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REPORT

Living alone with dementia: a neglected inequality

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Living alone with dementia: a neglected inequality

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Supplementary Appendix

- Research articles included in the scoping review
- Grey literature sources included in the scoping review
- Codes used to identify people living alone with dementia in the CPRD dataset

Available at: **https://denpruexeter.nihr.ac.uk/dementia-supplementary-appendix**

Summary

People with dementia who live alone, sometimes with little or no family or informal support, are an often-overlooked group that is that is increasing in number: possibly as many as one in three of all people with dementia live alone. There is still a widespread assumption that people with dementia have a carer available, and neither NHS 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 needs to change if we are to provide appropriate services and support for people who live alone with dementia.

The report outlines findings from an exploration of primary care data to examine the prevalence of living alone, a scoping review of research and grey literature that included 200 peer-reviewed journal articles, and consultations with people with lived experience, practitioners and other stakeholders. Forty per cent of people with dementia in the community were living alone in England in 2023. People living alone, predominantly older women, experience significant inequalities across the pathway in relation to diagnosis and support from services, in capability for living well, and extending to end-of-life care. We identified four main avenues through which these inequalities can be addressed:

1. Knowing the numbers
    - Understanding how many people are living alone with dementia in each area as a basis for commissioning appropriate service pathways
    - Designing systems to facilitate recording of living situation and informal support and making sure this is routinely recorded and appropriately shared
2. Making services more responsive
    - Services articulating how pathways and services are designed or adapted to meet the needs of people living alone, and proactively initiating and maintaining contact
    - Training and equipping practitioners to implement best practice
    - Giving people living alone access to a link worker or care co-ordinator to help navigate health, social care and community services
    - Services reviewing their approach to ensure they are welcoming and inclusive, and communicating with people in a way that meets their needs
3. Strengthening community support
    - Services providing support for distant carers, and engaging and communicating with them irrespective of where they are based
    - Strengthening the capability of community agencies to include people living alone and respond to their needs.
    - Including reference to people living alone in initiatives to raise public awareness of dementia.
4. Making research inclusive and practically relevant
    - Regarding living situation as a key indicator of inclusivity in dementia research and ensuring people living alone are included in research and where appropriate considered as a distinct group.
    - Targeting research funding towards developing and sustainably implementing good practice in supporting people living alone with dementia, and where relevant their families, and strengthening community agencies, networks and support.

The findings highlight the need for a paradigm shift in addressing the needs of people living alone with dementia. Increasing awareness is the first important step. By implementing the recommended actions, we can make this paradigm shift a reality and reduce the inequalities resulting from living alone with dementia. benefit NHS and social care services as well as transforming the experience of people who are coping with dementia alone.

Executive Summary

'Living alone with dementia is the next major challenge in aging.' (Splaine Consulting)

In 1994 a policy report 'Dementia and Living Alone' from the Alzheimer's Disease Society (as it then was) warned that people living alone with dementia experienced delays in diagnosis, challenges accessing support, difficulties with independent living and safety concerns, risk of isolation, and stigma and lack of understanding. Thirty years later, more people than ever are living alone with dementia, but the situation has scarcely improved. The assumption that people with dementia have a carer available is still widespread, and neither NHS dementia services nor community provision are designed to accommodate the needs of people living alone. This is unhelpful and costly both for individuals and for services. It is time for this to change.

In this project we:

- Analysed publicly-available primary care data to explore the number and proportion of people with dementia recorded as living alone in England.
- Reviewed research and grey literature to identify what is known about the characteristics and needs of people with dementia who are living alone and how best to support them.
- Consulted people with lived experience of dementia, practitioners, and other stakeholders about how to meet the support needs of people living alone with dementia in England.
- Identified policy implications, including highlighting gaps in knowledge, and used these to make recommendations for policy and practice.

Our analyses indicate that in England approximately 40% of people with dementia residing in the community lived alone in 2023, and the proportion is increasing. These analyses, and the research evidence we reviewed, demonstrate that the issue of living alone with dementia is one of inequality. There are two main elements to consider:

- Discrimination based on sex, age and ethnicity. People living alone with dementia are a diverse group and there are many reasons why someone may be living alone, but they are more likely to be female and older, with some pre-existing social disadvantage, and living in a deprived area. Older, less well-educated women with dementia are among those least likely to be receiving support from services. In England, people of black ethnicity are more likely to live alone than other ethnic groups.
- Poorer service provision. Evidence shows that people living alone with dementia do not differ from those living with others in dementia severity or symptoms, physical health, mental health or use of health services, but relative to people living with others, they experience significant inequalities across the pathway in relation to diagnosis and subsequent care.

We identified four main avenues through which these inequalities can be addressed:

1. Knowing the numbers
2. Making services more responsive
3. Strengthening community support
4. Making research inclusive and practically relevant

1. Knowing the numbers

Our analyses indicate that in England approximately 40% of people with dementia residing in the community live alone, and the proportion is increasing. In practice, living situation is often not recorded, or not recorded accessibly, and if recorded, it is often not shared. Practitioners may only find out someone is living alone at the point of crisis. While many of those living alone have some informal support, although not necessarily near at hand, but others have little or no informal support; evidence suggests this could be as many as 1 in 10. The most isolated individuals and those most in need are the least likely to access services.

We recommend that:

- All ICBs identify or estimate how many people are living alone with dementia in their area and use this information to commission appropriate service pathways.
- Systems are designed to facilitate up-to-date recording of living situation and informal support, and this is routinely recorded, so that information regarding living alone is accessible and can be shared appropriately among agencies and professionals.

2. Making services more responsive

Implementing what we already know about good service provision for this group would help to reduce inequalities. This includes designing flexible pathways that take account of the needs of people living alone, especially those living alone with little support, actively initiating and maintaining contact, and allowing time to build relationships and trust so that practitioners can make optimal decisions.

We recommend that:

- NHS dementia services articulate how provision and pathways are designed or adapted to meet the needs of people living alone with dementia, and how these features are implemented as part of routine practice.
- Practitioners are trained, equipped and supported to offer flexibility and implement good practice for people living alone with dementia.
- Services proactively reach out to people living alone, including those unexpectedly transitioning to living alone due to bereavement or relationship breakdown.

An important part of making services more responsive is to ensure they are accessible and inclusive. Navigating health and social care services is especially challenging for people living alone, and support with this is crucial. Even small adjustments can make services more inclusive, for example offering double GP appointments to allow more time and being flexible enough to communicate in the way that works best for people.

We recommend that:

- People living alone with dementia have access to a link worker or care co-ordinator who can assist with navigating NHS, social care and community provision, and identifying access and transport options.
- Services review their provision to ensure they are inclusive and welcoming for people living alone with dementia.
- All services, including GPs and primary care teams, communicate with people living alone with dementia in line with their preferences and offer written summaries following appointments.

3. Strengthening community responses

Many people living alone with dementia do have some informal support, although not necessarily near at hand. Distant carers typically receive little communication from services and little support for their role.

We recommend that:

- Services and agencies that support informal carers are encouraged to engage with and offer support to distant carers of people living alone with dementia.
- GPs and primary care teams engage with and communicate with non-resident carers even if they are based in a different area.

Community agencies and groups often exclude people who are living alone, and many community activities require people to attend with a carer. There is evidence that initiatives to enhance inclusion and responsiveness among community agencies can be beneficial.

We recommend that:

- Steps are taken to strengthen the capability of community agencies and groups to include people living alone and respond to their needs.
- Initiatives to increase public awareness and understanding of dementia include reference to people living alone with dementia.

4. Making research inclusive and practically relevant

People living alone have distinct needs and may respond differently to interventions, but many research studies exclude them. It is not acceptable to exclude people because they have no carer.

We recommend that:

- Researchers and research funders consider living situation as a key element of inclusivity in developing and conducting dementia research projects, ensure people living alone are included in research, and require sub-group analyses according to living situation where relevant and feasible.

Our review included 200 research papers, but hardly any of these provided evidence about good practice in providing services and support for people living alone with dementia. To be most useful, research in this area should inform and support good practice and reduce inequalities.

We recommend that:

- Research funders target funding towards actively developing and sustainably implementing good practice in supporting people living alone with dementia, and where relevant their families, and strengthening community agencies, networks and support.

Conclusions

The findings summarised here and outlined in more detail in the full report highlight the need for a paradigm shift in addressing the needs of people living alone with dementia. Increasing awareness is the first important step. We can make this paradigm shift a reality and reduce the inequalities resulting from living alone with dementia by acknowledging the scale of the issue, 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 dementia alone at home and increasing their capability to live well with the condition.

Introduction

'Living alone with dementia is the next major challenge in aging.' (Splaine Consulting)[1]

Thirty years ago, Alzheimer's Society issued a policy report titled 'Dementia and Living Alone'[2]. This emphasised the urgent need for better identification and support for people living alone with dementia, including tailored care services, improved community networks, and proactive interventions to reduce risks such as isolation, neglect, and harm, and calling for coordinated efforts across health, social care, and voluntary sectors. At that time, 12% of the UK population and 33% of people aged over 65 were living alone.

Today, almost 1 in 3 UK households (8.3m, 30%) are single person households, and this is now the second most common type of living arrangement. Half of over 65s are living alone[3], and a significant number will have dementia. Recent UK research suggests a figure somewhere between 17.5%[4] and 35%[5] while a recent US estimate suggests 25% to 30%[6]. Living situation is not reported in NHS Digital Primary Care Dementia Data for England.

Despite the early warning in the 'Dementia and Living Alone' report and awareness of the continued trends towards greater numbers of older people living alone, little progress has been made in recognising and addressing the needs of people living alone with dementia. The assumption that everyone with dementia has a carer available remains widespread. It is time for this to change.

People living alone with dementia, especially if they have no adult children and/or lack close family support, are a group with significant unmet needs, inequitable access to services and support, and increased risk of adverse outcomes including crises and emergency admissions, serious harms, and social isolation[7]. They experience difficulties engaging and interacting with services and may find services unresponsive to their situation and needs. It is important to provide equitable access and ensure that health and social care services can respond to their needs as these evolve over time, reducing the risk of crises and emergency admissions and enabling people to remain at home for as long as possible if they so wish.

In this policy research project, we set out to identify what changes in policy and practice could be introduced to better meet the needs of people living alone with dementia in England. We aimed to:

- Estimate the number and proportion of people with dementia who are living alone in England.
- Review what is known about the characteristics and needs of people with dementia who are living alone and how best to support them.
- Consult people with lived experience of dementia and other stakeholders to explore their views about how to meet the support needs of people living alone with dementia 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 dementia are living alone in England, we used Clinical Practice Research Datalink (CPRD Aurum, September 2024 release)[8] data which comprises routinely-collected anonymised electronic health records from almost 50 million people registered with UK primary care practices. The analyses covered a wider range of conditions but here we report only on information about people living alone with dementia. The methods used are described in full in Appendix 2. Codes used to identify people with the conditions of interest living alone are provided in the Supplementary Appendix. Where living situation was not directly recorded, we considered people to be living alone if they were the sole person from that address registered with the given GP practice.

