds a dimension of inequality. Furthermore, there is a stigma attached to being alone that is sometimes experienced in interactions with health professionals. Our research highlighted eight key areas where policy innovation could reduce inequalities and stigma and enhance capability to live alone with a progressive neurological condition:

1. Knowing the numbers to better plan support
    - Estimating the number of people with a progressive neurological condition living alone.
    - Adapting systems and processes to ensure living situation is recorded, updated and shared.
2. Reducing inequalities in access to services
    - Providing people living alone with a specialist nurse, key worker or care co-ordinator.
3. Providing flexible, personalised, co-ordinated care
    - Commissioning services with flexibility to meet the needs of people living alone.
4. Educating the health and care workforce and the public
    - Ensuring all health and social care professionals, commissioners and NHS Continuing Health Care assessors have an appropriate understanding of these conditions and are aware that some people live alone.
5. Facilitating access to financial support
    - Streamlining the process of applying for Continuing Health Care funding, including allowing professionals to apply on behalf of people living alone, and supporting people to claim benefit entitlements.
6. Strengthening community responses
    - Working with charities and community organisations to strengthen resources for providing practical support and reducing isolation and loneliness.
    - Promoting integration of disability-friendly design into new housing stock.
7. Supporting informal carers
    - Encouraging health and social care professionals to engage with and involve informal carers including those living at a distance.
8. Reviewing research priorities and inclusion
    - Identifying living situation as a required dimension of research inclusion.
    - Allocating funding to research that can lead to patient benefit in the short term, for example research on managing troublesome symptoms.

Executive Summary

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

Living alone is increasingly common. Today almost 1 in 3 households are single-person households. A significant number of people living alone, especially in later life, are contending with health problems including dementia and progressive neurological conditions. Our research on people living alone with dementia revealed a lack of understanding and provision, meaning that people living alone are subject to multiple sources of inequality. We extended this to explore the situation of people living alone with a progressive neurological condition, taking Parkinson's disease, Huntington's disease and motor neurone disease (MND) as exemplars. In the research reported here we:

- Reviewed research and grey literature to identify what is known about people with these conditions who are living alone and how best to support them.
- Analysed publicly-available primary care data to explore the number and proportion of people with these conditions recorded as living alone in England.
- 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 made recommendations for policy and practice.

Our findings show that living alone is common among people with these conditions, with one-third or more of those residing in the community living alone: 33% for Parkinson's disease and motor neurone disease, and 38% for Huntington's disease. People living in deprived areas or registered at urban GP practices are more likely to live alone. We also found notable differences by ethnicity, with people of Black ethnicity more likely to live alone and those of Asian ethnicity less likely to do so. This highlights the importance of targeted approaches for people in these groups. Addressing the specific challenges they face, such as access to care, social isolation, and financial hardship, could make a significant difference to their health and quality of life.

Research evidence was limited but supported the understanding that this is an inequalities issue, also echoed in the consultation. Many of the points raised potentially affect everyone diagnosed with a progressive neurological condition, but living alone adds a dimension of inequality. There is a perception that people living alone, especially if they have no informal carer to advocate for them, receive poorer quality care. The assumption that people with these conditions have a carer available is still widespread, and neither health and social care services nor community provision are designed to accommodate the needs of people living alone. Furthermore, there is a stigma attached to being alone that is sometimes experienced in interactions with health professionals.

Our research highlights eight key areas where policy innovation could enhance capability to live alone with a progressive neurological condition.

1. Knowing the numbers to better plan support

A first step is for commissioners and service providers to identify, or estimate, how many people are living alone with a progressive neurological condition in their area, and for practitioners to record living situation and appropriately share this information among services and agencies involved. Digital systems can be adapted to make it more obvious how and where to record information about living situation and to keep this information up to date.

Recommendations

- Integrated Care Boards (ICBs) estimate the numbers of people living alone with a progressive neurological condition.
- Adapt digital systems to facilitate recording of living situation, flag this in records, and make sure it is kept up to date.
- Identify processes through which information can be more readily shared between health and social care providers.

2. Reducing inequalities in access to services

There is tremendous variation in access to health and care services by area, including availability of specialist centres, provision of specialist nurses, and extent of social services involvement. One route to addressing this would be through ensuring that everyone living alone has a key worker or care co-ordinator. For both Huntington's and MND there is a need to establish a comprehensive and compassionate care pathway, and the Huntington's community requires a dedicated NICE Guideline to improve quality of care and equity of access.

Recommendations

- Ensure that everyone living alone with one of these conditions has access to a specialist nurse, key worker, link worker or care co-ordinator.
- Outline care pathways for Huntington's and MND that include consideration of the needs of people living alone.
- Commission a NICE Guideline for Huntington's and ensure it includes consideration of living situation.

3. Providing flexible, personalised, co-ordinated care

People living alone are likely to have not only more needs than those living with others but also different needs. This requires the flexibility to offer a personalised approach, including reaching out proactively rather than relying on patient-initiated follow-up, facilitating self management, responding quickly when needs change, and improving capacity assessments.

Recommendations

- Ensure that service commissioning allows for flexibility to meet the needs of people living alone in a personalised manner.
- Provide equitable access to tools that facilitate self-management and ensure that everyone with one of these conditions who may benefit, especially if living alone, receives timely evidence-based advice on falls prevention.
- Review the process of conducting capacity assessments in situations where there may be a lack of awareness of symptoms, changes or difficulties to determine what guidance would be helpful for practitioners.

4. Educating the health and care workforce and the public

There is a widespread need for education about these conditions, including the understanding that people can and do live alone and may not have a carer. Knowledge appropriate to role, grade and level of specialisation is essential for health and care professionals, commissioners, service providers, and NHS Continuing Health Care (CHC) assessors. Greater awareness among the public could help to foster greater social support for people living alone.

Recommendations

- Develop staff training and continuing professional development opportunities, and review training curricula, to ensure all health and social care professionals have an understanding of progressive neurological conditions that is appropriate to their role, grade and level of specialisation, and are aware that some people with these conditions live alone.
- Develop accessible information and educational materials for commissioners, service providers and CHC assessors and incorporate these into mandatory training.
- Identify ways of raising public awareness about these conditions, including understanding that some people with these conditions live alone.

5. Facilitating access to financial support

People living alone may need additional support with navigating the system and securing the financial support to which they are entitled, including access to NHS Continuing Health Care.

Recommendations

- Streamline the process of applying for NHS Continuing Health Care funding and allow health professionals to make the application on behalf of the person.
- Provide automatic access to benefits for people receiving a diagnosis of MND.

6. Strengthening community responses

Loneliness and isolation are a major issue for people living alone with a progressive neurological condition and can increase anxiety and exacerbate symptoms. Managing the practicalities of daily life, such as form-filling, banking, dealing with online systems and obtaining prescribed medication, is another major challenge. Appropriate housing is crucial to enabling people who are alone to maintain independent living.

Recommendations

- Work with charities and community organisations to strengthen resources for providing practical day-to-day support and reducing isolation and loneliness among people living alone.
- Work with the Ministry of Housing, Communities and Local Government to promote integration of disability-friendly design into new housing.

7. Supporting informal carers

Many of those living alone have support from a family member or other informal carer, who is vital to maintaining independent living. However, carers especially if living at a distance may find that health and social care professionals will not communicate with them.

Recommendations

- Health and social care professionals and services recognise the value of engaging and communicating with informal carers, even if living at a distance, and wherever possible seek to inform them about appointments and gather their views to support decision-making.

8. Reviewing research priorities

Our scoping review revealed a lack of research evidence. It is important that the voice of people living alone is included in research, and that funding is allocated to research that would lead to patient benefit in the short term.

Recommendations

- Specifically identify living situation as a dimension of research inclusion that should be considered in funding applications.
- Ensure that research funding is allocated to applied and clinical research that addresses the priorities and practical needs of people living with these conditions, including those living alone.

Introduction

Living alone is increasingly common. Today, almost 1 in 3 UK households (8.3m, 30%) are single-person households. This is now the second most frequent type of living arrangement, and among over 65s, as many as 50% are living alone[1]. A significant number of people living alone, especially in later life, will be contending with health problems including progressive neurological conditions. Our focus on this topic arose from research with people living with dementia[2]. It is typically assumed that a person with dementia lives with an unpaid carer, a family member or friend, who is available to provide support, but this is far from the reality. This lack of understanding and provision means that people living alone are subject to multiple sources of inequality. We wondered how people fare when living alone with other progressive neurological conditions.

When we began developing a research project to explore how policy changes could reduce the inequalities associated with living alone, we decided to include progressive neurological conditions alongside dementia and chose to focus on three exemplar conditions: Parkinson's disease, Huntington's disease, and motor neurone disease (MND). These were selected because we anticipated sufficient numbers for statistical analysis of patterns and trends, availability of relevant research evidence, and good potential to engage people with lived experience and practitioners with relevant experience in consultation. In the UK there are about **153,000 people living with Parkinson's** (Parkinson's UK, 2024), the fastest-growing neurological condition globally, **7,000 people living with Huntington's**[3], and **5,000 living with MND**[4]. These conditions are complex with diverse effects. People with Parkinson's experience a range of motor and non-motor symptoms often accompanied by cognitive impairment. Huntington's involves progressive motor, cognitive and psychiatric symptoms, and MND affects voluntary muscle function. Each of these conditions results in significant disability which increases over time, meaning that people require more support for daily living. The resulting symptoms cause significant concern and distress, both for the individual and those around them.

In this policy research project, we set out to identify what changes in policy and practice can be implemented to better meet the needs of people living alone with dementia, Parkinson's disease, Huntington's disease and MND in England. In this report we focus on progressive neurological conditions as exemplified by Parkinson's disease, Huntington's disease and MND; we report findings about dementia separately.

We aimed to:

- Estimate the number and proportion of people with these conditions who are living alone in England.
- Review what is known about the characteristics and needs of people with Parkinson's, Huntington's and MND who are living alone and how best to support them
- Consult people with lived experience and other stakeholders and explore their views about how to meet the support needs of people living alone with these conditions in England.
- Identify policy implications, including highlighting gaps in knowledge, and provide recommendations for policy and practice.

Methods

Prevalence estimation

To estimate how many people with Parkinson's, Huntington's and MND are living alone in England, we used Clinical Practice Research Datalink (CPRD Aurum, September 2024 release[5]) data. This consists of routinely-collected anonymised electronic health records from almost 50 million people registered with UK primary care practices. The methods used are described in full in Appendix 1. Codes used to identify people with the conditions of interest living alone are provided in the Supplementary Appendix.

We examined the overall prevalence of living alone in the period 01/01/2023 to 31/01/2023. We further examined prevalence of living alone according to sex, age, ethnicity, region, area deprivation, and urban/rural location. We used logistic regression to explore group differences in each case.

Scoping review

We systematically searched research and grey literature to identify information about the characteristics and needs of people with Parkinson's, Huntington's or MND who are living alone and how best to support them. The methodology is described in the protocol[6] and in Appendix 2 and briefly summarised here. The search also covered dementia, but here we report only on information about Parkinson's, Huntington's or MND.

