Living alone with dementia: managing without informal support to contact and navigate services

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Abstract

Purpose: People with dementia can and do live successfully on their own, but there are additional challenges for people living alone without informal support. This paper reports findings of the first study in the UK to examine needs and experiences of, and services for, people with dementia who live alone without informal support. **Method:** The study involved a service audit of 13 local authority commissioners in two English regions, interviews with 22 people with dementia who live alone without informal carers, and case studies of four services supporting this group. **Findings:** Awareness of this population among commissioners was limited. There were very few services which explicitly supported this group, and some mainstream services excluded people without carers. None of the local authorities collected data on numbers of people with dementia living alone, or those without informal support, in their area. Some participants with dementia had contacted social care, but this had not always resulted in appropriate support, and people reported problematic interactions with staff, assumptions that friends would provide care, and support not being available at the right time. Self-funders were left with little support. People with dementia were resourceful, using general services, technology, and other tactics, including cleaners, meal delivery, community taxis, and automatic reminders to organise their lives. However, as many of these additional services have a cost attached, there is potential to exacerbate existing inequalities. Participants wanted more support, particularly with finances and administrative tasks. Services can help this group with supported handovers, allowing self-referral back into a service, and keeping case files open. **Conclusions:** Both the number of people with dementia, and the number of people ageing without children, are rising, and it will therefore become increasingly important to facilitate effective support for people with dementia to live independently without informal support.

Keywords

Dementia, living alone, no informal care, social care

Background

People with dementia can and do live successfully on their own (York Minds and Voices, 2021), however, the right support is essential for this to happen. People with dementia who live alone have significantly more unmet needs than those living with others (Miranda-Castillo, Woods, Galboda et al., 2010), and there is increased risk of hospitalisation and institutionalisation, even when an informal carer is involved (Soto et al., 2015). Professionals have identified challenges for people living alone in relation to keeping safe, hygiene, nutrition, and managing money (Evans et al., 2016) and acknowledged the competing tensions between safety and independence (de Witt & Ploeg, 2016; Portacolone et al., 2023; Waugh, 2009). People with dementia who live alone have acknowledged struggles with medication management, including navigating medication-related bureaucracy, potentially leading to them withholding medication-related information from professionals to maintain their independence (Growdon et al., 2026). A recent systematic review of psychosocial needs of people with dementia living alone (Cheung-Cook et al., 2025) identified several distinct challenges for this group, most significantly the 'increased threat to personhood' without others present to maintain their sense of identity.

At the end of 2025, in England 512,466 people had a recorded dementia diagnosis - an estimated one in three people over 65 with dementia remain undiagnosed (NHS England, 2025). People with dementia living alone is increasingly prevalent. In England, approximately 40% of people with dementia who do not live in a care facility live on their own, an increase from an estimated 31% in 2009 (Clare et al., 2025).

While there are no confirmed figures, studies suggest that up to 18% of people with dementia who live alone may have no informal carer (Clare et al., 2020; Eichler et al., 2016). When people who live alone do have a carer, this is most commonly an adult child rather than a spouse (Soto et al., 2015), but an increasing number of people in the UK are ageing without children (Office for National Statistics, 2020), suggesting that the number of people with dementia who do not have an informal carer will correspondingly increase.

Unpaid care accounts for approximately £21.1bn annually in the UK – approximately 50% of the economic cost of dementia (CF/Pathway Touchpoint, 2024). Informal carers provide support for people with dementia with many tasks, from housekeeping and medication reminders to logistics and information management (Ponnala et al., 2020). Even when the person with dementia lives alone and the carer lives at a distance, carers often act as an 'orchestrator in the background', communicating with formal care providers and monitoring arrangements (Edwards, 2014, p. 176) and many such carers find it challenging to get timely information from care professionals (Edwards, 2014; Falzarano et al., 2022).