We examined prevalence of living alone in the calendar year 2023. We explored whether different groups were more likely to live alone, considering sex, age, ethnicity, region, area deprivation, and urban/rural location.

Scoping review

We systematically searched research and grey literature to identify information about the characteristics and needs of people with dementia who are living alone and how best to support them. The methodology is described in full in Appendix 2 and briefly summarised here. The search covered a wider range of conditions but here we report only on information about dementia.

Research literature

We used established procedures outlined in relevant guidelines[9]. We conducted searches with no date restriction for English-language publications in seven databases; details of search terms and databases searched can be found in Appendix 2. 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 dementia who live alone, either descriptively or in comparison with people who have other living arrangements. Where study participants were described as having 'cognitive impairment', we included the article if the term cognitive impairment was being used to indicate undiagnosed dementia, but not if the cognitive impairment was due to another condition such as stroke or reflected a formal diagnosis of mild cognitive impairment. 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.

Grey literature

We searched for reports, practice guidelines, and publications containing information and advice about living alone with dementia. We applied advanced Google search parameters to selected condition-specific websites hosted by organisations in English-speaking countries and prominent global health and/or social care organisations. Full details of our methods are provided in the protocol[10] and in Appendix 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.

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

Consultation

The core project team included two members with lived experience, a former carer for her mother who had lived alone with dementia, and a man living alone with Parkinson's disease. Discussions with members of the DeNPRU Exeter stakeholder and FRIEND (PPIE) networks were held throughout the project. Dedicated consultation workshops were held online in November 2024, one with professionals and one with people with lived experience.

Prevalence estimation findings

There were 205,507 people recorded as living with dementia in 2023 in the Clinical Practice Research Datalink (CPRD) database. Living situation was documented in clinical notes for 68% of these people. For the remainder, we considered people to be living alone if they were the sole person from that address registered with the GP practice. This allowed us to classify living situation for 99% of the sample.

Our analysis showed that 41% of the people with dementia were living in a care facility. Of those residing in the community in 2023, 40% lived alone and 60% lived with others. This represents an increase from about 31% of people with dementia living alone in 2009, 15 years ago; see Figure A1.1.

We explored whether the proportion of people living alone or with others in the community varied by factors such as gender, age, region, ethnicity, deprivation level, and whether the GP practice was in an urban or rural area. As shown in Table A1.1, women and older people are more likely to live alone. People registered at urban GP practices and those living in the most deprived areas were more likely to live alone. Regionally, rates of living alone were highest in London, the Midlands, the North-East and the North-West. People of white ethnicity were more likely to live alone than those of Asian ethnicity, while individuals of black ethnicity were the most likely to live alone.

Using clinical records to estimate the prevalence of living alone has limitations. For example, assuming that someone lives alone if no-one else at their address is registered with the same GP might result in some over-estimation. On the other hand, if we take having someone else from the same address registered at the GP practice as our criterion for assuming people do not live alone, this could underestimate the number; in our analyses, using this criterion reduced the estimate to 17%, which is relatively low compared to other studies, as shown in Figure A4.4. Similarly, although the proportion of people living alone appears to have increased since 2009, we do not know whether this reflects a real trend or is due to better recording of living situation. These findings underscore the critical need for GPs, as well as other service providers, to routinely document the living situation of people with dementia and keep this information up to date. Better documentation would lead to more reliable data, helping to improve care planning and support for people with dementia who live alone.

In summary, our findings suggest that among people with dementia in the community in England, as many as 40% live alone, and this proportion may be growing. The findings also emphasise the importance of considering multiple dimensions of inequality when addressing the needs of those living alone, particularly in the context of health and social care planning for vulnerable populations.

Scoping review findings

After screening research records, we included 200 peer-reviewed journal articles (162 quantitative and 38 qualitative) reporting on 161 discrete research studies (128 quantitative and 33 qualitative). The flowchart in Appendix 3, Figure A3.1 summarises the screening process. We additionally identified through other sources four conference abstracts containing brief reports of two intervention studies. A full list of included articles can be found in the Supplementary Appendix.

The earliest paper we identified was published in 1962, and the next appeared in 1984. Subsequent publication trends indicate a growing interest in this topic, peaking during the COVID-19 pandemic; see Appendix 4, Figure A4.1. We noted when embarking on this project that two relevant systematic reviews were in progress in England, both focused on interventions. We collaborated with the team leading a review of nursing interventions aimed at informing the practice of Admiral Nurses and shared information with the lead author of the other review.

The geographical distribution of the research is summarised in Appendix 4, Figure A4.2. Four-fifths of the studies (129; 79.6%) were conducted in or led from Europe (92; 56.8%) or North America (37; 22.8%). There were 34 studies (23 quantitative and one qualitative) conducted solely in the UK and three cross-national studies (two quantitative and one qualitative) that included UK data. In view of possible international differences, where appropriate in what follows we have highlighted findings from the UK as particularly relevant to the English context.

Living alone was the primary focus of 61 (30.5%) articles, of which 25 (12.5%) recruited only people living alone. In 20 (10%) articles with a broader focus, comparisons according to living arrangement were included alongside other analyses or as sub-group analyses. The remaining 119 (59.5%) articles considered living arrangement only in terms of describing the study sample. The focus of the included articles is summarised in Appendix 4, Figure A4.3.

Across the studies which included people living alone alongside people with other living arrangements, the proportion of people living alone varied from 2.2% to 82.6%. Variability is to be expected given different approaches to sampling and participant recruitment, but even when considering only information from sources such as national registries and routine health data, considerable variability remains. This is demonstrated in the UK context where separate studies yielded estimates of 42% of those taking dementia medication in the community in Northern Ireland[5], 17.5% of those admitted to a care home in Wales[4], and 23.4% of people with dementia aged 75+ who were conveyed to hospital by ambulance in England[11]. Appendix 4, Figure A4.4 provides a summary of the proportion of people living alone with dementia recorded in studies based on clinical records, administrative health data, national registries and large surveys, and across all included studies.

The flowchart in Appendix 3, Figure A3.2 summarises the screening process for grey literature. The search covered a pre-selected list of websites of relevant organisations and targeted documents in pdf format that offered information, support or advice to people living alone with dementia, their carers, or to the health and social care professionals who work with them. The search yielded four resources containing advice for professionals and eight resources containing advice for people living alone and/or their families.

We additionally identified through other sources three reports linked to a US community funding programme[6,12,13], an Australian resource for service providers[14], and resources from a recently-completed NIHR-funded UK research project that had not yet resulted in published papers[15]. We held discussions with the lead researcher on this project.

Who is living alone with dementia and why?

People living alone with dementia are a diverse group. The nature and extent of their family and social networks, and hence availability of informal support from family or other sources, vary widely. They may have lived alone throughout their lives or may be widowed or divorced; for some, the onset of dementia itself may have contributed to relationship breakdown[16]. Some are in good mental and physical health while others experience long-standing challenges in these areas, including substance abuse. Financial circumstances, suitability of housing and the potential to access local resources likewise vary considerably.

It is undisputed, however, that worldwide there are more women than men living alone with dementia. This finding is evident in all 35 studies reporting sex distribution, including 4 from the UK. Many of these women will be living alone following death of a husband. Most studies (25 of 30) including two from the UK[17,18] find that on average people living alone are older than those living with others, although a population-based analysis of people prescribed dementia medication from Northern Ireland[5] does not support this finding. There is little evidence about differences linked to ethnicity in the proportion of people living alone with dementia, and none from the UK. Compared to those living with others, levels of education (12 studies) and income (5 studies) are similar or lower, and UK evidence indicates that people living alone are slightly more likely to live in deprived areas[5]. A comprehensive UK study demonstrated that people living alone have higher levels of unmet need across multiple life domains[19].

Three important points arising from this evidence direct us to consider the issue of living situation through an inequalities lens. First, people living alone with dementia are more likely to be women and relatively older, possibly with a degree of pre-existing social disadvantage. Older women with fewer educational qualifications in the UK are the group least likely to be receiving support services[20]. Second, people living alone with dementia have more unmet needs than those living with others, with significant consequences for them and for health and social care services. Third, we have no evidence about related ethnic or cultural differences.

Inequalities related to dementia and health

People living alone with dementia do not differ to those living with others in terms of their dementia, but their circumstances and needs mean they require special consideration. Although research evidence overall suggests there are few clear differences specifically related to dementia or health status between people living alone and people living with others, there are some important indicators of inequality.

Comparing people living alone with dementia to those living with others provides little evidence for consistent differences in relation to dementia severity or symptoms, mental or physical health, prescribing of medication, or use of health care services; see Appendix 5. Where individual studies differ, this could be due to differences in participant recruitment or because samples are not well-matched. **The evidence does, however, highlight possible inequalities in relation to diagnosis and subsequent care.**

International literature from Europe and North America suggests that living alone may be linked to inequalities in timeliness and precision of diagnosis. Four of five studies exploring timeliness found people living alone were diagnosed later. Symptoms of dementia may be less readily recognised by family members or GPs in people living alone[21-23]. One study found that in specialist services people living alone received less detailed assessments, with fewer scans and less neuropsychological testing, and less precise diagnoses[24]. There may also be differences in patterns of prescribing cholinesterase inhibitors and memantine[5].

Once diagnosed, people living alone have more unmet needs, for example relating to cognition, physical health, mobility, eyesight and hearing[19,25]. Highlighting that the needs of people living alone can also be different to those of people living with others, there is some evidence that they may respond differently to interventions. Participation in intervention trials often requires close involvement of a carer, which means many people living alone are excluded, and where they are included, results are rarely disaggregated to allow a comparison of outcomes based on living situation. We found three trials that suggested differences in outcome for people living alone. They were more likely to improve physical performance during rehabilitation after hip fracture[26] but less likely to benefit from a cognitive training programme[27]. In the German DelpHi trial of dementia care management, 50% of participants lived alone, and while some outcomes were positive overall, quality of life improved only for those living with others[28].

Rates of hospitalisation do not differ, but when people living alone go into hospital, it is a consistent finding that they are less likely to be discharged home. Most studies find that rates of institutionalisation are higher for people living alone, and in a UK study institutionalisation became more likely over time[7]. Qualitative studies indicate that many people living alone with dementia find the prospect of moving into a care home frightening or unbearable[29,30], and institutional living may be particularly challenging for people used to living alone. People living alone are more likely to die in hospitals or long-term care settings[31,32], suggesting possible inequalities in provision of end-of-life care.