Research literature

We used established procedures outlined in relevant guidelines[7]. We conducted searches with no date restriction in seven databases; details of search terms and databases searched can be found in Appendix 2, with examples in Table A2.1. Two researchers independently screened titles and abstracts to identify potentially relevant articles. We further screened the full text of each identified article to determine whether it met inclusion criteria. We included peer-reviewed articles written in English that reported information about people with Parkinson's, Huntington's or MND who live alone, either descriptively or in comparison with people who have other living arrangements. We extracted information about study characteristics, samples, relevant variables (for quantitative studies) or themes and illustrative quotations (for qualitative studies), and any recommendations proposed by authors. As this was a scoping review, we did not formally assess study quality. Figure A2.1 in Appendix 2 summarises the process of screening research records.

Grey literature

We searched for reports, practice guidelines, and publications containing information and advice about living alone with Parkinson's, Huntington's or MND. We applied advanced Google search parameters to selected condition-specific websites hosted by organisations in the UK, EU, Canada, Australia or USA and prominent global health and/or social care organisations. Full details of our methods are provided in Appendix 2, Table A2.2, including a list of websites searched. We downloaded and screened the first 20 pdf files returned for each website, or all pdfs returned if the number was fewer than 20. We extracted information about the publication, methods used where relevant, the information, advice or recommendations made, and any other potentially useful details. Figure A2.2 in Appendix 2 summarises the screening process for grey literature.

We tabulated and summarised all information gathered. We present a narrative account of the findings for each of the three conditions below.

Involvement and consultation

The core project team included two members with lived experience, a former carer for her mother who had dementia and a man living alone with Parkinson's disease. Discussions with members of the DeNPRU Exeter Stakeholder Engagement and FRIEND (PPIE) Networks were held throughout the

project. Dedicated consultation workshops were held online in October and November 2024. For each of the three conditions we held one workshop with professionals and one with people with lived experience. In all of the workshops, we asked:

- How living status was recorded, or who knew they/their relative was living alone
- About particular challenges of living alone
- Any future worries concerning living alone, or transition points where professionals would feel more worried about those living alone

Additionally, in both Parkinson's disease workshops we summarised the research evidence and asked whether attendees felt these concerns reflected the major areas of importance for living alone with the condition. This was because there was sufficient research evidence to give consultees something to comment on.

Prevalence estimation findings: how many people are living alone?

We identified 40,244 people with Parkinson's disease, 3,515 people with MND, and 1,672 people with Huntington's disease recorded in the Clinical Practice Research Datalink (CPRD) database in 2023. Living situation was directly recorded in clinical notes for only 38-48% of individuals. To address this gap, we made assumptions based on the number of people registered at the same GP practice from a given address. This allowed us to estimate living situation for nearly everyone in the database.

Excluding people living in a care facility, we found that 33% of people with Parkinson's and MND lived alone, and 38% of people with Huntington's disease lived alone. This aligns with findings from the Huntington's Disease Association database, where we also identified 38% of people with Huntington's disease living alone.

For each condition, we investigated how living situation varied depending on factors such as sex, age, region, ethnicity, deprivation level, and whether the GP practice was in an urban or rural area (see Appendix 3, Table A3.1). The patterns we observed reveal some important insights about who might need the most support. For all three conditions, people who lived alone were more likely to live in more deprived areas or be registered at an urban GP practice. Other patterns differed by condition, as we describe below.

Parkinson's disease: who lives alone?
People with Parkinson's who lived alone were often older, with those aged 80 and above more likely to live alone. Women were more likely to live alone than men. We noticed regional differences, with higher numbers of people living alone in London, the West Midlands, the North-East and the North-West of England. Ethnicity also played a role. Compared to people of white ethnicity, those of Asian background were less likely to live alone, while those of Black ethnicity were more likely to live alone.

Motor neurone disease: unique patterns
For MND, men were slightly more likely to live alone than women (34% compared to 31%). Younger individuals – those with an onset of symptoms before the age of 45 – were less likely to live alone, suggesting that younger people may have stronger family or household support. As with Parkinson's disease, we found regional concentrations of people living alone in London and the Midlands, and living situation was influenced by ethnicity; people of Asian ethnicity were less likely to live alone, whereas those of Black ethnicity were more likely to do so.

Huntington's Disease: limited data
Due to the smaller number of people with Huntington's, we could not assess regional patterns or differences due to ethnicity. However, the overall proportion of people living alone was higher than for the other conditions at 38%. Unlike Parkinson's and MND, we did not observe significant differences by gender or age.

How have these patterns changed over time?

Over the last 15 years, we have seen shifts in the number of people living alone with these conditions (Figure A3.1). The number of people with Huntington's living alone has increased, while the number of those with MND living alone has slightly declined. For Parkinson's, the number has remained relatively stable.

Challenges in identifying people living alone

One of the biggest challenges in this study was accurately identifying who lives alone. Clinical records in the CPRD database only captured living situations for fewer than half of the individuals. To fill in the

gaps, we relied on assumptions, such as inferring household size from GP registration data. While this approach allowed us to estimate living situation for nearly everyone, it is likely to overestimate the number of people living alone. For example, people living with adult children or other relatives may not all be registered at the same GP practice. If we take a more cautious view, the true number of people living alone could be lower, potentially less than 10%. However, the consistency of our findings with external data like the Huntington's Disease Association database suggests that such a low figure would be an underestimation.

What needs to change

Our findings make it clear that better data is needed. GPs and healthcare providers should consistently document living situation in clinical records. This would make it easier to identify people at risk of social isolation and ensure they receive the support they need. In addition, there is a pressing need to focus on vulnerable groups, such as those living in deprived areas or people of Black ethnicity. These individuals may face unique challenges that require tailored solutions. Finally, more research is needed to explore the experiences of people living alone with progressive neurological conditions. Understanding the factors that contribute to their vulnerability and finding ways to address them will be key to improving care and support for these individuals.

Scoping review findings: what can we learn from existing evidence?

Parkinson's disease

For Parkinson's disease, the review of research literature included 18 articles, 17 quantitative and one qualitative, reporting on 17 discrete studies.

The earliest paper we identified was published in 1990. Since 2013 there has been a small but steady increase in references to people living alone; see Figure 3. There were five articles from the UK, nine from the EU (one each from seven countries and two from Italy), two from the USA of which one was a global survey, and one each from China and Australia; see Figure 4.

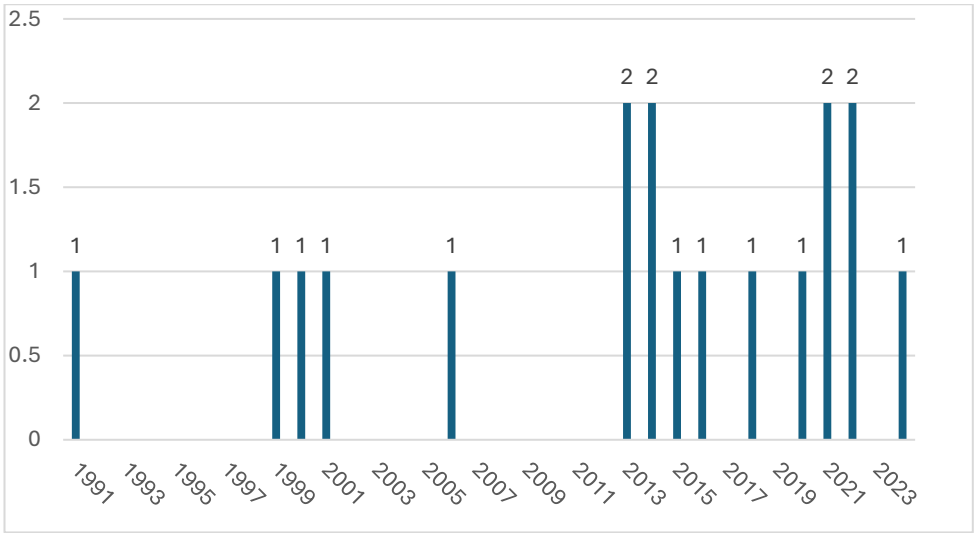

Figure 3. Number of articles published per year yielding evidence about people with Parkinson's living alone

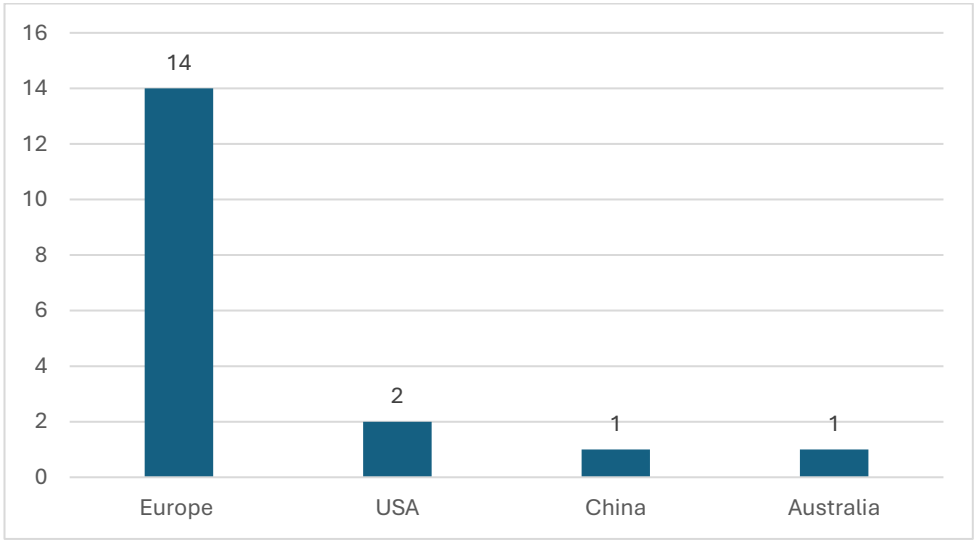

Figure 4. Number of included articles by region

Despite the increase in the number of articles yielding evidence about people living alone with Parkinson's, no studies focused specifically on people living alone with the condition or recruited solely people living alone. Comparisons according to living arrangement were included among other analyses or as sub-group analyses in 13 quantitative articles[8-20], while the one qualitative article explored the experiences of older women and included women living either alone or with others[21]. The remaining four quantitative articles considered living arrangement only in terms of describing the study sample[22-26].

Across the quantitative studies, the proportion of people living alone varied from 10% to 47%, with a mean proportion of 19.2% across the 15 studies that reported this information. For the four UK articles the proportion ranged from 17.8% to 27%, with a mean of 22.2%.

The most salient difference identified relative to people living with others is that people living alone with Parkinson's are at greater risk of depression, including severe depression, especially if they have no family support and limited access to community resources[10]. They have lower life satisfaction than those living with a spouse or other family members, although this was still better than levels recorded for people in care homes[11], and lower emotional well-being[14]. Two articles reported COVID-19 studies indicating that, compared to those living with others, people living alone with Parkinson's perceived more disruption of essential daily activities and medical care and more worsening of motor and non-motor symptoms, including anxiety[9,13].

There was no evidence for higher rates of impulse control disorders[20] or malnutrition[17] and no difference in time to loss of employment[16]. Although there is no evidence that people living alone were more likely to be malnourished[17], the motor symptoms of Parkinson's can affect shopping, food preparation and eating. The one qualitative study explored food shopping, cooking and eating habits in older women with Parkinson's, both living alone and living with others[21]. Shopping, cooking and eating presented challenges for all the women but while the married women had support from their husbands, those living alone needed external help, and this was both detrimental to self-esteem and 'fatal' to nutritional status.

Evidence about health and social care utilisation is limited. An early study[12] found no difference in number of GP, physiotherapist or psychotherapist appointments, but fewer neurologist visits for those living alone. One study[8] found an increased risk of admission to a nursing home, but another[15] found no increased risk. People who experience OFF episodes were less likely to live alone and more likely to be in a nursing home[18]. One study noted that people living alone were more likely to drop out of a research trial of device-assisted treatment, possibly due to problems with using the device[19].