When family are absent or estranged, people with dementia who live alone are less likely to have someone who could help in an emergency (Eichler et al., 2016) and may have no informal support to help them navigate the social care system or act as a point of contact for services. People with dementia may have good social networks that assist with shopping or practical support (Duane et al., 2013) but people who are not related may be reluctant to help with care decisions (Lowers et al., 2025; Samsi & Manthorpe, 2013). There is often nobody, other than the person themselves, to play that 'orchestrator' role.

In England, social care is defined in law as distinct from health care, and is the responsibility of local government. There are 153 local authorities in England with responsibility for adult social care. In areas with a two tier system of local government (usually county and district levels), social care responsibilities sit within the upper tier (county) level. In other areas, a single unitary authority is responsible for all local government services, including adult social care. In this paper, we use the phrase 'local authority' to refer to those local authorities who have responsibility for adult social care, whether they are unitary or upper tier authorities.

The Local Government Association (2026) states that: "Adult social care supports people to live independently, safely, and with dignity… through practical, personal, and community-based assistance, such as help with daily tasks, home adaptations, reablement, residential care, and support for carers". Importantly for this paper, it adds: "At its heart, adult social care is about rights, relationships, and enabling people to live the lives they choose. At its best, it ensures that everyone can pursue the things that matter most to them, regardless of age or health conditions".

Depending on context, the term "care" may refer to social care provision which is regulated by the Care Quality Commission (the independent regulator of health and adult social care in England), such as personal care at home, and residential home provision. The term "support" may apply to non-registered services, for example, information, companionship, or domestic tasks. The Care Act 2014 sets out the legal framework for adult social care and support. Statutory duties under the Care Act include promotion of wellbeing, arrangements for the provision of information and advice, and provision/commissioning of preventive support. These functions are important for people to live as well as possible with dementia. Where a public body has duties, there is an implication that people have rights; this paper explores how well people experiencing dementia whilst living alone, and without informal support, are able to access that support.

There is no single, widely agreed interpretation of what it means for a person with dementia to have 'no informal carer' or 'no informal support'. Definitions used in academic research vary, and have been based on lack of family (Duane et al., 2011), family living at a distance (Lowers et al., 2024; Smith et al., 2025); or an amount of

support under a defined threshold, for example less than one hour in the previous week (Clare et al., 2020) or less than four hours a week (Miranda-Castillo et al., 2010). As our research is concerned with provision and use of social care services, we therefore focus on people who do not have that 'orchestrator in the background' role described by Edwards (2014) – people who are accessing care and interacting with services on their own.

In this paper we describe findings of the first study in the UK to examine the specific needs and experiences of, and service provision for, people with dementia who live alone and who do not have informal carers to support them with contacting and navigating services. For the purposes of brevity, we will sometimes refer to this group in this paper as people with dementia living alone with no informal support. Our focus in this paper is on social care and community support, covering two of our research questions:

1. What social care provision exists in England for people with dementia who live alone who do not have someone to contact and navigate services?
2. What community and social care support is used by this group, what are their experiences of these, and what support do they want?

Methods

Study aims and approach

The study (Aspinal et al., 2023), conducted between April 2022 and May 2024, adopted a mixed method approach to examine what social care provision exists for people with dementia who live alone and who do not have informal support to contact and navigate services, and to explore what community and social care support is used, and is wanted, by this group.

This paper covers empirical work from three work packages:

1. A service audit of local authority services for this group in two English regions.
2. Interviews with people with dementia who live alone with no informal support to contact and navigate services.
3. Case studies of four services about the support they offered for this particular group.

Ethical approval

Approval for the service audit was given by the Association of Directors of Adult Social Services (ADASS) on 11th September 2022. The study was approved initially by the West Midlands – Coventry & Warwickshire Research Ethics Committee in September 2022 ((REC reference 22/WM/0185), with amendments approved by the Health Research

Authority and Health and Care Wales (for recruitment through NHS sites, June 2023, REC reference 22/WM/0185).

Participants in all stages, including those with dementia, provided written (or in a small number of cases, audio-recorded verbal) consent to participate and for anonymised information to be published.