Inequalities in informal support

These inequalities in diagnosis and care are likely to be linked to inequalities in availability of informal support. We can broadly think of people living alone as having either frequent support, some support, or no support (Knowles 2018). People living alone with dementia who have some informal support may have an identified carer, not necessarily near at hand and possibly in a different area, country or continent; often this is an adult child[33] whereas carers of those living with others are more likely to be spouses[19,34,35]. Those who have no identified carer often receive some informal support from various sources including relatives, neighbours and friends[36]. Relative to those living with others, the amount and adequacy of support these people receive is lower, with carers contributing fewer hours of care. In one US study 64% of those living alone felt the support they received was inadequate[37], while in the UK fewer than half of those living alone were visited daily by a carer[38].

Some people living alone with dementia have little or no informal support; they may have no family at all, or no relatives who are willing or able to provide care. **In the UK IDEAL cohort[17], 18% of those living alone (3% of the whole cohort) had little or no informal support.** As the cohort consisted of people with a medical diagnosis of dementia recruited through health services, the true proportion lacking informal support may be considerably higher. In a smaller UK study, the proportion with little or no informal support was 15%[39]. Studies in other European countries provide a point of comparison, with rates of 5.3% in Spanish memory clinic attenders[40], and 9.2% in a German study[41], a figure which included a preponderance of women, many unmarried and childless. **This study also highlighted that 6.9% of those living alone had no-one they could count on to help in an emergency at all, and another 9.3% had no-one who could respond within 24 hours.**

People living alone in difficult circumstances with no support are most likely to experience significant disadvantage. As they are also least likely to be included in research studies, these numbers may be an underestimate.

Inequalities in the experience of living alone with dementia

People living alone are at greater risk of experiencing loneliness and isolation. Two studies, one from the UK, concur that people living alone experience greater loneliness than those living with others[42,43] and the loneliness is more likely to be severe[43]. Social networks are similar in size or smaller[43], and people have less social support[41] and more unmet need for company[19]. People living alone are less likely to participate in social and cultural activities[17]; in a US study only just over half of those living alone went out for entertainment and only a quarter attended clubs or social activities[44]. Diminishing abilities and loss of confidence result in greater restrictions and fewer social interactions, and for some, the television or looking out of the window provide the only source of company[29,45].

This can lead to a sense of purposelessness and lack of meaning in life[46-50]. Although there was no evidence of differences in quality of life ratings across 11 studies, one UK study found lower scores for satisfaction with life[17], especially among those with little or no support. People with dementia experience various losses in their lives that affect their independence and sense of who they are, and the emotional impact of these may be felt more profoundly when living alone[29,46,47,51,52].

Inequalities in managing everyday life

Connected to this, people living alone experience greater challenges in managing everyday life at home. Although levels of functional ability and independence are the same or higher, living alone places additional demands on abilities and resources, resulting in more unmet need in relation to everyday activities, household tasks and self-care[19,25]. People living alone are more likely to buy in social care services to cover household tasks such as cleaning or food preparation, meal delivery services, or support for personal care, but this comes at a cost and is only available to those who can afford it. There may be gender-based inequities; a Swedish study noted that women living alone were less likely to receive home care than men living alone[53].

People living alone with dementia participating in qualitative studies describe the strategies they use to manage by themselves, including careful planning, following a set routine, writing things down, allowing extra time, and finding ways to stay active and socially engaged[29,46,47]. They acknowledge the paradoxical importance of asking for and accepting help to maintain their autonomy. Our grey literature search identified eight resources providing advice for people living alone with dementia and their families, five from the UK[54-58], two from Canada[59,60] and one from Australia[61]. These offer advice on managing at home (organising the home, staying safe, food and meal preparation), social networks (building a support network, support from professionals, support from family and friends), financial independence and safety, avoiding falls and using assistive technology.

People living alone are more likely to use assistive technology than those living with others[62]; in a UK study[17], 82% of those living alone used some form of assistive technology, compared to 63% of those living with others. Specifically, they were more likely to use memory aids (28% vs. 11%), fall prevention aids (40% vs. 11%), aids to support activities of daily living (65% vs. 50%), and mobility aids (60% vs. 44%). Another UK study noted that people living alone were more likely to have safety-related products such as pendant alarms and smoke alarms whereas those living with others were more likely to have devices to track their whereabouts if they were lost[38]. User-activated social alarms that enable people living alone to call for help in an emergency are common[62], but their utility has been questioned; many people with dementia when asked did not know they had one, and one-third of carers thought they were of no value[63].

As dementia progresses coping strategies become harder to implement, especially where more complex tasks such as managing finances are involved[64], and people living alone may become less willing to seek or accept help and more suspicious of the intentions of others[65,66]. Over time, difficulties arise with self-care, hygiene and nutrition[66-68], with problems due to not eating or drinking most frequently causing concern[69]. Safety at home is more compromised and people are at increased risk of harm through their own actions, such as inadvertently starting a fire, and more vulnerable to crime[66,70]. In the event of an emergency, they are less likely to be prepared and to have evacuation plans or emergency supplies[71]. They go missing with the same frequency as those living with others[66] but are more likely to die before they are found[72,73].

Implications for family members and practitioners

Evaluating and managing risk is a key concern for family members involved in providing or arranging care from a distance. Family members are generally supportive of the person's preference to remain at home, try to balance the perceived risks of living alone against the risks associated with institutionalisation[30,74], and are willing to live with a degree of 'acceptable' risk. However, over time 'red flags' such as observations of weight loss, changes in personal hygiene, a build-up of unwashed laundry, a failure to return phone calls, or suspected exploitation or financial abuse mark the transition from acceptable to 'unacceptable' levels of risk. This is compounded where the person with dementia resists measures aimed at increasing vigilance such as bringing in paid carers[30,74,75] and where it is difficult to find trustworthy paid carers[76].

Practitioners involved in supporting people living alone with dementia grapple with the dilemma of 'safety and supervision versus risk and independence' and the challenge of finding the best balance[77] in a situation where 'few decisions are perfect'[78]. Decision-making is especially hard where there are communication difficulties or a lack of awareness of difficulties and needs[79], or the person's capacity is in question. Practitioners identify concerns about diminishing inability to manage everyday living including personal care, medication, communication, meal preparation, household tasks, shopping, transport, managing finances and staying socially connected[80] as well as risks connected with poor hygiene, malnutrition, fire hazards, wandering, possible abuse or exploitation, and reductions in family support due to changed circumstances. Practitioners find it challenging when family members do not understand dementia or view the person as needing help, or where there are tensions among family members about the best course of action, or where their own commitments or health issues preclude them being involved[50,77]. They often feel constrained by systemic limitations such as inflexible service structures, cutbacks and resource shortages[78] which impede their ability to support people with dementia living at home.

Implications of living alone for costs of care

We identified 13 papers outlining nine distinct studies that examined costs of care for people with dementia who lived alone. Of the nine studies four were from the UK[18,81-84]; the remainder were one each from South Korea[85], China[86], Japan[87], Germany[88-91] and Finland[34]. The majority were cohort studies comparing individuals with dementia or cognitive impairment either living alone or living with others, and some included care home residents. Only one paper compared the cost-effectiveness of an intervention for those living alone and those living with others[90]. Whilst the evidence relating to costs was generally sparse, there was relatively good consensus within the available evidence across geographical locations.

Health and social care

In respect of formal services, health and social care costs are higher for those living alone than for those living with family and friends but less than for people in care homes[18,81,84,85,88,89]. Estimates of the magnitude of the difference varies. For example, one study estimates a 35% higher cost of health and social care for those living alone compared with living with others[83] whilst another study estimates health care (including lost productivity) to be three times more costly for those living alone[34].

The drivers of these differences are myriad. Those living alone tend to have a higher probability of admissions to care homes and hospitals[84]. Social care packages tend to be larger or more intensive, and thus more costly, for those living alone compared to those living with others[18]. Costs of packages are primarily driven by home care but services such as day care can also be costly drivers[34].

Societal perspective

If we widen out the costs to include the value of informal care and out of pocket costs, the picture changes. Societal costs (health and social care, out of pocket costs and unpaid care) are *lowest* for those that live alone compared to those in a care home or living with others[81]. The value of informal caring provided by co-resident carers is high, and the cost of social care packages for those living with a carer is relatively low when compared with people with dementia who live alone[18,81]. The observation of higher home care costs for those living alone supports the notion that care for people with dementia has shifted from the social care sector to informal caregiving where a family member is available[34].

The use of societal costs, whilst acknowledging the value of provision of informal care by family and friends, risks masking the higher health and social care costs for those living alone compared to those living with others. It is important to note that the cost of residential care typically exceeds the cost of domiciliary social care, but when the costs of social care and informal care are combined, the situation becomes less clear.

Catastrophic expenditure

Catastrophic expenditure is defined as expenditure that exceeds a specific proportion of a household's income[92]. Living alone with dementia or cognitive impairment can have a high burden of catastrophic expenditure [50]. However, the limited evidence, from a single study, is based on the cost of health care to the individual and their family, so has less relevance to the UK with its universal, free at the point of access health system.

Cost-effectiveness

One study assessed the cost-effectiveness of collaborative dementia care management (DCM) vs usual care[90]. Based on the German DelpHi trial (n=444), in addition to the main cost effectiveness a secondary analysis was undertaken based on living situation to assess who benefits most from DCM; 50% of participants lived alone. The analysis was undertaken from the health system (public payer) perspective. Dementia care management was shown to be cost-effective compared with usual care due to a lower hospitalization rate and delayed institutionalization (7 months). The probability of DCM being cost-effective overall was 88% at willingness-to-pay thresholds of 40,000€ per QALY gained. When results were disaggregated the probability of DCM being cost-effective was higher in people living alone compared to those not living alone (96% vs. 26%).

Improving support for people living alone with dementia

The large body of research summarised in this review provides evidence that **people living alone with dementia have not only more unmet needs but also different needs to those living with others**. Despite this, **few of the identified studies explored ways addressing these needs, reducing inequalities and better supporting people who live alone**. In this section we discuss the available evidence on interventions designed to address the needs of people living alone with dementia and consider the application of assistive technology. We then turn to accounts of community-based programmes addressing the support needs of people living alone and discussions of what constitutes good practice on the part of service providers and practitioners.