The grey literature search yielded six resources providing advice to people living alone with Parkinson's and/or their family carers, three from the UK, two from Canada and one from the USA[27-32]. A list of these resources can be found in Appendix 2, Table A2.3. All include information about identifying and addressing hazards around the home to reduce the risk of falling, which becomes especially important where someone is living alone due to the consequences of falling without immediate assistance being available. Examples of hazards addressed include decluttering the home, modifying the living space, rearranging furniture, using slip mats in the bathroom, and installing handrails or grab bars. Other issues explored are the importance of planning for the future, which is emphasised across five resources, covering aspects such as financial planning, what to do in an emergency, and future personal care wishes, including living arrangements[27-31]. Staying active and socially connected is also highlighted in five resources, with a strong emphasis on participating in exercise classes to maintain muscle strength and manage symptoms of Parkinson's disease[27-31]. Building a strong support network is mentioned in four resources, encompassing health and social professionals, friends, neighbours, and, when applicable, family carers[27,28,30,31]. There is a focus on medication management across two resources[27,31].

Huntington's disease

For Huntington's disease, the review of research literature identified one article reporting on a quantitative study and one doctoral thesis reporting qualitative work.

The single quantitative study[33] did not focus specifically on living alone but was a retrospective review of 11 instances of suicide in Huntington's families aiming to identify characteristics that could alert health professionals to increased suicide risk. The single most important risk factor was having no children but being unmarried and living alone were among the other factors leading to slightly increased risk.

The doctoral thesis[34] explored the 'delicate equilibrium' of living with Huntington's by using interviews and observational methods over time to build 15 case studies each centred on an individual with Huntington's and including information from a family carer and health or social care professional. These included three women living alone with Huntington's, demonstrating the extent of support required to continue living alone as the condition progressed and the importance of ongoing contact and engagement – as one nurse specialist described it, 'keeping an eye on them and getting things in place sooner'.

The grey literature search yielded only one resource, a COVID-19 leaflet on strategies, ideas and resource for families from The Huntington Society of Canada[35] offering practical tips on how to support a person living alone with Huntington's and cognitive impairment to follow precautions of handwashing and staying indoors.

Motor neurone disease

For MND, the search of research literature yielded no studies meeting inclusion criteria, and the search for grey literature found no relevant resources. However, while working on this review, colleagues at the Motor Neurone Disease Association (MNDA) told us that they were aware of the challenges experienced by people living alone who were diagnosed with MND and were preparing a booklet specifically for this group. We were invited to review the draft and share evidence from our work. The booklet is now available on the MNDA website[36].

As the booklet explains, the condition and its treatment and care are the same irrespective of living situation. However, people living alone face specific challenges in adjusting to the diagnosis, especially if they have no family or friends available to help, and they need to plan for the future and make important decisions earlier. The booklet starts by exploring sources of emotional support for the shock of receiving a diagnosis and for adjusting to life with MND, including explaining symptoms and changes to family, friends and colleagues, and notifying organisations such as banks and the DVLA. It acknowledges how the condition can affect feelings about oneself, communication, relationships and interactions, participation in activities and ability to get out and about. It encourages people to think about practical steps to prolong independence, such as home help, adapting the home, securing financial support, arranging provisions for dependents and pets, and putting legal provisions in place. It explains how to navigate health and social care services and the relevance of advance care plannings and advance decisions about withdrawal of treatment. Accepting that people are unlikely to continue living alone as the condition progresses, it encourages readers to make choices about home care and moving into residential or nursing care at an early stage. Readers are referred to more resources produced by MNDA that cover these issues in more detail.

Consultation: Parkinson's disease

People with lived experience

We spoke online with two men living alone with Parkinson's and by email with a former carer living at a distance.

The research evidence was felt to reflect *"the basics"*, with the emphasis on hazards in the home relating more to advanced Parkinson's. The few home adaptations required to safely navigate home life were considered *"aids rather than hazards"*: a grabber for dropped items; a 'Soxon' device for putting socks on; and an under-mattress unit to help with turning over or getting out of bed. Practical challenges only came into focus when something happened: one participant had unrelated surgery and struggled with the daily bedsheet changes required to prevent infection.

Both participants would put isolation and loneliness at the forefront of any research or messaging regarding living alone with Parkinson's. The importance of social contact came out strongly, since *"when you're together with a group of Parkinsons' people, you're at one with yourself … it's not threatening anymore."* Participants were proactively trying to maintain their independence. One found the DOCOBOAPP (a remote monitoring app) provided by the local NHS Trust *"comforting"*. This involved submitting vitals weekly and receiving a phone call if any readings were unusual. However, the carer living at a distance found the insistence on technical capability impossible for their parent, which led to breakdowns in medical communications.

Living comfortably alone was precarious. One person only got an accessible flat because the GP visited and deemed the stairs unsuitable. Others had been denied home visits despite severe difficulties. In another case, a routine procedure resulted in a leg bandage needing changing. The GP surgery nurse had no availability, so sent the patient back to the hospital, where they were challenged by a receptionist before seeing a nurse who *"understood that I couldn't reach down and take off the bandage and change it."* Standard procedures may need amending for those living alone.

Non-sharing of medical information and living situation left others in potentially dangerous situations. One person caring at a distance a two-hour journey away tried to manage the wrong medications being prescribed, dispensed to a detached greenhouse their parent could not walk to, medical history being unavailable or ignored, and no accommodations being given for physical disabilities. This lack of care co-ordination left the relative on constant alert.

Fears for the future centred on falling and loss of independence. One participant had a neighbour living alone with advanced Parkinson's who had fallen and not been found for 12 hours and was subsequently bed-bound following an elongated hospital stay. There was also concern for future planning. One participant had witnessed the difficulties involved when lasting Power of Attorney (POA) is not set up in advance.

Participants requested key changes to policy and practice:

- a digital, shareable record kept by GP, and this information fed back at a regional and national level
- data sharing: local authorities give a 25% single-occupancy discount for council tax and check living alone status annually.

Participants felt strongly that if *"you just knew the numbers"* this would help to connect the dots between systems. An NHS professional could proactively reach out to those isolated every six months.

Professionals

We held an online workshop with three professionals: two specialist nurses and the secretary of a community Parkinson's team, who was also separately facilitating a support group.

Professionals were asked whether living alone status is recorded and how, and about challenges associated with living alone. Living situation was noted either in referrals or clinic notes but was not routinely electronically recorded. However, during the consultation, professionals discovered that their NHS systems (EMIS and SystmOne, respectively) did have a method for recording some facts about household, although it was not obvious. With small adjustments, electronic recording of living situation could be possible.

Maintaining social activities was paramount for those living alone, although challenging due to difficulties with transport and confidence. There was also the concern that those living alone would not seek help. This is particularly worrying given that due to increasing caseloads, some services operate a patient-initiated follow-up (PIFU) system. Social prescribers were identified as helpful contacts, especially for their knowledge beyond the Parkinson's-specific. However, befrienders would only visit the housebound, leaving many in need.

Why someone was living alone affected their management of living alone with Parkinson's. A lifetime bachelor was more able to adjust than someone newly bereaved. Those bereaved had not just practical challenges (of driving, or household tasks), but also a loss of emotional support in a confidant. Those living alone were more likely to be advised about pendant alarms and technologies like Alexa at an early stage.

While living alone could pose a challenge at any point in the Parkinson's journey, initial adjustment to the diagnosis and changes in medication regimes were highlighted as moments of concern. More broadly, professionals noted the difficulty of accessing reliable information about disease progression without another person there to recognise differences: behaviour changes such as hypersexuality would often be reported by a partner among patients living with someone.

Professionals were clear on the changes which would improve the lives of those living alone with Parkinson's disease:

- A flag system for living alone so that all professionals accessing the record could know immediately and advise accordingly.
- Giving community Parkinson's teams the flexibility to conduct home visits as they found necessary
- Promoting and providing access to digital monitoring technology like the Parkinson's KinetiGraph (PKG™) watch. Many of these devices are self-funded, creating further inequity.

"It's probably your richer patient might be able to afford to live alone longer than someone who is on benefits."

- Acknowledging the role of specialist nurses and secretaries in supporting all people living with Parkinson's, but especially those living alone.

Consultation: Huntington's disease

People with lived experience

We held an online workshop with two experts by experience, a carer several times over and a gene positive pre-symptomatic woman, caring for her mother living alone with Huntington's. We consulted by email with another carer who experienced supporting two male relatives living alone with Huntington's, and six carers and two people living alone with Huntington's contributed anonymously.

The variability of situations was pronounced among people with Huntington's. One person was co-ordinating care for their mother while sharing responsibility with siblings. When diagnosed, the family was assigned a neurological nurse, who was helpful in the initial set-up, sorting "*a dietician, physio, putting handles in the bathroom … a letter for [Mum's] employer*". Another person's family had had significant delay in getting a neurological nurse. There seems to be a postcode lottery in availability of services and information.

While one person was largely unknown to services, their mother was *"quite happy"*: what she needed could be provided by the family. However, another contributor's relative had largely cut themselves off from family involvement. Despite a wealth of professionals across health and social care knowing they were living with Huntington's, their living situation was on a downward spiral: *"He isn't managing basic household chores and isn't self-caring. He doesn't wash his clothes, or bathe himself, … he has been eating mouldy food."*

One person was worried about social services putting their relative in a care home against their wishes. Meanwhile, others were failing to be in contact with social services at all, or to encourage them to take action. Social services involvement varied by area.

Participants mentioned home adaptations that had helped enabled relatives to remain living alone. These included a Lifeline alarm, a message in the bottle in the fridge, easy-open windows and adding handles in the bathroom.

As our participants detailed the ways in which they advocated for family members, they became concerned for those who had no-one:

"When you haven't got that network, what's going to happen to those people? Who's going to do it? Who's going to step in and sort out their finances?"

This initially started as a practical discussion, regarding financial and administrative tasks. However, it became more of a conceptual discussion around self-awareness:

Huntington's is progressive over a very long period of time. I think you actually can live on your own very well… But there is always going to be a point where that changes and who recognises that change?"

The behavioural symptoms mean that living alone might be preferable: *"when I lived with my Mum, the family tension was very, very bad … now I have that distance from her I get on with her better."* This was confirmed by others contributing anonymously. However, living apart posed significant problems for carers in terms of recognition. Carers living further away (in a different local authority/NHS Trust) were not classified as primary carers: neither health care nor social services would speak to them. Even where

support existed, precariousness was emphasised: care plans can fall apart if the primary carer dies and nothing is set up with other family members; power of attorney expires on the named individual's death; and others may not know that Huntington's is in the family.

The burden on carers at a distance was clear – they felt powerless to help, reporting fears over their relative's safety and the possible neglect of their living environment. One anonymous contributor's relative had made *"repeated suicide attempts whilst living alone. They've had failed placements in care homes and with carers at their home."*

Experts by experience sought the following changes to policy and practice:

- Keeping and updating records of living situation.
- Linking the health records of the person with Huntington's and the carer, so that they receive duplicate information.
- For professionals to adopt a more personalised approach and not panic when they hear someone is living alone with Huntington's.
- Better understanding of Huntington's from social services and health professionals, and a preparedness to work with wider family members.
- The option of home visits from medical professionals. This would reduce anxiety for the person with Huntington's and help with access (particularly when mobility or cognitive/anxiety issues are present).