Public involvement

We involved people with dementia who live alone without informal support throughout the study. One co-investigator (DM) was responsible for coordinating and overseeing public involvement. In planning this study, we consulted members of this population via two peer support groups who contributed ideas and suggestions.

We recruited four people with dementia who live alone without informal support to the advisory group through adverts on the Join Dementia Research[i] portal and through the Dementia Engagement and Empowerment Project (DEEP) network[ii]. Join Dementia Research is an online service in the UK which allows members of the public to register their interest in taking part in research, and researchers to post about their ongoing studies. It is run by the National Institute for Health and Care Research (NIHR) in partnership with Alzheimer Scotland, Alzheimer's Research UK and Alzheimer's Society. NIHR is the national body for health and social care research. The DEEP network is the UK network of dementia voices – a network of around 80 peer support groups of people with dementia. Researchers can advertise research opportunities in the DEEP newsletter, distributed to all groups in the network.

We used the DEEP guidelines for involving people with dementia as advisers in research (DEEP, 2016), including using inclusive and accessible language, sending specific questions for people to consider before meetings, and summaries after meetings, and offering individual discussion so people could contribute in a way that suited them, whether or not they attended meetings. We paid rates recommended by NIHR for public involvement. The advisory group also included representatives from local authorities, and local and national voluntary organisations.

Researcher characteristics

Our research team was a mix of experienced social care/health researchers (JB, FA, AW), a senior commissioner with a role spanning Integrated Care Board and local authority social care teams (TS), and co-director of Innovations in Dementia, a Community Interest Company supporting people with dementia (DM). All are experienced in working with people with dementia, and the latter in particular has many years of experience of supporting people with dementia to have their say, both in research and other areas. The team met regularly to discuss all aspects of the project.

Service audit of local authority social care services

Two English regions (Yorkshire and the Humber, and North Thames) were selected because they include unitary and county councils and offer a diversity of socio-economic and demographic characteristics and rural-urban characteristics. Tables 1 and 2 show demographic data for the local authority areas within each of our two regions. In Tables 1 and 2, data in for total population, population aged 65+ and percentage of population aged 65+ are from the Office for National Statistics (2025) mid-2024 population estimates. Data for number of people age 65+ with dementia diagnosis are from NHS Digital (2026) Primary Care Dementia Data. Data for the percentage of Census Lower Super Output Areas (a small consistent geographic unit used for census statistics) in the 10% most deprived nationally is from the Ministry of Housing, Communities and Local Government (2025) English Indices of Deprivation. Data for the percentage of population identifying as 'White UK' is from the Office for National Statistics (2022). Data for single person households and people over 65 living alone is from the Office for National Statistics (2024) Census 2021 Household composition by age data.

Table 1: Demographic information for local authority areas in Yorkshire & the Humber									
	Total population	**Population aged 65+**	**% of population aged 65+**	**No. of people age 65+ with dementia diagnosis**	**Estimated % of people aged 65+ with dementia diagnosis**	**% of Census Lower Super Output Areas in 10% most deprived nationally**	**% of all-age population identifying as "White British"**	**Single-person households aged 65+**	**% of population aged 65+ who live alone**
ENGLAND	58,620,101	10,981,092	18.7%	495,413	4.5%	10%	73.5%	3,123,462	28.4%
YORKSHIRE & THE HUMBER									
BARNSLEY	251,770	50,538	20.1%	2,393	4.7%	21.6%	92.6%	14,727	29.1%
BRADFORD	563,605	87,497	15.5%	4,683	5.4%	36.9%	56.7%	26,076	29.8%
CALDERDALE	210,929	41,290	19.6%	1,837	4.4%	20.2%	82.7%	12,857	31.1%
DONCASTER	319,765	62,691	19.6%	2,672	4.3%	23.1%	86.6%	18,804	30.0%
EAST RIDING OF YORKSHIRE	355,884	96,404	27.1%	3,594	3.7%	6.1%	94.6%	25,206	26.1%
KINGSTON UPON HULL, CITY OF	275,401	42,699	15.5%	1,994	4.7%	41.7%	83.9%	14,603	34.2%
KIRKLEES	447,847	80,976	18.1%	3,389	4.2%	13.5%	70.5%	23,405	28.9%
LEEDS	845,189	131,845	15.6%	7,047	5.3%	17.2%	73.4%	42,019	31.9%
NORTH EAST LINCOLNSHIRE	159,911	34,590	21.6%	1,757	5.1%	27.1%	92.6%	10,446	30.2%
NORTH LINCOLNSHIRE	171,336	39,266	22.9%	1,783	4.5%	11.7%	88.7%	10,727	27.3%
NORTH YORKSHIRE	635,270	165,203	26.0%	6,236	3.8%	2.6%	93.3%	43,950	26.6%
ROTHERHAM	276,595	54,357	19.7%	2,997	5.5%	21.2%	88.3%	15,765	29.0%
SHEFFIELD	582,493	97,761	16.8%	4,862	5.0%	21.9%	74.5%	31,040	31.8%
WAKEFIELD	367,666	70,221	19.1%	2,842	4.0%	17.2%	88.2%	20,706	29.5%
YORK	209,301	40,218	19.2%	1,838	4.6%	0.0%	87.3%	12,046	30.0%