Approaches designed specifically to address the needs of people living alone

Through other sources we identified two small-scale studies reported in descriptive accounts, conducted in the USA by the same researcher. The first described a virtual support group for 12 recently diagnosed individuals living alone with dementia, most of whom had no identified carer, finding that participants increased understanding of dementia and care planning, felt empowered to manage the condition and had sense of greater social support[44,93]. In connection with this, one of our lived experience participants told us about her experience of leading northern and southern hemisphere virtual support groups for people living alone with dementia through Dementia Alliance International. These started because **comments from those living with others about having good back-up from family members led people living alone to point out that 'it's different for us'.**

The second was a proof-of-concept study aimed at establishing feasibility of a case management intervention, Services to Age in Your Home (STAY Home), to increase utilization of health and social care services for people living alone with dementia or cognitive impairment[94,95]. This social work-led study targeted some of the most vulnerable individuals, identified for example because they frequently called emergency services for inappropriate reasons. Only 42% of participants had seen a service provider of any kind in the last year, only 33% had been in contact with health services, most had very limited social support, and there were high levels of unmet need. Twelve participants received a weekly in-person visit by a social worker for 12 weeks. Adherence was good and quality of life scores improved post intervention, but increasing access to formal services remained challenging due to distrust and limited financial resources coupled with long waiting lists for services. Increasing use of services in this way might add to costs in the short term but could be cost-effective over a longer period. Although not specifically designed for people living alone, as noted above, sub-group analysis of the German DelpHi trial described above showed that care management was likely to be cost-effective for people living alone.

A UK study of befriending for isolated individuals with dementia was not limited to those living alone but provided three case studies illustrating the way in which facilitated friendships can contribute to addressing unmet needs for social contact among people with dementia living alone[96]. A case study from China[97] implemented a personalised, intensive community-based social care intervention incorporating support for socialising, non-pharmacological interventions and family and community education for an individual living alone. The intervention was not designed specifically for people living alone, but the case study demonstrated the application of this approach to enable an isolated person living alone with dementia to reintegrate into the community and maintain functional ability.

Assistive technology

Assistive technology can potentially be applied to enable people to continue living alone and alert carers or service providers to changes that might signal an emergency. We found a few small-scale studies describing the use of such technology specifically for people living alone. The relatively small number of studies may reflect the need for caution as adopting and using various forms of assistive technology may require input and oversight from a carer or other supporter. It is essential to ensure that any assistive technology deployed is fit for purpose and useful, and this is not always the case[63].

In-home monitoring systems involve placing sensors in key areas of the home that identify activity and movement and send details to an online platform, without requiring active involvement of the person with dementia. This makes it possible to build a picture of the person's daily routine and typical activities which helps with care planning and makes it possible to detect changes in routine that may indicate an emergency. One report describes use of the Just Checking system in the UK by the NHS and local authorities, and provides illustrative case studies[98]. A recent UK pilot study explored the use of a digital plug that monitors use of a routinely-used appliance such as an electric kettle, finding this was acceptable to participants[99]. In a Dutch study where a monitoring system was installed in the homes of 63 people with dementia who lived alone, carers and case managers indicated that they found the system helpful; people with dementia were not interviewed, but were said to have been largely unaware of the system[100].

Other monitoring approaches require more direct engagement of the person with dementia. In a small US study[101] participants living alone were contacted by a nursing assistant according to their medication schedule, either using a video system or by telephone, and prompted to take their medication, which appeared to stabilise medication compliance and cost less than home visits. A case study from Japan described how an information support robot that monitored activity and provided information about the day's schedule alleviated restlessness in a person living alone with dementia[102].

Community-based programmes

Community agencies play an important role in supporting people with dementia and may be well-placed to understand and address the specific needs of people living alone. An early demonstration of this was a programme run by the Alzheimer's Association of Los Angeles which focused on support for long-distance carers of a person with dementia[76]. This was not limited to carers of people living alone, but approximately a quarter of the care recipients did live alone. The programme involved carers working with a family consultant, which could include provision of written information, appropriate referrals, a home visit to the care recipient, and personalised follow up. Carers also had access to a guide to local resources, a website, telephone-based legal consultations, and a system for returning individuals who become lost. Satisfaction with this service among participating carers was high.

A recent US initiative demonstrated the potential value of supporting community agencies to address the needs of people living alone with dementia. The US national Plan to Address Alzheimer's Disease identified provision of services for people living alone as a key gap. This formed one target of the US Department of Health and Human Services Alzheimer's Disease Initiative – Specialised Supportive Services (ADI-SSS) programme which awarded grants to community-based and state agencies from 2014 to 2017. Of 29 organisations that completed and reported on their projects by 2021, 25 focused on services for people living alone[13]. The evidence-based or evidence-informed initiatives implemented included case management or care navigation, implementing referral systems to make it easier for people to access services and support, creating adult day programs, developing assessments to monitor progression of symptoms. Additional activities included training professionals, supporting and educating carers, providing information for people with dementia, and promoting community awareness. Across all the initiatives, providers found that the needs of people living alone with dementia were more extensive and complex than initially expected, requiring more input from qualified staff, and that approaches and systems needed modification, for example allowing more time for engaging and building trust and checking in with people more frequently, and simplifying data collection. Sustainability of the initiatives was achieved through developing community partnerships and working groups, creating information resources, securing further funding from other sources, and charging fees for programme elements such as day care for those who could afford to pay.

Linked to this, we were put in touch with Splaine Consulting, an organisation with a strong focus on supporting people living alone with dementia. They hold community summits across the USA and online to learn from people living alone and enable communities to come together and engage in action planning to better support people living alone[103]. They also support the 'Living alone and connected' Facebook group for people living alone with dementia[104].

Key elements of good practice for service providers and practitioners

Several resources set out key elements of good practice in supporting people living alone with dementia[12,14,105,106] that could be implemented by service providers and practitioners. These can be grouped under five headings:

1. Knowing who is living alone with dementia

Commissioners of services should be aware of this group and estimate the likely number of people in their area living alone and especially living alone with no support. Service providers should include this information in record systems and ensure it is available to the teams and individual practitioners involved. Connections between services and among community members can be crucial to identifying people living alone with dementia with no support. Emergency services may be the first point of contact with someone in this situation, while for many older women the hairdresser may be one of few regular contacts and the first to recognise needs. Making the public aware that people can and do live alone with dementia and how to help could be an important step.

2. Developing tailored care pathways or adapting existing pathways

People living alone will require a higher level of case management, with a named person co-ordinating care and provision of support services and more frequent contact. Short, regular interactions are recommended, and home visits can be especially informative. Continuity of care is vital, and services should not discharge people in this situation. If onward referrals are made, these should be followed up to ensure support is in place before withdrawing. Similarly, any signposting to community support should be followed up rather than assuming it has been acted on. People living alone have different patterns of need, and support requires a different approach compared to what is suitable for people living with others. For example, there may be a greater need for emotional support, and absence of a live-in carer will affect the selection of practical strategies or assistive technologies. They may need someone to accompany them to groups or activities initially and assistance with finding transport options. Flexibility to respond to individual needs is essential.

3. Ensuring services and facilities are inclusive

Facilities should be accessible and welcoming for people attending alone. It is wrong to assume that people living alone cannot benefit from certain types of support, for example goal-based reablement or rehabilitation approaches; instead, it is important to consider how any approaches to support or intervention can be adapted for people living alone, and or what additional measures might need to be put in place to enable them to access these. Community providers often exclude people who have no carer due to safeguarding and other concerns, so there is a need to find ways of promoting inclusion.

4. Building relationships and trust

People living alone, especially those with little support, may value their privacy and fear that services will remove them from their homes. Building relationships and trust needs to start as early as possible and can take time. Focusing on what is important to the person, and on capabilities and strengths, is helpful. Practitioners can focus on developing a support network around the person and enhancing its resilience through sharing information by agreement.

5. Managing risk

Addressing the above four points will facilitate the capability to make good decisions and uphold people's rights when it comes to balancing autonomy and risk and evaluating capacity. Planning for future needs, understanding a person's wishes and implementing specific processes such as the Herbert Protocol soon after diagnosis can help to avoid crises and support the person's preferences. Our grey literature search identified resources to support practitioners and guide decision-making about the ability of a person with dementia to continue living alone at home[107-110]. Where this is not feasible, it is important to support necessary transitions to new settings.

Consultation findings

People with lived experience

In November 2024 we held an online workshop with two people living alone with dementia and a former carer who provided support for a person living with dementia from a distance. They told us that personalised, high-quality dementia care that promotes independence should be available for everyone with the condition, but extra flexibility is needed where someone lives alone. Previous experience of living alone can help prepare people for coping with dementia:

> *'When the extra challenges [of dementia] came on, I looked to adapt to that.'*

Strategies include knowing the importance of developing good networks, making sure relevant people or organisations are aware of the situation, and establishing good relationships with people who can help look out for you, possibly including the local police:

> *'It's for my protection. It's necessary – or I feel it's necessary for my protection.'*

However, many people are not well equipped to manage the challenges of living alone with dementia, and awareness among service providers, practitioners and people in public-facing roles in the community can be limited. Carers, especially if they live at a distance, may be less likely to receive support than co-resident carers.

For a person living alone, there is no-one to act as a spokesperson. There are major difficulties with accessing services and support, especially as community groups often require people to be accompanied by a carer. It is hard to navigate the system and find the right services and support:

> *''There are so many agencies that we're trying to beat our way through... they don't communicate with one another, it's so hard to juggle the different professions and to know how to find your way through the system to get the support that you need.'*

There is a need for a named person or advocate who can work with people living alone and help them 'tie up all the loose ends'. People living alone with dementia also need support during medical appointments, which can often feel rushed and pressurised:

> *'When you're in that position where you're the patient and you know their timer is running as soon as you walk through the door, the pressure's on. You know you've only been allocated a maximum of about 10 minutes so you're in a very vulnerable situation.'*

Co-ordination and communication between health and social care services is essential so that professionals are aware of peoples' circumstances and can tailor support appropriately. The way in which services communicate with people living alone with dementia also needs consideration. One of our participants had positive experiences with a GP who communicated by text and email and provided a written record of what was discussed during appointments. Others found GPs failed to register their living situation and offered no choice about communication methods, forcing them to use complicated health apps and phone calls, which they found difficult. When caring at a distance it is helpful to receive copies of appointment letters, but this may not happen, meaning appointments are missed and potentially leaving the person with dementia distressed when 'nasty' letters follow complaining about non-attendance. Adapting communication methods to suit people's needs is essential.

Finally, our participants commented that people living alone with dementia have been routinely left out of research, and this must change:

> *'Stop researchers from excluding people living alone with dementia from research.'*

Professionals

In the early stages of the project, we held one-to-one meetings with professional stakeholders to find out about specific provision for people living alone with dementia and how living alone status might be recorded. These stakeholders were an NHS commissioner, a GP, and a regional community-interest company officer who had worked on a two-year project with local police to better support those living with dementia.

In November 2024, once the scoping review had been completed, we held an online workshop with nine health and social care professionals: three occupational therapists, one advanced clinical practitioner, one social prescribing link worker, one integrated practice support officer and three third sector service providers. We asked them to consider two main questions: how they know or find out that someone is living alone, and what needs to change to better meet the needs of people living alone.

Practitioners may only find out that someone is living alone incidentally, for example when called out to a home visit or when neighbours raise concerns. Living situation is recorded by some agencies and in some systems, but the information may be 'hidden in case notes' or otherwise difficult to access and may not be updated if a person's situation changes. Differences in systems mean the information is often not shared even when this would be relevant and useful. Shared systems that could communicate with each other would help to ensure information is recorded and passed on, and if there is a carer, also potentially linked it to the carer's own record.