Professionals

We held an online workshop with five professionals: the Head of Services and a youth worker from Huntington's Disease Association (HDA), two specialist nurses, a consultant nurse and a matron.

Professionals were asked how they discover whether someone is living alone; this is not routinely recorded. HDA heard mainly from relatives or professionals, but occasionally from concerned neighbours. For clinical professionals, it might be mentioned in a referral letter, but the team might need to triangulate information between the individual, the family, and any third sector support.

> *"Probably the hardest bit for us is when people are still deemed to have capacity, but are making very, very risky decisions, and everyone's almost waiting for a crisis to happen."*

The symptom profile of Huntington's means that people are often unaware of their own behaviours and lose the ability to think through the consequences of decisions. Echoing the fears of family members, professionals noted the problem of determining capacity to protect the individual:

> *"If this is their fourth flat … someone has to stop at some point and say yes, we want that person to have independence and we want them to have choice, but we're not managing this in the right way."*

Participants agreed that building up a relationship of trust with someone with HD took time and could be challenging, noting routine refusals of help.

Living alone with Huntington's was associated with worries about loneliness and isolation, worsening mental health and fears about neglect. The pattern of neglect means that often adults living alone with Huntington's are known to several services across the local authority and health board. However, these do not always co-ordinate information to best effect. With Safeguarding Adults Reviews (SARs, previously known as Serious Case Reviews) concerning Huntington's disease, a high proportion of those observationally are living alone. Examples include 'Hannah' in Camden[37] and 'Ben' in Devon[38].

Education was another topic: educating the individual on living with Huntington's, families on strategies of mitigating symptoms, and the systems in place to help. Lack of understanding of Huntington's, particularly its progression, was mentioned in reference to mental health teams, Integrated Care Boards (ICBs), social services and Continuing Healthcare Funding (CHC). In one example, difficulty of negotiating a realistic discharge plan with an ICB ended in a failed discharge. Similarly, professionals spoke of feeling their *"hands are tied"* by funding systems. There was also concern for single parents with Huntington's raising minors. This group might also be classed as living alone.

Requested policy changes focused on improving things for everyone with Huntington's which would then have consequential benefits for those living alone:

- An established clinical pathway and a NICE guideline to prevent individuals slipping through the net.
- Providing care co-ordination due to the many potential symptoms and thus the different services and systems to which they may be directed (and redirected) throughout the changing disease profile.
- Better communication between professionals, service providers, families and the individual to ensure a realistic picture of the situation is known and monitored.
- Medical professionals who deal with physical and mental health holistically.

Consultation: Motor neurone disease

Early consultations with professionals revealed the difficulties of living alone with MND. The speed of progression, expensive equipment and the safety aspects of non-invasive ventilation (NIV) combined to make living alone particularly challenging. We found one specific peer-support group, 'Living Alone with ALS Support Group' who meet online monthly, facilitated by the ALS Association in North America. Speaking with the group facilitator, these sessions enable people to share frustrations and problem-solve together.

People with lived experience

We held an online workshop with three people living alone with MND. Two further people contributed via a Word document due to communication difficulties. There was a contrast between those with more functional ability and strong social networks, and those more reliant on others, where living alone had got harder.

All participants had some assistive technology or environmental adaptations to enable them to live alone, from a power chair, pendant alarm or Apple watch through to adapted bathrooms, stair lifts and ramps. One person had some overnight care; another had carers in four times a day. It is worth noting that a significant number of these were self-funded.

There were many aspects of living alone with MND which participants found challenging:

- *"Overwhelming"* loneliness *"even when carers are present"*.
- Having a bad day: it might *"only be one day a month, but it takes its toll on you mentally and physically."*
- Losing confidence to go out alone.
- Managing hospital appointments. For some, this meant collaborating with friends to transport and accompany them. Hospital cars or taxis were a problematic solution: they require booking; larger wheelchairs may not fit; and frail drivers may be unable to manage someone with MND with unstable mobility.

Spotlight on good practice:

"When I was diagnosed, I remember walking down the corridor and thinking 'How on earth am I going to cope? I'm on my own.' A couple of days later, I had a phone call from the co-ordinator of the care and research network based at the Hospital. She said I would be invited to a clinic with a doctor to talk to and I would have a specialist nurse visit me, an occupational therapist visit me and I would be automatically enrolled in the MNDA and invited to support groups. And that phone call gave me a future – that was wonderful."

For those who were *"fiercely independent"*, this is posed challenges of its own. One person only realised they needed more support following struggling alone during a bout of unrelated illness. Now they were re-evaluating the assessment where *"I sat there with the council and said, 'I'm fine, I'm all right, there's nothing wrong' … It probably wasn't the smartest thing to have done"*. Another person compromised to have overnight carers three times a week to monitor ventilator use. They had found it nice to sometimes wake up to company and could line up helpful tasks (jars to be opened, ironing) for the carers.

Future worries were minimised as participants focused on getting *"something good out of each day."* However, there was an awareness of increasing care needs, and people worried about worsening communication and mobility. One participant was conscious that her autonomy relied on others:

> *"I mainly worry that I'm no-one's priority as family live far away and the only people who can provide for all my physical and some emotional needs work on a zero-hour contract for an agency who don't pay them enough."*

Indeed, care workers should be paid commensurately with *"the level of skill and training that's needed to keep a person with MND alive and thriving."*

Participants had many ideas for improvements to help those living alone. Practically, they sought:

- a comprehensive and compassionate care pathway available to all;
- clarity regarding access to CHC;
- increased research into symptoms which would have direct patient benefit (such as secretion and neck restraints);
- medical staff to be educated about MND;
- issuing a blue badge, radar key, Personal Independence Payments (PIP) and other benefits if appropriate upon diagnosis;
- creating administrative roles in surgeries and hospitals: these professionals could guide people through the system;
- appropriate transportation to hospital appointments being readily available.

Socially, they wanted

- to connect with others living alone with MND;
- greater advertisement to ensure that everyone heard about available activities.

Environmentally, they suggested

- appropriate housing;
- ability to convert garages to wet rooms without 'covenants' preventing this;
- ample and well-designed disabled parking, automatic doors and seating with armrests in healthcare environments;
- continued opportunities to bank in-person to enable those with voice and motor control, and to have cash to *"settle up"* with neighbours and friends picking up things in town:

> *"A friend spent over an hour on the phone explaining I couldn't speak and why the clerk kept asking me to verify who I was verbally which I couldn't especially as my voice disappears with increased anxiety."*

Participants worried about those less well equipped to navigate MND, either through lack of personal finances or technological know-how.

Professionals

We spoke with three professionals: a specialist physiotherapist with a community MND team, a nurse specialist and an academic working with people living alone with MND.

Living situation is recorded within clinic notes and letters, but not officially on a system. This information may not be known to other professionals that patients encounter.

The challenges associated with living alone were amplified by the heterogenous nature of MND. Cognitive changes could often be overlooked in favour of more obvious symptoms. It was not necessarily living alone which posed a problem, but *"people that live alone that are also socially isolated and don't have that other support"*. Other challenges for those living alone included:

- Filling in forms
- For those unable to verbally communicate or use a computer, rescheduling an appointment or contacting a service for help
- Sharing struggles for fear of losing independence.

Bureaucracy can fail those living alone. While some patients were never discharged from local services, others were, causing difficulties with liaison and follow-up from the specialist MND clinic. Professionals could experience *"a battle"* trying to keep someone on a service's books. The second example concerned CHC. In a Kafkaesque situation of reversed logic, patients were denied funding for not using the very apparatus they were unable to use without help:

> *"If someone is not using their NIV because they don't have overnight care, it's practically impossible to get CHC granted unless their blood gases are really deteriorating. … they'll say 'well they're not using their own NIV and it's fine'. … the patient will never be able to use it because there is nobody at home to be able to support them with it."*

Rapid changes in the presentation of MND and symptoms could pose serious risk to those living alone. While the situation could change rapidly, a care package could not be sourced in the same timeframe. Of particular concern were those:

- whose 'in-between' mobility put them at risk of falling.
- with increasing communication issues.
- whose function was beginning to limit their NIV usage.

There were concerns that people living alone were treated unequally: *"it's almost like they don't receive the same level of care and it's purely because they don't have that advocacy."* Similarly, given scarce resources, professionals felt that with advance care planning, conversations with those living alone could be harder *"because sadly the reality of the current health and social care possibly doesn't allow people to stay at home for longer."*

It was evident that there was much about current systems which needed fixing for everyone with MND and that within that population, certain groups (like those living alone) were likely further disenfranchised. Areas for improvement were clearly identified:

- **Equity of access to services**. Some people are well served by having an MND Care Centre nearby, but others are not. While NICE guidelines mention a range of professionals who might be involved in MND care, these options lead to a range of experiences rather than a uniform pathway.
- **Improving cross-Trust working**. Variations by area were amplified when aspects of a patient's care might come under a different Trust or team. This led to difficulties in attempting to access services on a patient's behalf, including wheelchairs.
- **Keyworkers.** Professionals felt strongly that if every patient had a keyworker, an advocate with knowledge of MND, it would improve equity of access to the wraparound services that MND care requires.
- **Improving the CHC process**. Assessors often knew little about MND and high staff turnover made offering education difficult. The CHC process could be streamlined to the benefit of all involved:

> *"It's 2024. We should be able to contact somebody over the phone. If a person has this condition, it should almost be a given. We should be able to remove some of those tasks away from a patient because we should be able to be trusted healthcare professionals."*

Policy implications and recommendations

There is very little research on how many people with progressive neurological conditions live alone, let alone on differences due to living situation. Our findings show that living alone is common among people with these conditions, with one-third or more of those residing in the community living alone. This may mean many individuals are likely to need additional care and support. Certain groups are especially affected. People living in deprived areas or registered at urban GP practices are more likely to live alone. We also found notable differences by ethnicity, with people of Black ethnicity more likely to live alone than their white counterparts and those of Asian ethnicity less likely to do so. This highlights the importance of targeted approaches for people in these groups. Addressing the specific challenges they face, such as access to care, social isolation, and financial hardship, could make a significant difference to their quality of life.

Many of the issues raised in our research potentially affect everyone diagnosed with a progressive neurological condition, but living alone adds a dimension of inequality. People living alone '*don't receive the same level of care because they don't have that advocacy*' that a co-resident partner or family member provides, especially if they are socially isolated and have little or no family or other informal support, or such support is available but precarious. Systems and services operate on the assumption that people have a carer or support network. There is a sense of an increasing reliance on families to provide care, given *'the reality of current health and social care'*, meaning that people living alone will be further disadvantaged. More than this, there is a stigma attached to being alone that is sometimes experienced in interactions with health professionals; this is unacceptable.

Progressive neurological conditions themselves and the reasons why people with these conditions may be living alone are diverse and varied. Often, living alone can be managed well given the right support, and in some cases, especially for people with Huntington's, it may be the best arrangement, although with a progressive condition increasing levels of support will be needed over time and the necessary support may not be available. Our research has highlighted eight key areas where policy innovation could enhance capability to live alone with a progressive neurological condition:

1. Knowing the numbers to better plan support
2. Reducing inequalities in access to services
3. Providing flexible, personalised, co-ordinated care
4. Educating the health and care workforce and the public
5. Facilitating access to financial support
6. Strengthening community responses
7. Supporting informal carers
8. Reviewing research priorities and inclusion

We discuss each of these below. Most of the points covered here are relevant across conditions, although some may be more salient for a given condition than others. A few are condition-specific, and we have indicated where this is the case.