Table 2: Demographic information for local authority areas in North Thames region									
	Total population	**Population aged 65+**	**% of population aged 65+**	**No. of people age 65+ with dementia diagnosis**	**Estimated % of people aged 65+ with dementia diagnosis**	**% of Census Lower Super Output Areas in 10% most deprived nationally**	**% of all-age population identifying as "White British"**	**Single-person households aged 65+**	**% of population aged 65+ who live alone**
ENGLAND	58,620,101	10,981,092	18.7%	495,413	4.5%	10%	73.5%	3,123,462	28.4%
NORTH THAMES									
BARKING AND DAGENHAM	232,747	20,012	8.6%	869	4.3%	1.7%	30.9%	6,310	31.5%
BARNET	405,050	60,658	15.0%	2,960	4.9%	0.5%	36.2%	15,868	26.2%
CAMDEN	216,943	26,312	12.1%	1,387	5.3%	3.1%	35.4%	10,254	39.0%
ENFIELD	327,434	48,037	14.7%	2,149	4.5%	18.0%	31.3%	12,805	26.7%
HACKNEY	266,758	22,600	8.5%	1,035	4.6%	16.1%	33.9%	8,025	35.5%
HARINGEY	263,850	29,751	11.3%	1,436	4.8%	19.1%	31.9%	9,482	31.9%
HAVERING	276,274	47,709	17.3%	1,842	3.9%	0.7%	66.5%	13,253	27.8%
ISLINGTON	223,024	21,630	9.7%	1,196	5.5%	4.0%	39.7%	8,160	37.7%
NEWHAM	374,523	28,208	7.5%	1,116	4.0%	5.4%	14.8%	6,762	24.0%
REDBRIDGE	321,231	40,364	12.6%	1,848	4.6%	1.8%	23.2%	10,064	24.9%
TOWER HAMLETS	331,886	19,559	5.9%	1,021	5.2%	13.0%	22.9%	6,192	31.7%
WALTHAM FOREST	279,737	30,067	10.7%	1,199	4.0%	0.7%	34.0%	8,699	28.9%
CENTRAL BEDFORDSHIRE	315,877	57,456	18.2%	2,410	4.2%	0.0%	83.5%	14,502	25.2%
SOUTHEND-ON-SEA	185,256	35,809	19.3%	2,073	5.8%	11.1%	81.6%	11,370	31.8%
THURROCK	180,989	24,516	13.5%	1,036	4.2%	3.0%	66.2%	7,067	28.8%
HERTFORDSHIRE	1,236,191	216,310	17.5%	9,922	4.6%	0.1%	70.0%	61,373	28.4%
LUTON	239,090	27,193	11.4%	1,652	6.1%	13.6%	31.8%	7,674	28.2%

Commissioners responsible for dementia services in all local authorities (n=32) across these regions were identified using local authority websites or by emails to a generic commissioning team. Commissioners were invited to complete a short survey about social care services specifically for this population either via Qualtrics (an online platform), or during an online meeting with a researcher, which allowed them to talk through their responses and ambiguities to be clarified immediately (Bernard et al., 2010).