> *'As we don't share the same systems it can be difficult to pass on information.'*
>
> *'If people don't have children this can delay concerns being raised'*

Commissioners need to know how many people are living alone with dementia in their area and should require services to meet the needs of this group. Services should be in regular contact with people who are living alone with dementia. This could be achieved through various means, such as regular check-ups with the GP, GPs inviting people in who have not been in contact for a long time, improving systems such as annual dementia reviews that do not work well, or simply implementing the NHS health check. There should be capacity for regular follow up, such as telephone welfare calls, to ensure continuity. It is important to build a relationship so that the person feels confident to ask for help, and to break down the stigma around asking for help. Home visits are valuable as they can expose difficulties that are not evident over the telephone or at an appointment, such as self-neglect or hoarding. The fire service offers home safety checks and is highly trusted and able to 'get behind closed doors'.

'Know your numbers – if you know how many people with dementia you've got on your patch, make the time to find out how many of those are living alone.'

'I feel it's the people living alone who are seen once they are in crisis and get admitted.'

Some of the most isolated people, and an underserved group, are those with mental health or addiction issues and low health literacy. Some may not wish to have services involved. Professionals can face ethical dilemmas in balancing the person's rights to choose against perceived risks.

'Is it our right to decide their home is unsuitable?'

Social support is crucial for keeping people at home and facilitating safe discharge from hospital. There needs to be a network of support workers and befrienders, and community groups that the person can get to and are not time-limited. People living alone in particular need support to navigate the care system and connect with services and networks.

'We need to be better connecting people to services and networks that do exist and particularly people that live alone. Who does that care navigation for them? Who supports them to be aware of what's available in the local area? What if they find a really good group that stops running? Who takes the time to connect them to another group?'

Involving the many key people in local communities who may be in contact with people living alone, such as hairdressers, church leaders, postal workers, taxi drivers, and newsagents, could help to form a network of support. Finally, it was emphasised that people living alone with dementia need appropriate housing options and adequate financial support, and that provision of self-help resources would help to reduce the likelihood of crises.

Policy implications

With demographic changes resulting in as many as 40% of people with dementia in the community living alone, a trend that is likely to increase, it is time to pay attention to the implications of this shift. This means, in effect, that **we need to start thinking differently about how to support people with dementia**. In this report we have **highlighted living alone with dementia as an issue of inequality**. People living alone with dementia have more needs, and different needs, to those living with others. This is especially the case for those with more limited informal support, perhaps from family at a distance, and for those who have little or no informal support.

People living alone with dementia are likely to be diagnosed later, receive less formal support, and move into residential care sooner. They experience greater loneliness and isolation and more challenges in managing everyday life. They are less likely to be discharged home from hospital or to die in their own home. Individuals living alone, or their families, incur greater costs for care while costs to the state tend to be lower overall than for people living with others. Inequalities arising from living alone intersect with other sources of inequality, such as older age, female sex and ethnicity; we know for example that older women are less likely to receive services. Those living alone with dementia who have multiple mental or physical health problems or addictions, limited resources and low health literacy are an underserved group with especially high levels of need.

This has important implications that can be addressed through policy innovation. Here we highlight four key areas.

- **Knowing the numbers.** A first step in addressing these issues is for commissioners to know, or estimate, how many people are living alone with dementia in their area, and for practitioners and providers to record living situation and appropriately share this information among agencies and professionals involved.

- **Making services more responsive.** Dementia services are not typically designed around the needs of people living alone, especially those with little or no support. The specific needs of people living alone with dementia must be acknowledged so that services and pathways can be adapted or developed to ensure they are suitable for and accessible to this group, offer flexible approaches to engagement and communication, proactively maintain contact, and provide continuity and where necessary supported transitions. GPs and primary care teams have a crucial role to play and need to ensure people can access and benefit from their support, with good communication a fundamental prerequisite. Navigating health and social care services is especially challenging for people living alone, and support with this is crucial. Even small adjustments can make services more inclusive, for example offering double GP appointments to allow more time and being flexible enough to communicate in the way that works best for people. We already know a good deal about the characteristics of good statutory service provision for this group, meaning that changes could be implemented in a short timescale.

- **Strengthening community responses.** The challenges facing distant carers, who are not typically well supported, must be acknowledged and support options made available. Provision of good social support is crucial. There is great potential to involve and support community agencies to address the needs of people living alone with dementia, strengthen community networks and support, and improve public awareness and understanding.

- **Making research inclusive and practically relevant**. People living alone with dementia are often excluded from research, especially intervention trials, despite evidence that they may respond differently to some treatments. It is important to ensure people living alone are included. A considerable amount of research has explored the characteristics, experiences and needs of this group, and arguably there is little need to fund further research in this area. In contrast, there has been little attention to research on effective ways of supporting people living alone or implementing changes in services or pathways to better meet their needs. This would be a valuable focus for future research efforts.

Recommendations

We recommend the following actions are implemented.

Knowing the numbers

- All ICBs identify or estimate how many people are living alone with dementia in their area and use this information to commission appropriate service pathways.
- Systems are designed to facilitate up-to-date recording of living situation and informal support, and this is routinely recorded, so that information regarding living alone is accessible and can be shared appropriately among agencies and professionals.

Making services more responsive

- NHS dementia services articulate how provision and pathways are designed or adapted to meet the needs of people living alone with dementia, and how these features are implemented as part of routine practice.
- Practitioners are trained, equipped and supported to flexibly implement good practice for people living alone with dementia.
- Services proactively reach out to people living alone, including those unexpectedly transitioning to living alone due to bereavement or relationship breakdown.
- People living alone with dementia have access to a link worker or care co-ordinator who can assist with navigating NHS, social care and community provision, and identifying access and transport options.
- Services review their provision to ensure they are inclusive and welcoming for people living alone with dementia.
- All services, including GPs and primary care teams, communicate with people living alone with dementia in line with their preferences and offer written summaries following appointments.

Strengthening community responses

- Services and agencies that support informal carers are encouraged to engage with and offer support to distant carers of people living alone with dementia.
- Steps are taken to strengthen the capability of community agencies and groups to include people living alone and respond to their needs.
- Initiatives to increase public awareness and understanding of dementia include reference to people living alone with dementia.

Making research inclusive and practically relevant

- Researchers and research funders consider living situation as a key element of inclusivity in developing and conducting dementia research projects, ensure people living alone are included in research, and require sub-group analyses according to living situation where relevant and feasible.
- Research funders target funding towards actively developing and sustainably implementing good practice in supporting people living alone with dementia, and where relevant their families, and strengthening community agencies, networks and support.

Conclusions

The findings described in this report highlight the need for a paradigm shift in addressing the needs of people living alone with dementia. Increasing awareness is the first important step. We can make this paradigm shift a reality and reduce the inequalities resulting from living alone with dementia by acknowledging the scale of the issue, 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 dementia alone at home and increasing their capability to live well with the condition.

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Appendices

Appendix 1. Prevalence estimation methodology and results

We conducted a period prevalence study investigating living alone amongst people in England with a diagnosis of dementia. 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 dementia 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 not residing in a care facility such as a care home or hospice, were not a long-term hospital in-patient, 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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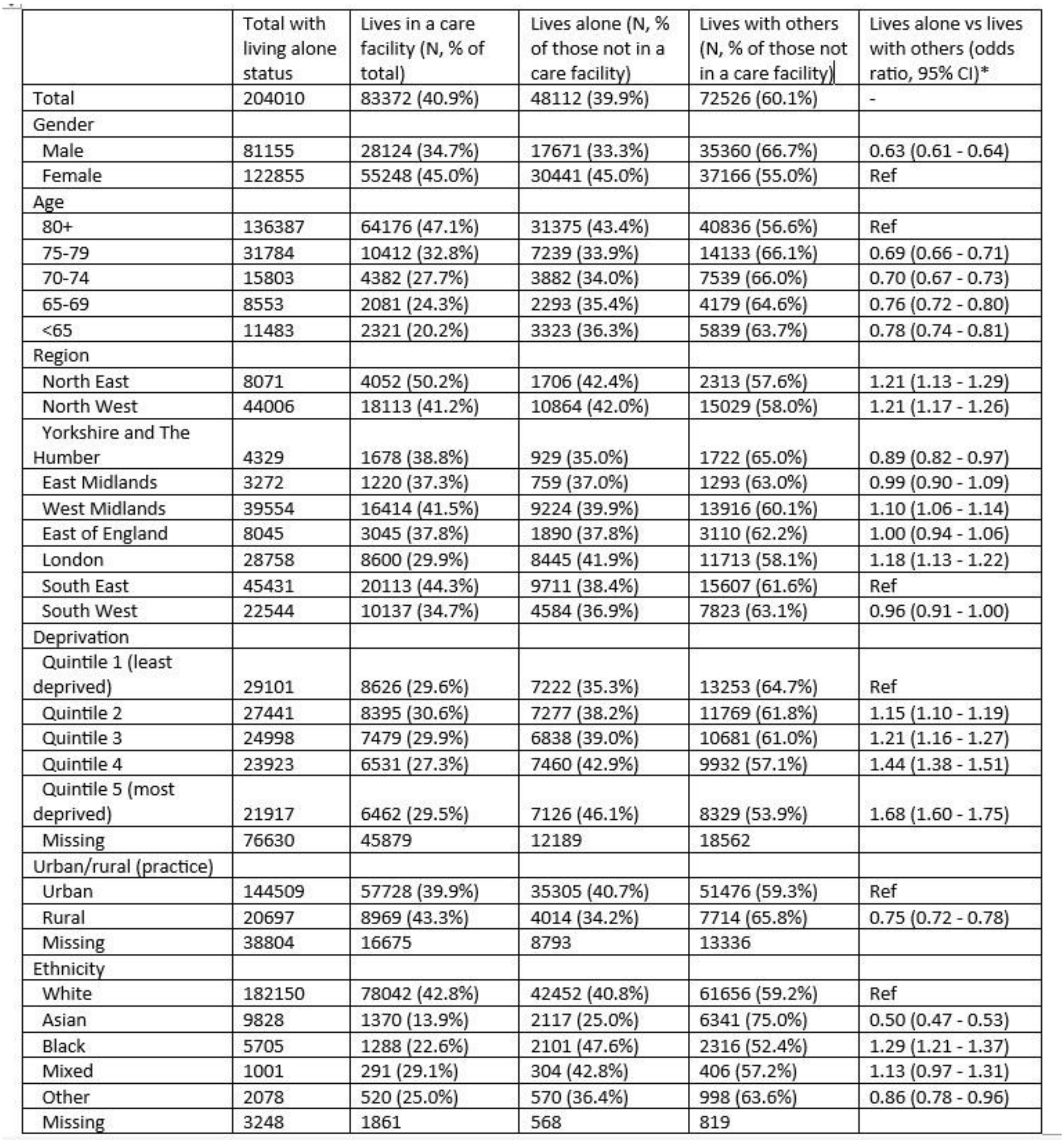
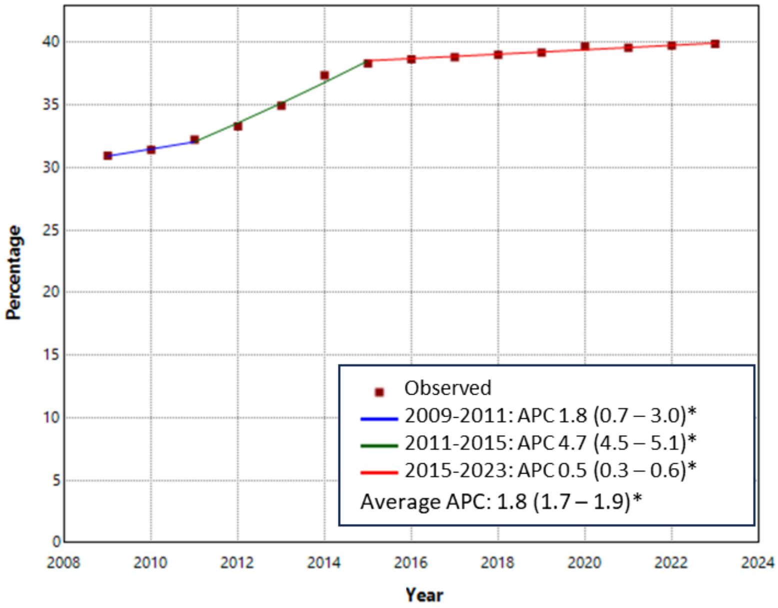
Table A1.1 Living situation of people with dementia in 2023 stratified by measures of inequality