1. Knowing the numbers to better plan support

A first step is for commissioners and service providers to know, or estimate, how many people are living alone with a progressive neurological condition in their area, and for practitioners to record living situation and appropriately share this information among services and agencies involved. Digital systems can be adapted to make it more obvious how and where to record information about living situation and to keep this information up to date.

Recommendations

- *ICBs identify or estimate how many people are living alone with a progressive neurological condition in their area and use this information when commissioning service pathways.*
- *Adapt digital systems to facilitate recording of living situation, flag this in records, and make sure it is kept up to date.*
- *Identify processes through which information can be more readily shared between health and social care providers.*

2. Reducing inequalities in access to services

There is tremendous variation in access to health and care services by area, including availability of specialist centres, provision of specialist nurses, and extent of social services involvement. Services in neighbouring areas may have radically different approaches; for example, some discharge people after a contact episode while others keep them on the caseload. One route to addressing this would be through ensuring that everyone living alone has a key worker, link worker or care co-ordinator, or is allocated a specialist practitioner such as a Parkinson's nurse or equivalent. This would help to improve equity of access and is especially important for people living alone for whom it is especially challenging to navigate service systems and access the necessary support. For rarer conditions where the number of people in a given area is insufficient to justify a post dedicated to one condition, a specialist post could cover several neurological conditions.

For both Huntington's and MND there is a need to establish a comprehensive and compassionate care pathway, and the Huntington's community requires a dedicated NICE Guideline to improve quality of care and equity of access.

Recommendations

- *Ensure that everyone living alone with one of these conditions has access to a specialist nurse, key worker, link worker or care co-ordinator.*
- *Outline care pathways for Huntington's and MND that include consideration of the needs of people living alone.*
- *Commission a NICE Guideline for Huntington's and ensure it includes consideration of living situation.*

3. Providing flexible, personalised, co-ordinated care

People living alone are likely to have not only more needs than those living with others but also different needs, with some groups disproportionately affected. This requires the flexibility to offer a personalised approach. Such an approach includes allowing time to build relationships and trust, maintaining continuity, reaching out proactively at regular intervals rather than relying on patient-initiated follow-up, offering more intensive input at key stages and transitions such as adjusting to diagnosis or changes in treatment regimes, providing support with practicalities such as organising power of attorney, and especially for people with MND being able to get care packages in place quickly when needs change. Conversations about advance care planning may need to happen earlier and may be more difficult, again especially for people with MND where it has to be acknowledged that there is insufficient support available to enable them to continue living at home. Services need the flexibility to offer home visits when necessary, rather than restricting these to people who are housebound; availability of home visits from a range of professionals would improve equity of access for people living alone. Where hospital appointments are necessary, people living alone may need extra support with organising transport and navigating hospital settings.

Supporting and strengthening capability for self-management is an important element in enabling people to continue independent living, especially if they are alone. For example, risk of falling is a concern that is

highly relevant for people living alone that can be addressed through education and advice on self-management. Digital monitoring technology helps people with Parkinson's to self-manage but may only be available to those who can afford it, so allowing equitable access would facilitate effective self-management.

One issue raised by practitioners is the difficulty of determining capacity among people living alone when seeking to balance the right to choice and independence with the need to manage risk. People may be reluctant to reveal the extent of their difficulties as they fear losing their independence, may not necessarily be aware of some changes or difficulties, or, especially in the case of people with Huntington's, may not consider they have any difficulties. Practitioners felt this could be addressed by involving third parties who know the person well in capacity assessments.

Recommendations

- *Ensure that service commissioning allows for flexibility to meet the needs of people living alone in a personalised manner.*
- *Provide equitable access to tools that facilitate self-management.*
- *Ensure that everyone with one of these conditions who may benefit, especially if living alone, receives timely evidence-based advice on falls prevention.*
- *Review the process of conducting capacity assessments in situations where there may be a lack of awareness of symptoms, changes or difficulties to determine what could be improved and what guidance would be helpful for practitioners.*

4. Educating professionals and the public

There is a widespread need for education about these conditions, including the understanding that people can and do live alone and may not have a carer, and the skill required to support them in the community. Knowledge appropriate to role, grade and level of specialisation is essential for health and care professionals, commissioners, service providers, and NHS Continuing Health Care assessors. In-patient hospital care for people with these conditions is often unsatisfactory, especially for people living alone who have no carer to advocate for them, and educating hospital staff is essential; for example, the Parkinson's UK 'Get It On Time' campaign has highlighted lack of awareness of the time-critical nature of Parkinson's medication and the need to improve delivery of time-critical medication in acute hospital settings[39]. Crucially, professional medical education needs to consider how to equip practitioners to address all aspects of complex, progressive neuropsychiatric conditions in an integrated manner rather than, for example, considering mental health aspects as separate. Greater public awareness could help to foster better social support and inclusion especially for people living alone.

Recommendations

- *Develop staff training and continuing professional development opportunities, and review training curricula, to ensure all health and social care professionals have an understanding of progressive neurological conditions that is appropriate to their role, grade and level of specialisation, and are aware that some people with these conditions live alone.*
- *Develop accessible information and educational materials for commissioners, service providers and CHC assessors and incorporate these into mandatory training.*
- *Identify ways of raising public awareness about these conditions, including understanding that some people with these conditions live alone.*

5. Facilitating access to financial support

People living alone may need additional support with navigating the system and securing the financial support to which they are entitled. Seeking financial support through NHS Continuing Health Care is challenging for everyone but especially for people who live alone and do not have a family member who can act as advocate. This could be improved by streamlining the process, allowing professionals to apply on behalf of the person, and as noted above educating CHC assessors about progressive neurological conditions. People diagnosed with MND who are likely to experience rapid progression could be automatically issued the appropriate benefits along with a blue badge and radar key.

Recommendations

- *Streamline the process of applying for NHS Continuing Health Care funding and allow health professionals to make the application on behalf of the person.*
- *Provide automatic access to benefits for people receiving a diagnosis of MND.*

6. Strengthening community responses

Loneliness and isolation are a major issue for people living alone with a progressive neurological condition and can increase anxiety and exacerbate symptoms. Loss of confidence and feelings of vulnerability limit and restrict activity and participation. This can be compounded by difficulty finding out about and accessing suitable community activities and a lack of opportunity to connect with others who are living alone with the same condition. It can be difficult for people who are alone to attend support groups or activities dominated by couples, and some activities require people to attend with a carer, thus excluding people living alone.

Managing the practicalities of daily life, such as form-filling, banking, dealing with online systems and obtaining prescribed medication, is especially challenging for people living alone who have little informal support. Practical help from a trusted individual can be invaluable.

Appropriate housing is crucial to enabling people who are alone to maintain independent living. Support for home adaptations, where feasible, and installation of alarms can allow people to stay at home longer. In the longer-term, designing new housing to be potentially suitable or readily adaptable for people with disabilities would be beneficial.

Recommendations

- *Work with charities and community organisations to strengthen resources for providing practical day-to-day support and reducing isolation and loneliness among people living alone.*
- *Work with the Ministry of Housing, Communities and Local Government to promote integration of disability-friendly design into new housing.*

7. Supporting informal carers

Many of those living alone have support from a family member or other informal carer, who is vital to maintaining independent living. It is important for these carers to be informed about the person's care including appointments and home visits, and their contribution is essential where the person may not be aware of difficulties or is unable to seek help when needed. However, carers especially if living at a distance may not be recognised as the primary carer and find that health and social care professionals will not communicate with them. Working with carers and where relevant the person's wider network is a key element in supporting people living alone.

Recommendations

- *Health and social care professionals and services recognise the value of engaging and communicating with informal carers, even if living at a distance, and wherever possible seek to inform them about appointments and gather their views to support decision-making.*

8. Reviewing research priorities and inclusion

Our scoping review revealed a lack of research evidence about the needs of people living alone with progressive neurological conditions. This raises two issues. First, people who have no carer, or no co-resident carer, are often excluded from research, but as noted above their needs may be both greater and more diverse, and it is important that their voice is heard and included. Second, research on these conditions may not be addressing the priorities of people with lived experience, including those living alone. Consultees called for more research that would lead to patient benefit in the short term, for example research focusing on managing troublesome symptoms, which in turn would help people to maintain independence and continue living at home.

- *Specifically identify living situation as a dimension of research inclusion that should be considered in funding applications.*
- *Ensure that research funding is allocated to applied and clinical research that addresses the priorities and practical needs of people living with these conditions, including those living alone.*

Conclusions

The findings highlight the need for a paradigm shift in addressing the needs of people living alone with progressive neurological conditions. Increasing awareness is the first important step. We can make this paradigm shift a reality and reduce the inequalities resulting from living alone with one of these conditions by adapting pathways and services to provide more responsive, personalised care, enhancing community support and making research more inclusive and practically relevant. 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 a progressive neurological condition alone at home.

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Appendices

Appendix 1 Prevalence estimation methodology

Appendix 2 Scoping review methodology

Appendix 3 Prevalence estimation findings

Appendix 1. Prevalence estimation methodology

We conducted a period prevalence study investigating living alone amongst people in England with a diagnosis of Parkinson's disease, Huntington's disease or MND. The main study period was for the year 2023 (1 January to 31 December), but prevalence was also estimated at yearly intervals from 2009 to 2023.

We used data from the Clinical Practice Research Datalink (CPRD). CPRD contains routinely collected electronic health records from UK primary care practices[1,2]. This study uses CPRD Aurum (September 2024 release) which contains anonymised records from almost 50 million research acceptable patients[3]. The median follow-up time for active patients at the time of release was 9.7 years.

Study population

Patients with one of the three conditions were identified in CPRD by searching all records for the medical codes listed in the Supplementary Appendix and by searching linked Hospital Episode Statistics for the ICD-10 codes listed in the Supplementary Appendix. When a relevant code appeared in records, that patient was assumed to have a diagnosis from that point forward. Patients were included in the annual prevalence estimate if their registration start date was before or within the study period. Patients were excluded if their registration end date, practice last collection date, or death date occurred before the study period. Patients were excluded if living alone status could not be determined from their records.

Defining living alone status

Living alone status is a time varying measure, and a binary indicator of living alone status (lives alone vs does not live alone) was created for each year from 2009-2023, for people alive and registered within each study year. A separate category was created for those living in a care facility (care homes, hospices or long-term hospitals). Living alone status is not well recorded in clinical records so the following procedure was used:

- Where possible for a given year, living alone status was determined from medical codes in the consultation and observation files (see Supplementary Appendix). People who were homeless were excluded.
- Where living alone status was missing for a given year, but a patient had a medical code indicating they were married or in a relationship, patients were assumed not to live alone (see Supplementary Appendix).
- Where living alone status was missing for a given year, the nearest available living alone status from surrounding years was used.
- If living alone status was still missing, then where available information was taken from the 'family number' variable as previously described[4]. The family number variable is a unique number given to each patient from the same household at a given practice. If two or more people are alive and registered and are from the same household, those people were considered to not live alone. However, family number does not have a time attached to it, so an assumption is made that this was recorded at the registration start date.

Statistical analysis

Annual prevalence of living alone was estimated for the year 2023 (01/01/2023 - 31/12/2023). This analysis was repeated at yearly intervals going back 15 years (2009-2023). Annual prevalence was calculated by dividing the total number living alone by the population at risk of living alone. The population at risk of living alone were those who had both a diagnosis and an available living alone status, were contributing acceptable quality data to CPRD during the study period and were alive and registered within the study year.