The questionnaire was developed with support from our advisory group, and was designed to be completed within 20 minutes. It covered:

- Local authority prevalence analysis specifically about people with (i) dementia who (ii) live alone and (iii) do not have any informal support to contact or navigate services.
- Support services (either provided or commissioned by the local authority) for people with dementia which specifically cater for people living alone with no informal support.
    - For each named service that was specifically for people who live alone, or who live alone without informal support, we collected information about: who pays; whether it was provide in-house or contracted out; what age groups it catered for; what stage of dementia it was aimed at; how people with dementia were referred into the service; where the support was provided; what type of support was provided; and how long someone could receive support from this service.
    - For each named service that was aimed at older people or people with dementia more generally, we asked for details of any specific arrangements to support people who live alone, or who live alone with no informal support.
- Other local initiatives (not provided or commissioned by the local authority) providing support for this group.

Non-responders were sent reminders via email up to three times, and recruitment remained open for twelve months due to difficulty recruiting in one region.

Interviews with people with dementia

Recruitment was national for this work package, and we used several approaches for inviting people with dementia to take part. We placed an advert on the Join Dementia Research portal, and distributed an invitation to the DEEP network of around 80 UK peer support groups. We asked relevant local and national voluntary organisations across England to pass on information about the study to people who met our inclusion criteria. As well as electronic information, we sent hard copies of information leaflets, and stamped, self-addressed envelopes for potential participants to respond. In some

cases, we visited group meetings in person to introduce the study – in all such cases we sent study information to the group in advance, and took paper copies of information leaflets with us. We linked with the DETERMIND project[iii], a large study of health inequalities and dementia, who identified those amongst their participants who met our criteria and who had agreed to be contacted about further studies – we were given contact details for this group by DETERMIND researchers, and contacted potential participants directly. We also attempted recruitment through three National Health Service memory clinics, although this was unsuccessful as none were able to identify any potential participants who met our inclusion criteria within the study timeframe.

We planned to recruit 30 people with dementia over six months. We extended this timeline for as long as possible to maximise opportunities for recruitment, and stopped after fifteen months.

People were eligible to participate if they (i) reported to have a dementia diagnosis (self-reported or reported by the participant-identifying organisation) (ii) lived alone, and (iii) had no informal support to contact or navigate services. We did not administer the Mini-Mental State Examination (Folstein et al., 1975) as this was never designed to screen for dementia (Carnero-Pardo, 2014) and there is evidence that cultural differences may have an impact on performance (Wood et al., 2006). We did not assess severity of dementia, but participants had to have capacity to give informed consent to take part in an interview themselves. There were no age restrictions. Researchers had preliminary conversations with all interested people via telephone or email to explore eligibility. Those who were unable to give informed consent or were currently experiencing a crisis (e.g. been recently bereaved), were excluded.

People could choose to have another person (e.g. friend) with them during the interview and to take part in person at a place preferred by them, or via online video call. Information and reminders were sent via participants' preferred routes.

Interviews lasted 45-90 minutes, and covered what the person found positive and negative about living alone; what a typical day might look like; who helped them and how; what activities they did not receive support with; whether they used any community services (e.g. community groups, church activities, etc.); whether they used social care services; positives and negatives about services, including ease of contacting them; and things they may do differently in the future.

Interviews were recorded using an encrypted audio recorder, transcribed using an external transcription service, and de-identified by a researcher. We gave all participants pseudonyms for analysis and writing.

Case studies of local authority services

Through our service audit and wider networking, we identified four services provided or commissioned by English local authorities which specifically supported our population

of people with dementia who live alone without informal support, including supporting people with more severe cognitive impairment who may not have met our inclusion criteria around consent for Work Package 2. This was to ensure that the research overall covered a range of experiences. Our original aim was to recruit case studies from within the two regions covered by our service audit. However, we were unable to identify enough services for this group within those regions, and therefore opened recruitment across England.