	Total with living alone status	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	204010	83372 (40.9%)	48112 (39.9%)	72526 (60.1%)	-
Gender					
Male	81155	28124 (34.7%)	17671 (33.3%)	35360 (66.7%)	0.63 (0.61 - 0.64)
Female	122855	55248 (45.0%)	30441 (45.0%)	37166 (55.0%)	Ref
Age					
80+	136387	64176 (47.1%)	31375 (43.4%)	40836 (56.6%)	Ref
75-79	31784	10412 (32.8%)	7239 (33.9%)	14133 (66.1%)	0.69 (0.66 - 0.71)
70-74	15803	4382 (27.7%)	3882 (34.0%)	7539 (66.0%)	0.70 (0.67 - 0.73)
65-69	8553	2081 (24.3%)	2293 (35.4%)	4179 (64.6%)	0.76 (0.72 - 0.80)
<65	11483	2321 (20.2%)	3323 (36.3%)	5839 (63.7%)	0.78 (0.74 - 0.81)
Region					
North East	8071	4052 (50.2%)	1706 (42.4%)	2313 (57.6%)	1.21 (1.13 - 1.29)
North West	44006	18113 (41.2%)	10864 (42.0%)	15029 (58.0%)	1.21 (1.17 - 1.26)
Yorkshire and The Humber	4329	1678 (38.8%)	929 (35.0%)	1722 (65.0%)	0.89 (0.82 - 0.97)
East Midlands	3272	1220 (37.3%)	759 (37.0%)	1293 (63.0%)	0.99 (0.90 - 1.09)
West Midlands	39554	16414 (41.5%)	9224 (39.9%)	13916 (60.1%)	1.10 (1.06 - 1.14)
East of England	8045	3045 (37.8%)	1890 (37.8%)	3110 (62.2%)	1.00 (0.94 - 1.06)
London	28758	8600 (29.9%)	8445 (41.9%)	11713 (58.1%)	1.18 (1.13 - 1.22)
South East	45431	20113 (44.3%)	9711 (38.4%)	15607 (61.6%)	Ref
South West	22544	10137 (34.7%)	4584 (36.9%)	7823 (63.1%)	0.96 (0.91 - 1.00)
Deprivation					
Quintile 1 (least deprived)	29101	8626 (29.6%)	7222 (35.3%)	13253 (64.7%)	Ref
Quintile 2	27441	8395 (30.6%)	7277 (38.2%)	11769 (61.8%)	1.15 (1.10 - 1.19)
Quintile 3	24998	7479 (29.9%)	6838 (39.0%)	10681 (61.0%)	1.21 (1.16 - 1.27)
Quintile 4	23923	6531 (27.3%)	7460 (42.9%)	9932 (57.1%)	1.44 (1.38 - 1.51)
Quintile 5 (most deprived)	21917	6462 (29.5%)	7126 (46.1%)	8329 (53.9%)	1.68 (1.60 - 1.75)
Missing	76630	45879	12189	18562	
Urban/rural (practice)					
Urban	144509	57728 (39.9%)	35305 (40.7%)	51476 (59.3%)	Ref
Rural	20697	8969 (43.3%)	4014 (34.2%)	7714 (65.8%)	0.75 (0.72 - 0.78)
Missing	38804	16675	8793	13336	
Ethnicity					
White	182150	78042 (42.8%)	42452 (40.8%)	61656 (59.2%)	Ref
Asian	9828	1370 (13.9%)	2117 (25.0%)	6341 (75.0%)	0.50 (0.47 - 0.53)
Black	5705	1288 (22.6%)	2101 (47.6%)	2316 (52.4%)	1.29 (1.21 - 1.37)
Mixed	1001	291 (29.1%)	304 (42.8%)	406 (57.2%)	1.13 (0.97 - 1.31)
Other	2078	520 (25.0%)	570 (36.4%)	998 (63.6%)	0.86 (0.78 - 0.96)
Missing	3248	1861	568	819	

*Adjusted for age category and sex. We were able to determine living alone status for 204,010 of the people living with dementia in 2023. There were 22 people who were homeless; they were not included in further analyses. Care facility includes care homes, hospices and long term hospitals.

Figure A1.1 Trend over the past 15 years in prevalence of living alone with dementia (Joinpoint analysis)



By gender:	**Segment**	**APC (95% CI)**
Female	2009-2011	2.2 (0.8 – 3.9)*
	2011-2015	6.0 (5.6 – 6.7)*
	2015-2023	0.7 (0.5 – 0.9)*
Male	2009-2012	1.7 (0.4 – 2.7)*
	2012-2015	3.6 (0.5 – 4.1)*
	2015-2023	0.2 (0.0 – 0.4)*

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

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.

Search 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 A1 below.

Eligibility criteria

The populations of interest were people who lived alone with a diagnosis of a relevant neurodegenerative condition, irrespective of type, severity, or age. While dementia, Parkinson's, Huntington's, and motor neurone disease were specific targets in the search, studies that included people with rarer neurodegenerative 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.

Where study participants were described as having 'cognitive impairment', the article was eligible if the term 'cognitive impairment' was being used to cover probable undiagnosed dementia, but not if it reflected a formal diagnosis of mild cognitive impairment, as most people diagnosed with mild cognitive impairment either remain stable or revert to normal cognitive functioning for their age[111]. Studies that included people with people classified as "cognitive impairment not dementia" or "CIND", people with cognitive impairment due to head injury, stroke, or other acute insults, or people with multiple sclerosis were excluded. 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 shows the article selection and screening process; see Figure 1. 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 neurodegenerative 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.

Grey literature

Search strategy

The grey literature search covered a pre-selected list of 39 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 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:alzheimers.org.uk “Living alone” OR “Live alone” OR “Lives alone” OR “Lived alone” filetype:pdf

For the 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 dementia, their carers, or to the health and social care professionals who work with them.
- Addressed topics of relevance to people living alone with dementia, 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 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.

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

Dementia-specific websites

1. Alzheimer Europe
2. Alzheimer Scotland
3. Alzheimer Society of Canada
4. Alzheimer's Association
5. Alzheimer's Disease International
6. Alzheimer's Society
7. Alzheimer's Society of Ireland
8. All-Party Parliamentary Group on Dementia
9. Alzheimer’s Research UK
10. Dementia Australia
11. Dementia Society of America
12. Dementia UK
13. Lewy Body Dementia Association
14. Lewy Body Dementia Canada
15. Lewy Body Ireland
16. Lewy Body Society
17. Rare Dementia Support
18. World Dementia Council

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 Organisation (WHO)