For 2023, prevalence of living alone was stratified by sex, age, ethnicity, region, IMD deprivation quintiles, and urban/rural location where possible (a sample size >5 is required to minimise reidentification risk). Logistic regression was used to explore differences by group.

Changes in temporal trends in prevalence of living alone were explored using the annual prevalence estimates from 2009 to 2023 using Joinpoint regression. Joinpoint analyses were performed using Joinpoint Program 4.9.1.0[5].

All data organisation and other analyses were conducted using R.

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Appendix 2. Scoping review methodology

Research literature

Search strategy

We searched for relevant literature in seven databases, selected to cover a wide range of research disciplines: PubMed; Web of Science Core Collection; CINAHL ultimate and Ageline via EBSCOhost; and EMBASE, PsycInfo, and Social Policy and Practice via OVID. The search in these databases was conducted on 18th January 2024. The only restriction applied to the search was for publications to be published in English; this restriction was applied to all databases except Social Policy and Practice which does not support this restriction. No date restrictions were applied.

Terms used in the search were:

dement* OR Alzheimer* OR Parkinson* OR Lewy OR Fronto* OR Parkinsonism OR Huntington* OR Chorea OR amyotrophic lateral sclerosis OR ALS OR motor neuron* disease OR MND OR progressive muscular atrophy OR Gehrig OR neurodegen* OR neurolog* OR cognitive impairment

AND

Living alone OR Live* alone OR Single-living OR One-person household OR Singlehood OR Single people OR Single person OR Single men OR Single women OR solo

The exact search strings used in each database are shown in Table A2.1 below.

Eligibility criteria

The populations of interest were people who lived alone with a diagnosis of a relevant progressive neurological condition, irrespective of type, severity, or age. While dementia, Parkinson's, Huntington's, and MND were specific targets in the search, studies that included people with rarer progressive neurological conditions were also eligible to be considered. For a study to be included, at least 80% of the sample had to have one of the conditions of interest.

There were no restrictions on research design. Quantitative, qualitative, mixed method, and case studies reporting cross-sectional and/or longitudinal associations were all eligible. Where studies reported trials, baseline information was included, and outcomes were included where data were disaggregated according to living situation and compared for people living alone and with others. Reviews, editorials, letters, opinion pieces, and published conference abstracts were excluded. Published conference abstracts were used to find subsequently published articles that were not already included in the review. When articles were found via this route, they were included in the 'Identification of studies via other methods' section of the PRISMA flowchart.

Table A2.1 Specific search strings used in applicable databases

Database	Search string
PubMed	((((((((((((((((((dement*[Title/Abstract]) OR (Alzheimer*[Title/Abstract])) OR (Parkinson*[Title/Abstract])) OR (Lewy[Title/Abstract])) OR (Fronto*[Title/Abstract])) OR (Parkinsonism[Title/Abstract])) OR (Huntington*[Title/Abstract])) OR (Chorea[Title/Abstract])) OR (amyotrophic lateral sclerosis[Title/Abstract])) OR (ALS[Title/Abstract])) OR (motor neuron* disease[Title/Abstract])) OR (MND[Title/Abstract])) OR (progressive muscular atrophy[Title/Abstract])) OR (Gehrig[Title/Abstract]) OR (neurodegen*[Title/Abstract]) OR (neurolog*[Title/Abstract]) OR (cognitive impairment[Title/Abstract])))))))) AND ((((((((((Living alone[Title/Abstract]) OR Live* alone[Title/Abstract]) OR (Single*living[Title/Abstract])) OR (One-person household[Title/Abstract])) OR (Singlehood[Title/Abstract])) OR (Single people[Title/Abstract])) OR (Single person[Title/Abstract])) OR (Single men[Title/Abstract])) OR (Single women[Title/Abstract])) OR (Solo[Title/Abstract])
Web of Science	(TI=(dement* OR Alzheimer* OR Parkinson* OR Lewy OR Fronto* OR Parkinsonism OR Huntington* OR Chorea OR amyotrophic lateral sclerosis OR ALS OR motor neuron* disease OR MND OR progressive muscular atrophy OR Gehrig OR neurodegen* OR neurolog* OR cognitive impairment)) AND (TI=(Living alone OR Live* alone OR Single-living OR One-person household OR Singlehood OR Single people OR Single person OR Single men OR Single women OR solo)) OR (AB=(dement* OR Alzheimer* OR Parkinson* OR Lewy OR Fronto* OR Parkinsonism OR Huntington* OR Chorea OR amyotrophic lateral sclerosis OR ALS OR motor neuron* disease OR MND OR progressive muscular atrophy OR Gehrig OR neurodegen* OR neurolog* OR cognitive impairment)) AND (AB=(Living alone OR Live* alone OR Single-living OR One-person household OR Singlehood OR Single people OR Single person OR Single men OR Single women OR solo))
EBSCOhost (CINAHL and Ageline)	TI (dementia OR Alzheimer* OR Parkinson* OR Lewy OR Fronto OR Parkinsonism OR Huntington OR Chorea OR amyotrophic lateral sclerosis OR ALS OR motor neuron disease OR MND OR progressive muscular atrophy OR Gehrig OR neurodegen* OR neurol*) AND TI (Living alone OR Single-living OR One-person household OR Singlehood OR Single people OR Single person OR Single men OR Single women OR solo) OR AB (dementia OR Alzheimer* OR Parkinson* OR Lewy OR Fronto OR Parkinsonism OR Huntington OR Chorea OR amyotrophic lateral sclerosis OR ALS OR motor neuron disease OR MND OR progressive muscular atrophy OR Gehrig OR neurodegen* OR neurol*) AND AB (Living alone OR Single-living OR One-person household OR Singlehood OR Single people OR Single person OR Single men OR Single women OR solo)
Ovid (EMBASE, PsycInfo, and Social Policy and Practice)	((dement* or Alzheimer* or Parkinson* or Lewy or Fronto* or Parkinsonism or Huntington* or Chorea or amyotrophic lateral sclerosis or ALS or motor neuron* disease or MND or progressive muscular atrophy or Gehrig or neurodegen* or neurolog* or cognitive impairment) and (Living alone or Live* alone or Single-living or One-person household or Singlehood or Single people or Single person or Single men or Single women or solo)).ti,ab.

Procedure

The PRISMA flowchart in Figure A2.1 shows the article selection and screening process. EndNote was used to manage records throughout all stages of the review. Duplicate entries were removed using the EndNote duplicate function and then checking during the screening process for any duplicate titles that were previously missed.

Titles and abstracts of all returned records were screened by two reviewers working independently. Where it was not clear whether articles should be included, decisions about eligibility were discussed by the two reviewers. Full texts of articles selected as being potentially relevant were obtained and screened for eligibility by one researcher. To check for consistency, 20% of these were screened by a second researcher, blinded to the decision of the first. Following discussion of any differences in coding, the two researchers reached 100% agreement.

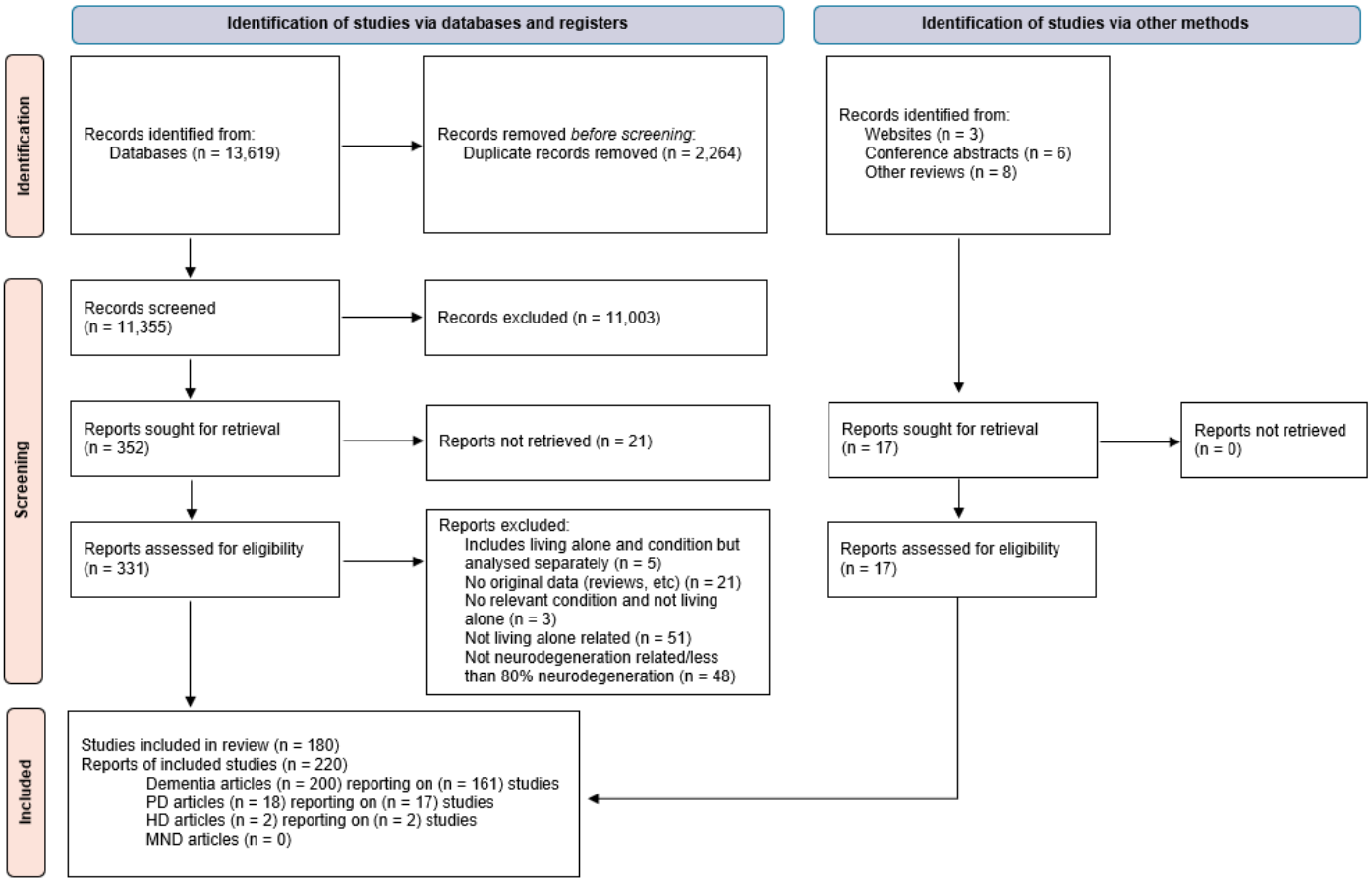
Multiple articles using data from the same study were identified and collated to avoid duplication of reporting. Where the same variables were included across multiple articles from the same study, priority was given to the article reporting the largest sample size. Where sample sizes were identical and where the same variables were included, priority was given to the most recently published article.

Data and study characteristics from articles that met inclusion criteria following full text screening were extracted into Excel. For quantitative articles, details of the measures used, and summary statistics were extracted. For qualitative studies, overarching themes and subthemes, representative quotations, and main findings related to living alone were extracted. Data were then classified into predetermined categories and sub-categories to summarise the evidence. Included papers were scanned by five reviewers and common themes and sub-themes were identified, for example ‘Personal characteristics’, ‘Condition-related characteristics’, ‘Health and well-being’, ‘Informal care and support’, ‘Use of health and social care services’, and ‘Costs’. These were further subdivided to aid interpretation.