In each service, we conducted semi-structured interviews with staff and managers via an online video platform. Interviews lasted 30-60 minutes, were audio recorded, then transcribed by an external transcription service, and de-identified by a researcher before analysis. Interviews covered the key components of the service; dementia care pathways (whether usual care pathways – processes for referrals and advice, for example - were modified for people living alone, for example by adding additional monitoring or referrals); and service delivery practice for our target population. We also reviewed relevant publicly available service and policy documents to increase understanding of the local service context.

Data analysis

One researcher (FA) conducted descriptive analysis on the numerical service audit data using a statistical analysis platform (SPSS)[iv] to summarise regional service provision and provide a wider context to help inform data collection in later work packages. Text-based data from the service audit was used to inform development of topic guides for interviews for people with dementia and professionals in case sites.

We conducted an inductive Framework analysis using the computer assisted qualitative data analysis (CAQDAS) package NVivo[v] to manage data from interviews with people with dementia (Spencer et al., 2013). Two researchers (JB and AW) independently read and coded two transcripts, and created an initial coding framework, refined through application to another two transcripts. The same two researchers then used this refined coding framework to code the remaining transcripts, initially using Nvivo, then Excel to create matrices allowing comparison within and across participants. The core research team (JB, FA, and AW) then met to refine analysis.

We then conducted two analysis workshops with people with dementia who lived alone with no informal carer. Invitations were sent to project advisers and participants with dementia who had indicated previously that they would be happy to receive these. We held one in person workshop, attended by our four project advisers, and one online workshop, attended by four interview participants – both were also attended by four members of the research team (JB, FA, AW, and DM). We sent a short video to attendees beforehand explaining what to expect. The purpose was to sense-check and get additional perspectives on analysis and interpretation as well as to identify any further

gaps between services provided (identified through our service audit) and those needed (identified through interviews). The in-person workshop with project advisers proved a more fruitful discussion, as there was more time, and advisers were already familiar with the project and with the research process, however both yielded useful discussions.

We used the Framework approach (Spencer et al., 2013) to manage interview transcripts and the content of documents from each case site. This approach allows analysis on a case-by-case basis to produce an in-depth understanding of the local context before making comparisons across cases. The core research team (JB, FA, and AW) created an initial coding framework based on the previous work packages. Two researchers (AW and FA) then independently read and coded two transcripts and two policy documents, and the core team met to refine the framework. One researcher (AW) coded documents and transcripts for each local authority, then the team met to make comparisons across cases.

Findings

A total of 13 out of 32 local authorities responded to our service audit, an overall response rate of 41%. In one region the response rate was much higher at 67% (10 out of 15 local authorities), while the other region had high staff turnover and we struggled to recruit, giving a response rate of 17% (3 out of 17 local authorities).

We conducted 22 interviews with people living with dementia in total, 18 in person, and four online via Zoom at the request of the interviewee. Five in-person interviewees asked to have someone else present. Table 3 shows demographic characteristics for participants. We did not request information about ethnicity, gender, or sexuality – some participants did disclose this information, but many did not. We have not reported individual-level data as the small sample size and distinctive characteristics of some participants mean that doing so would risk identification.

Table 3: Demographic characteristics of interviewees with dementia (n=22)

Characteristic	**Value**
Age (n=15)	Range 59-89, median 71
Time since diagnosis (n=20)	Range 1-10 years, median 5 years
Housing type (n=20)	Sheltered/warden-controlled housing (n=3) Non-sheltered (e.g. private rented, council-owned, owned house) (n=17)
Formal care involvement (n=21)	Yes (n=5) No (n=16)
Type of dementia (n=14)	Young-onset dementia (n=5) Alzheimer's Disease (n=2) Posterior Cortical Atrophy (PCA) (n=2)

	Vascular dementia (n=2) Frontotemporal dementia (n=1) Lewy body dementia (n=1) Parkinson's dementia (PDD) (n=1)

Family situations also varied, from having no family at all, to family being unable to provide informal care (due to incapacity, ill health, or other caring responsibilities), or being estranged. Across our four case sites, we conducted a total of nine interviews (two or three per site) with members of staff responsible for service delivery or management. Table 4 gives details of the case studies and interview participants.