Appendix 3. Flowcharts for literature searches

Figure A3.1 Flowchart showing the selection process for research articles

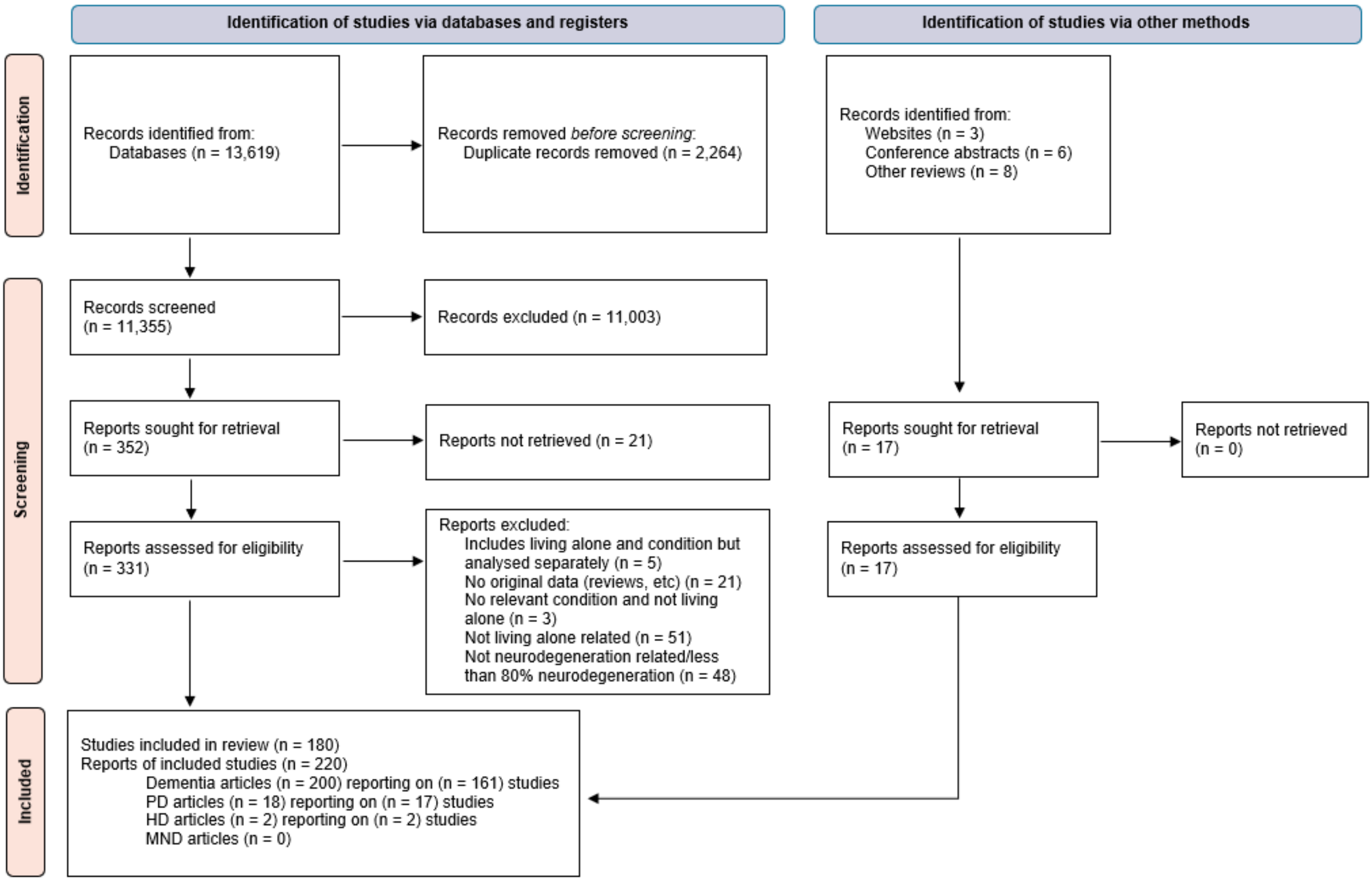
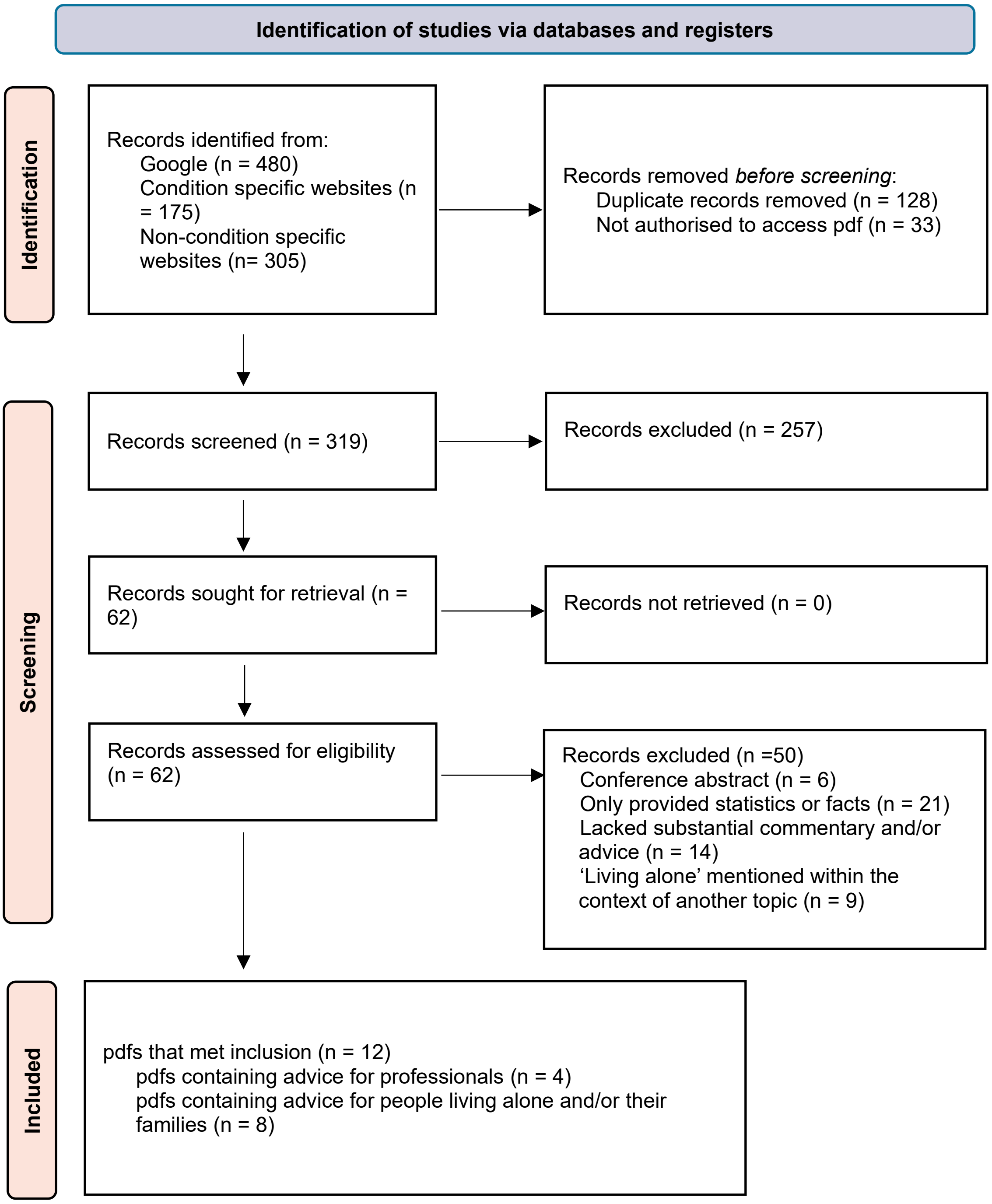


Figure A3.2 Flowchart showing the process of identifying grey literature



Appendix 4. Characteristics of studies included in the scoping review

Figure A4.1 Research articles included in the scoping review by publication date

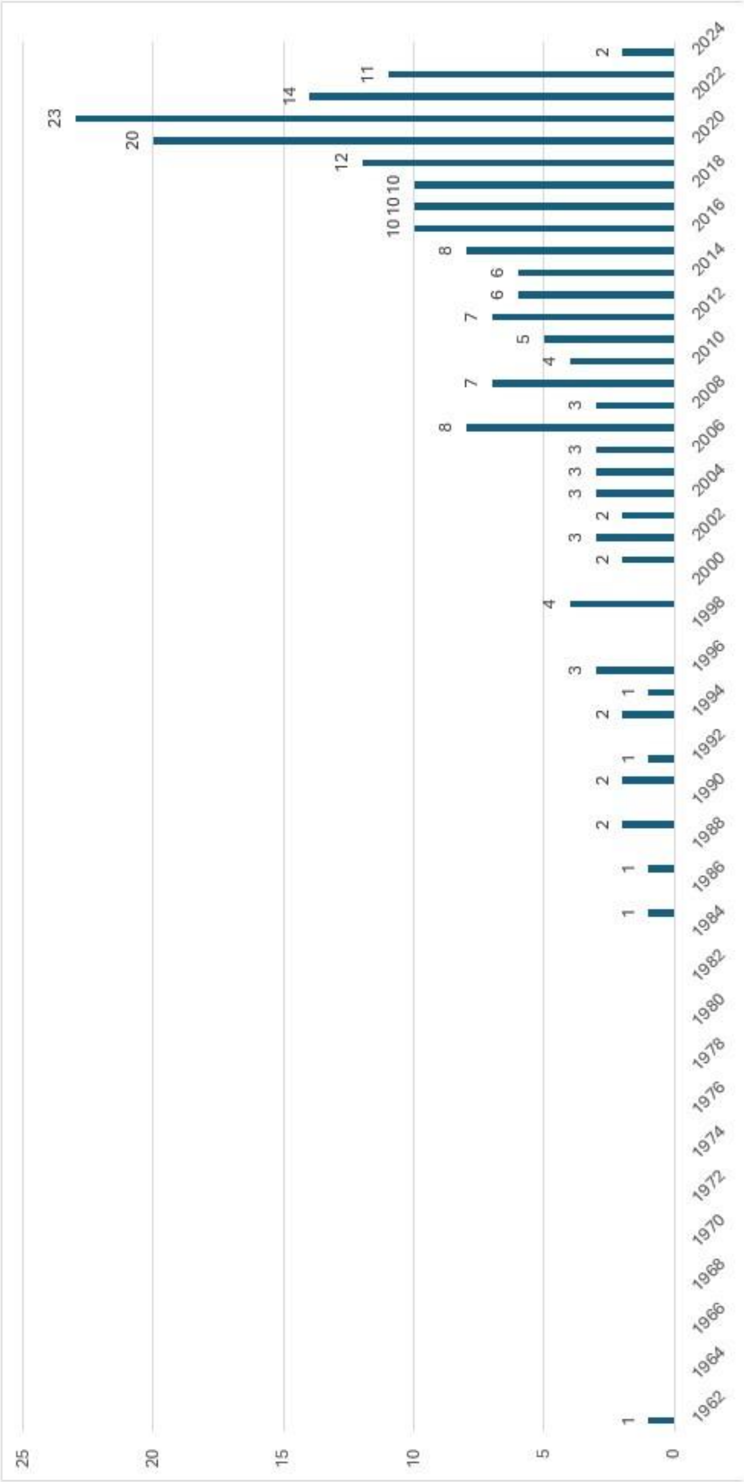
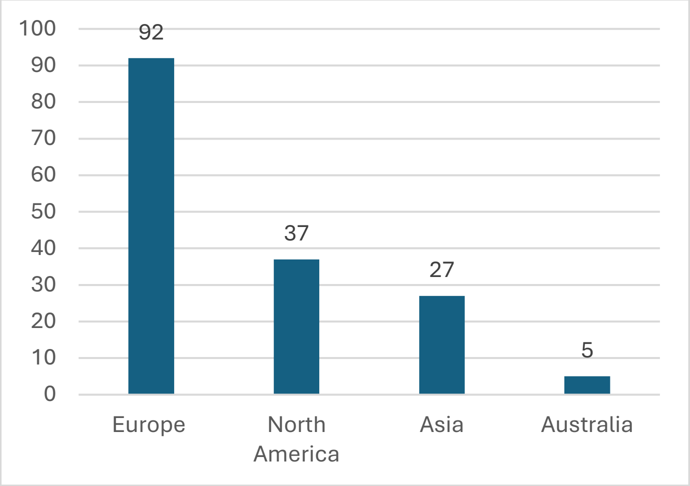