Data synthesis approach

Quantitative data from eligible studies were prioritised as the main source of evidence to guide the findings and conclusions of the review. These data offered a systematic perspective on trends, patterns, and associations relevant to people living alone with progressive neurological conditions. At the same time, qualitative studies were examined to supplement this perspective, providing greater depth of insight into personal experiences and challenges. Representative quotes from qualitative studies were incorporated to illustrate and contextualise quantitative findings. This allowed for a comprehensive synthesis, ensuring that both empirical data and lived experiences informed the findings of the review.

Figure A2.1 PRISMA flowchart showing the selection process for research articles



Grey literature

Search strategy

The grey literature search covered a pre-selected list of 59 websites. These were the main English language condition-specific websites for dementia hosted by organisations in the UK, the USA, Canada, Europe, or Australia, or websites of widely known health and social care organisations; see Table A2.2 for a full list. We searched these websites using advanced Google search parameters between March 26th and April 4th, 2024.

For condition-specific websites, we used these living alone synonyms only:

"Living alone" OR "Live alone" OR "Lives alone" OR "Lived alone"

An example search string for a condition-specific website is:

site:hda.org.uk "Living alone" OR "Live alone" OR "Lives alone" OR "Lived alone" filetype:pdf

For the 21 non-specific websites, we used each of these four search terms separately, combined with the condition terms for dementia, Parkinson's disease, Huntington's disease and MND.

An example search string is:

- site:who.int "living alone" dementia OR demented OR Alzheimer OR Parkinson OR Lewy OR Fronto OR Huntington OR Chorea OR "amyotrophic lateral sclerosis" OR ALS OR "motor neuron disease" OR MND OR "progressive muscular atrophy" OR Gehrig OR neurodegenerative OR neurodegeneration OR "cognitive impairment OR "cognitively impaired" filetype:pdf

Eligibility criteria

The search targeted documents in pdf format. Documents were included if they:

- Offered support or advice to people living alone with Parkinson's, Huntington's or MND, to their families, or to the health and social care professionals who work with them.
- Addressed topics of relevance to people living alone with these conditions, such as managing autonomy and risk, loneliness, ensuring home safety, or planning for future care.

Documents were excluded if they:

- Referred to living alone but lack substantial commentary, advice, or relevance to the experience or needs of people living alone with dementia and/or their families.
- Were published conference abstracts; these were used to find subsequently published articles where available.

Procedure

The flowchart in Figure A2.2 summarises the screening process. The first 20 pdfs returned by Google for each website were downloaded for screening, based on the expectation that the most relevant pdfs would appear at the top of the search results. If fewer than 20 pdfs were available, all were downloaded. Table A2.3 lists the sources included in the review.

After removing duplicates and records for which access was prohibited the remaining pdfs were scanned for relevance and any that clearly did not meet inclusion criteria were excluded. Full-text screening was conducted with the remainder.

Table A2.2 List of websites searched for grey literature

Condition-specific websites

1. **ALS Association**
2. **ALS Society of Canada**
3. **ALS Therapy Development Institute**
4. **American Parkinson Disease Association (APDA)**
5. **APPG on MND**
6. **APPG on Parkinson's**
7. **APPG on Rare, Genetic and Undiagnosed Conditions**
8. **Davis Phinney Foundation for Parkinson's**
9. **European Huntington Association**
10. **European Huntington's Disease Network**
11. **Fight MND**
12. **Huntington Society of Canada**
13. **Huntington's Australia**
14. **Huntington's Disease Association**
15. **Huntington's Disease Society of America**
16. **Huntington's Disease Tasmania**
17. **Huntington's Disease Youth Organisation**
18. **International Alliance of ALS/MND Associations**
19. **International Huntington's Disease Association**
20. **International Parkinson and Movement Disorder Society**
21. **Irish Motor Neurone Disease Association**
22. **Les Turner ALS Foundation**
23. **MND Scotland**
24. **MNDA**
25. **National Institute of Neurological Disorders and Stroke**
26. **New South Wales HD Association**
27. **Parkinson Canada**
28. **Parkinson's Australia**
29. **Parkinson's Europe**
30. **Parkinson's Foundation**
31. **Parkinson's Ireland**
32. **Parkinson's UK**
33. **Queensland HD Association**
34. **Scottish Huntington's Association**
35. **Shake It Up Foundation**
36. **South Australia and Northern Territory HD Association**
37. **Victoria HD Association**
38. **Western Australia HD Association**

Non-specific websites

1. Age UK
2. Ageing Well Without Children (AWOC)
3. American Association of Retired Persons (AARP)
4. Association of British Neurologists
5. British Psychological Society
6. British Society of Gerontology
7. Centers for Disease Control and Prevention
8. Centre for Ageing Better
9. Health Policy Partnership
10. International Federation on Ageing
11. Joseph Rowntree Foundation
12. Meaningful Ageing Australia
13. Neurological Alliance
14. NHS England
15. Royal College of General Practitioners
16. Royal College of Occupational Therapists
17. Royal College of Psychiatrists
18. The Health Foundation
19. The King's Fund
20. UK Government
21. World Health Organization (WHO)

Figure A2.2 Flowchart showing the process for identifying grey literature

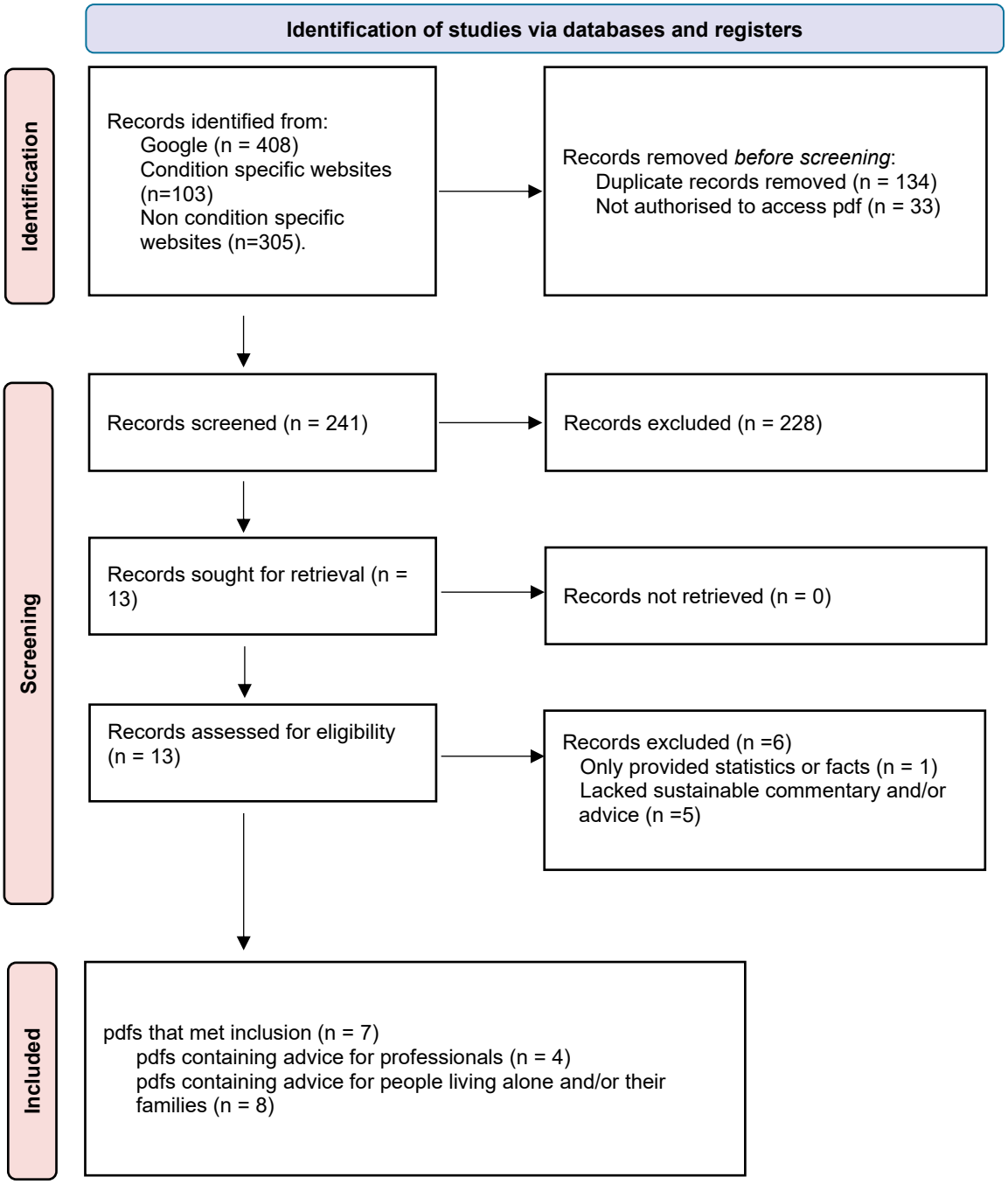


Table A2.3 Grey literature resources included in the review

Huntington Society of Canada. (2020). Covid-19 Strategies, ideas, and resources for families. **https://www.huntingtonsociety.ca/wp-content/uploads/2020/05/47-COVID-19-Strategies.pdf**. Huntington Society of Canada.
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Appendix 3. Prevalence estimation findings

Table A3.1 Living situation in 2023 stratified by measures of inequality

Parkinson's disease

	Total (N)	Lives in a care facility (N, % of total)	Lives alone (N, % of those not in a care facility)	Lives with others (N, % of those not in a care facility)	Lives alone vs lives with others* (odds ratio, 95% CI)
Total	39753	6419 (16.1%)	11048 (33.1%)	22286 (66.9%)	-
Gender					
Male	23569	3488 (14.8%)	6042 (30.1%)	14039 (69.9%)	0.72 (0.69 - 0.75)
Female	16184	2931 (18.1%)	5006 (37.8%)	8247 (62.2%)	Ref
Age					
80+	15788	4028 (25.5%)	4399 (37.4%)	7361 (62.6%)	Ref
75-79	9063	1275 (14.1%)	2366 (30.4%)	5422 (69.6%)	0.74 (0.70 - 0.79)
70-74	6118	639 (10.4%)	1711 (31.2%)	3768 (68.8%)	0.78 (0.72 - 0.83)
65-69	3854	254 (6.6%)	1117 (31.0%)	2483 (69.0%)	0.77 (0.71 - 0.84)
<65	4930	223 (4.5%)	1455 (30.9%)	3252 (69.1%)	0.77 (0.71 - 0.82)
Region					
North East	1705	287 (16.8%)	521 (36.7%)	897 (63.3%)	1.31 (1.16 - 1.47)
North West	7622	1232 (16.2%)	2216 (34.7%)	4174 (65.3%)	1.20 (1.12 - 1.29)
Yorkshire and The Humber	942	139 (14.8%)	222 (27.6%)	581 (72.4%)	0.87 (0.74 - 1.02)
East Midlands	662	89 (13.4%)	166 (29.0%)	407 (71.0%)	0.91 (0.75 - 1.09)
West Midlands	7246	1302 (18.0%)	2020 (34.0%)	3924 (66.0%)	1.16 (1.08 - 1.21)
East of England	1763	242 (13.7%)	485 (31.9%)	1036 (68.1%)	1.05 (0.93 - 1.18)
London	5342	624 (11.7%)	1742 (36.9%)	2976 (63.1%)	1.31 (1.21 - 1.41)
South East	9797	1665 (17.0%)	2518 (31.0%)	5614 (69.0%)	Ref
South West	4674	839 (18.0%)	1158 (30.2%)	2677 (69.8%)	0.97 (0.89 - 1.05)
Deprivation					
Quintile 1 (least)	7498	718 (9.6%)	1920 (28.3%)	4860 (71.7%)	Ref
Quintile 2	6499	603 (9.3%)	1806 (30.6%)	4090 (69.4%)	1.12 (1.04 - 1.21)
Quintile 3	5271	483 (9.2%)	1659 (34.6%)	3129 (65.4%)	1.35 (1.25 - 1.46)
Quintile 4	4639	485 (10.5%)	1561 (37.6%)	2593 (62.4%)	1.53 (1.41 - 1.66)
Quintile 5 (most)	3387	335 (9.9%)	1291 (42.3%)	1761 (57.7%)	1.91 (1.75 - 2.09)
Missing	12459	3795	2811	5853	
Urban/rural					
Urban	27167	4407 (16.2%)	7823 (34.4%)	14937 (65.6%)	Ref
Rural	5102	730 (14.3%)	1195 (27.3%)	3177 (72.7%)	0.71 (0.67 - 0.77)
Missing	7848	1282	2030	4172	
Ethnicity					
White	35899	6012 (16.7%)	10023 (33.5%)	19864 (66.5%)	Ref
Asian	1959	139 (7.1%)	398 (21.9%)	1422 (78.1%)	0.55 (0.49 - 0.62)
Black	716	66 (9.2%)	289 (44.5%)	361 (55.5%)	1.57 (1.34 - 1.84)
Mixed	193	26 (13.5%)	57 (34.1%)	110 (65.9%)	1.04 (0.75 - 1.42)
Other	396	30 (7.6%)	126 (18.9%)	540 (81.1%)	1.07 (0.86 - 1.33)
Missing	590	146	155	289	

*Adjusted for age category and sex. We were able to determine living alone status for 39,753 of the people living with Parkinson's disease. 6 people were homeless and were excluded.

b) Motor neurone disease

	Total (N)	Lives in a care facility (N, % of total)	Lives alone (N, % of those not in a care facility)	Lives with others (N, % of those not in a care facility)	Lives alone vs lives with others* (odds ratio, 95% CI)
Total	3456	500 (14.5%)	975 (33.0%)	1981 (67.0%)	-
Gender					
Male	2043	282 (13.8%)	605 (34.4%)	1156 (65.6%)	1.16 (0.99 - 1.35)
Female	1413	218 (12.4%)	370 (31.0%)	825 (69.0%)	Ref
Age					
75+	873	207 (23.7%)	232 (34.8%)	434 (65.2%)	Ref
65-74	796	136 (17.1%)	215 (32.6%)	445 (67.4%)	0.90 (0.71 - 1.13)
55-64	672	91 (13.5%)	209 (36.0%)	372 (64.0%)	1.05 (0.83 - 1.32)
45-54	401	40 (10.0%)	124 (34.3%)	237 (65.7%)	0.98 (0.75 - 1.30)
<45	714	26 (3.6%)	195 (28.3%)	493 (71.7%)	0.74 (0.59 - 0.94)
Region					
North East	142	19 (13.4%)	40 (32.5%)	83 (67.5%)	1.25 (0.82 - 1.88)
North West	675	97 (14.4%)	200 (34.6%)	378 (65.4%)	1.35 (1.06 - 1.72)
Yorkshire and The Humber	92	10 (10.9%)	24 (29.3%)	58 (70.7%)	1.05 (0.62 - 1.72)
Midlands	699	104 (14.9%)	228 (38.3%)	367 (61.7%)	1.60 (1.26 - 2.01)
East of England	152	30 (19.7%)	31 (25.4%)	91 (74.6%)	0.87 (0.56 - 1.35)
London	582	66 (11.3%)	187 (36.2%)	329 (63.8%)	1.53 (1.19 - 1.96)
South East	794	111 (14.0%)	192 (28.1%)	491 (71.9%)	Ref
South West	320	63 (19.7%)	73 (28.4%)	184 (71.6%)	1.01 (0.73 - 1.39)
Deprivation					
Quintile 1 (least)	533	71 (13.3%)	111 (24.0%)	351 (76.0%)	Ref
Quintile 2	504	69 (13.7%)	124 (28.5%)	311 (71.5%)	1.24 (0.92 - 1.67)
Quintile 3	480	54 (11.3%)	134 (31.5%)	292 (68.5%)	1.49 (1.11 - 2.01)
Quintile 4	471	50 (10.6%)	164 (39.0%)	257 (61.0%)	2.11 (1.57 - 2.83)
Quintile 5 (most)	435	42 (9.7%)	150 (38.2%)	243 (61.8%)	2.03 (1.51 - 2.74)
Missing	1033	214	292	527	
Urban/rural					
Urban	2447	350 (14.3%)	717 (34.2%)	1380 (65.8%)	Ref
Rural	389	56 (14.4%)	72 (21.6%)	261 (78.4%)	0.51 (0.39 - 0.67)
Missing	620	94	186	340	
Ethnicity					
White	2897	439 (15.2%)	810 (33.0%)	1648 (67.0%)	Ref
Asian	266	20 (7.5%)	56 (22.8%)	190 (77.2%)	0.64 (0.46 - 0.87)
Black	118	17 (14.4%)	49 (48.5%)	52 (51.5%)	2.04 (1.36 - 3.05)
Mixed	49	7 (14.3%)	16 (38.1%)	26 (61.9%)	1.43 (0.74 - 2.68)
Other	70	10 (14.3%)	26 (43.3%)	34 (56.7%)	1.66 (0.98 - 2.80)
Missing	56	7	18	31	

*Adjusted for age category and sex. We were able to determine living alone status for 3,456 of the people living with motor neurone disease. The East Midlands and West Midlands were combined into Midlands due to the small number of people from the East Midlands.

c) Huntington's disease

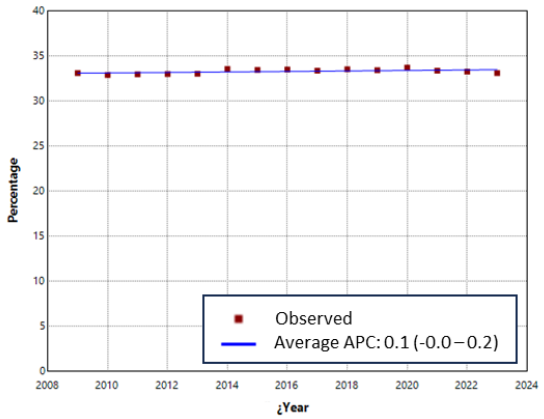
	Total (N)	Lives in a care facility (N, % of total)	Lives alone (N, % of those not in a care facility)	Lives with others (N, % of those not in a care facility)	Lives alone vs lives with others* (odds ratio, 95% CI)
Total	1649	489 (29.7%)	442 (38.1%)	718 (61.9%)	-
Gender					
Male	790	227 (28.7%)	218 (38.7%)	345 (61.3%)	1.05 (0.83 - 1.33)
Female	859	262 (30.5%)	224 (37.5%)	373 (62.5%)	Ref
Age					
75+	200	67 (33.5%)	51 (38.3%)	82 (61.7%)	Ref
65-74	324	120 (37.0%)	71 (34.8%)	133 (65.2%)	0.86 (0.55 - 1.35)
55-64	476	172 (36.1%)	113 (37.2%)	191 (62.8%)	0.95 (0.63 - 1.45)
45-54	332	82 (24.7%)	105 (42.0%)	145 (58.0%)	1.16 (0.76 - 1.79)
<45	317	48 (15.1%)	102 (37.9%)	167 (62.1%)	0.98 (0.64 - 1.51)
Deprivation					
Quintile 1 (least)	196	30 (15.3%)	43 (25.9%)	123 (74.1%)	Ref
Quintile 2	197	49 (24.9%)	56 (37.8%)	92 (62.2%)	1.77 (1.09 - 2.87)
Quintile 3	235	61 (26.0%)	58 (33.3%)	116 (66.7%)	1.47 (0.92 - 2.36)
Quintile 4	247	68 (27.5%)	72 (40.2%)	107 (59.8%)	1.99 (1.25 - 3.17)
Quintile 5 (most)	216	42 (19.4%)	91 (52.3%)	83 (47.7%)	3.17 (2.01 - 5.07)
Missing	558	239	122	197	
Urban/rural					
Urban	1138	313 (27.5%)	325 (39.4%)	500 (60.6%)	Ref
Rural	187	60 (32.1%)	37 (29.1%)	90 (70.9%)	0.64 (0.42 - 0.96)
Missing	324	116	80	128	

*Adjusted for age category and sex. We were able to determine living alone status for 1,649 of the people living with Huntington's disease. 3 people were homeless and were excluded.

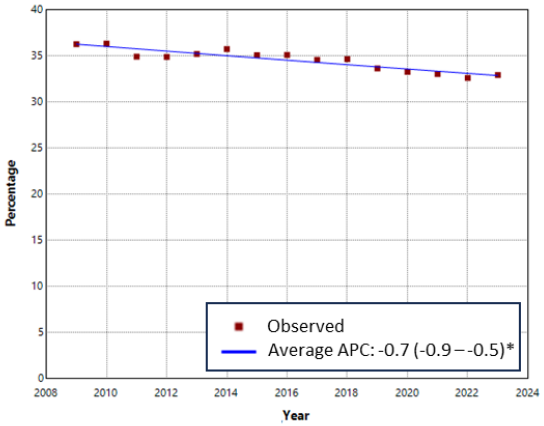
Notes. CI, confidence intervals. Care facilities include care homes, hospices and long-term hospitals. Urban/rural is based on the location of an individual's GP practice. Deprivation is based on the postcode of the individual.

Figure A3.1 Trend over the past 15 years in prevalence of living alone with a) Parkinson's disease, b) motor neurone disease, and c) Huntington's disease, using Joinpoint analysis.

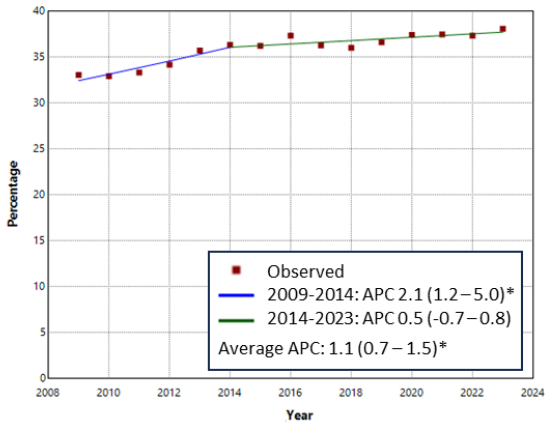
a) Parkinson's disease



b) Motor neurone disease



c) Huntington's disease



Models with 0-2 JoinPoints were tested and the model with the better fit chosen. * indicates that the Annual Percent Change (APC) is significantly different from zero (P < 0.05).

Thank you for reading the report. Our contact details can be found below.

denpru@exeter.ac.uk

denpruexeter.nihr.ac.uk

@denpruexeter.bsky.social