Figure A4.2 Geographical distribution of the included studies

a) By region



b) European studies by country

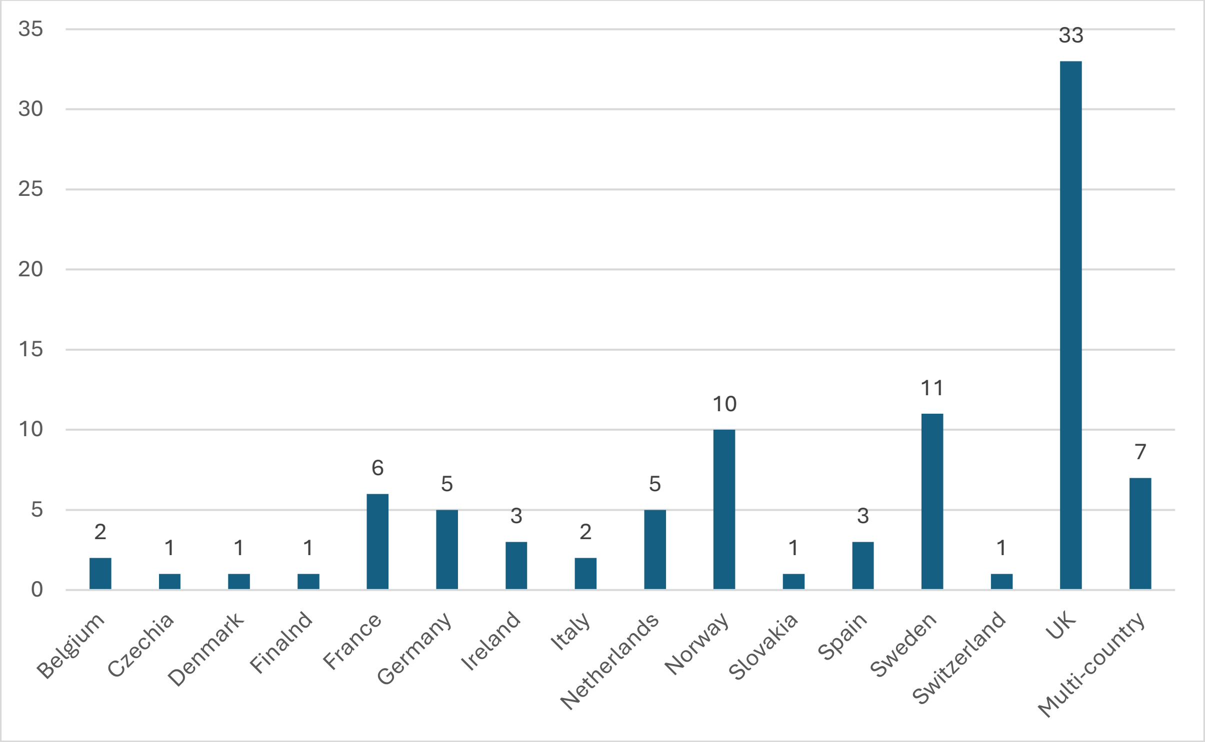


Figure A4.3 Focus of the included articles

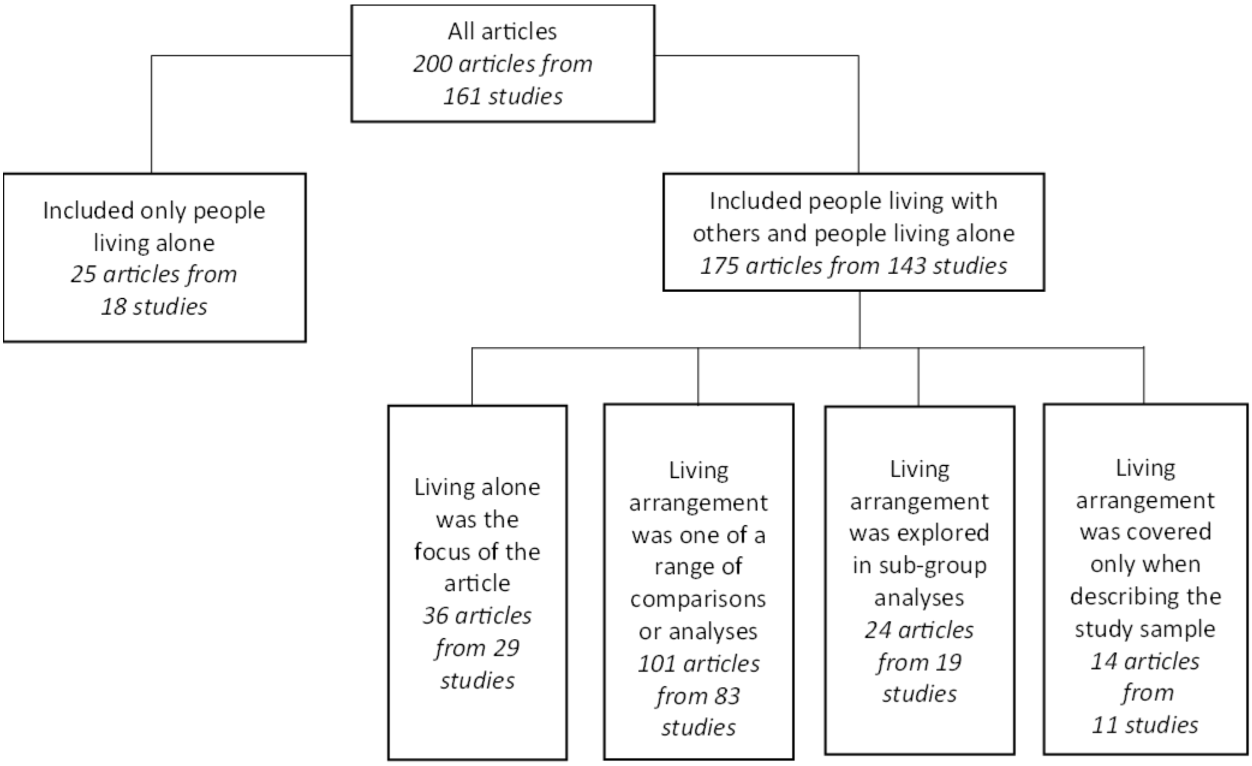


Table A4.1 Proportions of people with dementia living alone by data source

Type of data	Source of data	Total number of Plwd	% Plwd living alone	Publication date
Clinic records	Barcelona (Spain)[40]	5792	23.4%	2017
Administrative health data	SLAM NHS Trust London[84] Dutch Primary Care Data[112]	3075 1040 3471 5423 1078	26% 21% under 70y 33% 70-80y 52% 80-90y 70% 90-100y	2016 2020
National registries	SveDem (Sweden)[113] Several Swedish registries[53]	64955 43372	47.4% 62.0%	2021 2021
Large surveys	Health and Retirement Survey (USA)[114] English Longitudinal Study of Ageing[115] Survey of Health, Ageing and Retirement (EU and Israel)[115] China Health and Retirement Longitudinal Study[115]	4760 1157^ 5166^ 2069^	36.8% 42.4% 36.3% 10.2%	2022 2023 2023 2023
Specific groups	Plwd who applied for long-term care services (Japan)[116] Plwd prescribed dementia medication (Northern Ireland)[5] Plwd not using long-term care insurance (South Korea)[85] Plwd 75+ who conveyed to hospital by ambulance (England)[11] Plwd admitted to a care home (Wales)[4]	23638 25418 278215 8277 34514	18.8% 42% 7% 23.4% 17.5%	2017 2020 2021 2021 2021
All quantitative studies included in scoping review*	Studies with sample size 500+ (32 studies) Studies with sample size <500 (81 studies)	range 503-7609 range 4-468	2.3% - 81.5% 2.2% - 82.6%	

Plwd = people living with dementia. ^ This paper reported person-waves rather than number of people for prevalence of living alone. *Excluding studies that recruited only people living alone.

Appendix 5. Overview of findings related to dementia, health, and service utilisation

Topic	Articles	Summary of findings
Dementia		
Dementia severity[18,19,23,34,35,117,118]	7	Less in 4, similar in 3
Dementia progression over time[7,119,120]	3	Similar in 2, slower in 1
Cognitive ability[7,17-19,21,23,24,33,34,41,66,70,117,118,120-125]	21*	Better in 10, similar in 9, poorer in 2
Functional ability[17-19,21,23,33,34,41,64,66,68,70,117,118,120,122-126]	20	Better in 10, similar in 8, poorer in 2
Distress or neuropsychiatric symptoms[7,19,21,65,66,117,118,120,123,127]	10**	Similar in 6, more in 3, fewer in 2
Mental and physical health		
Depression[7,17,21,41,66,120,122,123,128-131]	14	Similar in 9, more in 3
Physical health[7,17,26,35,120,130]	6	Similar in 2, better in 2, similar or worse in 2
Co-morbid conditions[7,24,33,34,70,86,120,122]	8	Similar in 6, more in 2
Mortality rates[33,68,117,120,132-134]	7	Lower in 3, similar in 2, higher in 2
Falls[41,66,135]	3	Similar in 1, more in 1, fewer in 1
Malnutrition or weight loss[33,41,66,117,120-122,136-138]	10	Similar in 5, worse in 5
Medication		
AChEI and memantine prescribing[5,17,24,33,34,68,139]	7	Similar in 3, less in 2, mixed picture in 2
Antipsychotic prescribing[5,24,33,68,140,141]	6	Similar in 2, more in 2, less in 2
Antidepressant prescribing[5,24,33,68]	4	Similar in 2, higher in 2
Anxiolytic prescribing[5,24,33]	3	Similar in 3
Health care utilisation		
GP home visits[7,17,34,142]	4	Similar in 1, more in 3
GP office attendance[7,17,19,34,41,125]	7	Similar in 2, more in 1, fewer in 4
Nurse home visits[17,34,35,66,142-144]	7	Similar in 4, more in 2, fewer in 1, mixed in 1
OT or physiotherapy consultations[17,34,35,66]	4	Similar in 3, fewer in 1
Outpatient appointment attendance[17,19,33,35,37,66,116,122,145]	9	Similar in 4, more in 4, fewer in 1
Emergency department attendance[17,34,35,142]	4	Similar in 3, less frequent in 1
Ambulance use[11,34]	2	Higher in 2
Hospitalisation rates[33,35,41,84,117,120,122,125,133,142,146]	11	Similar in 5, more frequent in 3, lower in 3
Discharge home from hospital[112,133,147-149]	5	Less likely in 5
Social and home care utilisation		
Social worker visits[17,34,35,37]	4	Similar in 2, more in 1, fewer in 1
Use of meal delivery services[17-19,35,37,41,66,117,125,142,144,150]	13*	More in 10, same in 3
Use of home help or cleaner[7,17,41,66,117,125,142,150]	8	More in 5, same in 3, fewer in 1
Use of home care[17-19,33-35,37,41,53,66-68,112,117,120,123,125,137,142-145,150-156]	29	Similar in 10, more in 17, less in 2
Day care use[7,17,18,34,35,41,66,123,144,152,154,156]	14*	Same in 7, more in 5, less day care use in 1
Rate of admission to residential care[4,18,32-34,53,66,68,84,112,117,120,123,132,133,144,152,156-166]	28	Higher in 22, similar in 6

*One article[66] included data from two separate studies so is counted twice here. ** one article looked[21] at agitation and number of psychiatric symptoms so is counted twice here.

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

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