Table 4: Details of case study sites

	Site 1	**Site 2**	**Site 3**	**Site 4**
Location	North of England	North of England	South East England	North of England
Type of site	Local authority area with specialist commissioned service for people with dementia living alone	Information, advice and signposting service for all people with dementia	Community dementia hub for all people with dementia	Local authority area with general commissioned service for all people with dementia
Commissioning/ funding arrangements	Specific service commissioned by local authority, provided by charity.	Charity partnership, commissioned by local authority	Charity	Commissioned by local authority, provided by charity providers
Number of interviewees	2	3	2	3
Roles of interviewee	Regional manager of charity (n=1) Director of private domiciliary care provider in same area (n=1)	Dementia advice workers (n=3)	Programme manager (n=1) Dementia advice worker (n=1)	Dementia advice worker (n=1) Independent living coordinator (n=1) Engagement/ outreach worker (n=1)

Social care provision in England for people with dementia living alone with no informal support

None of the 13 local authorities in our study held data about how many people with dementia lived alone or how many had no informal carer in their area (see Table 5

below). Some commissioners assumed GPs or services kept this information, but could not access it themselves and therefore could not use it to inform commissioning decisions.

Table 5: Local authorities completing prevalence analysis			
Local prevalence analysis	**Yorkshire & Humber**	**North Thames**	**Total**
Dementia, living alone, no carer	0	0	0
Dementia, living alone	0	0	0
Dementia	8	2	10
Don't know/Not responded	2	1	3
Total	***10***	***3***	***13***

To summarise: most local authorities in our study did not commission services for this group, instead they presumed that existing services were available and accessible to them, but this was not always the case.

Only two out of the 13 local authorities responding to our service audit had specific arrangements to support people with dementia living alone (whether they had informal support or not). Across these two local authorities, there were a total of four services providing support to this group. One of these services involved assisting with travel to a community-based service, two services undertook specific needs assessments for this group; three of these services offered ongoing support until other services was in place (for example one made weekly telephone calls to those living alone, and another provided temporary transport to a day service until another service was in place). Two of these services allowed self-referral back into their living alone pathways as people's needs changed even when people were supported by other long-term services, and one provided annual reviews to monitor circumstances and care needs.

None of the services for people living alone were specific to people without informal support, and a small number of commissioners noted that some services, including some memory cafes, were only available to people with a carer, meaning people without an informal carer were excluded.

Two of the services mentioned above became case sites, along with another two services which had not been part of the service audit. All four case sites provided a variety of support, information, and advice to different groups of people with dementia, not just our target group. In addition, one also provided home care, and another provided an independence service – this latter also had care pathway specifically for people living alone with dementia without family and friends nearby. These care pathways included home visits rather than telephone advice, supported referrals and a higher frequency of check-in phone calls.

The importance of supported referrals was emphasised:

> ‘They have so many appointments across the health and social care system… we can even support people in those appointments if that’s what they really need, rather than giving people a cold referral’ (Case study site 3)

Not all services were able to attend appointments with clients, but making calls with them present, being able to directly introduce them to a named person in the new service, following up to ensure this was properly in place, and then allowing the person to return if anything went wrong, were key elements of this.

Taking time to get to know clients was important, as was going at the pace of the person with dementia.

> ‘I had a lady who lived on her own and she just wanted a little bit of information at a time. It was almost just little bite sizes, she said, that she could manage’ (Case study site 2).

Taking the time to learn about local services, and understand clients’ needs and wishes, could help professionals support people’s choices, autonomy and independence.

> ‘It’s about doing the minimum you need to do to enable somebody to make those choices themselves and keep control’ (Case study site 1).

Ongoing contact with these clients and their service needs was also emphasised:

> ‘Somebody who lives on their own, we do give that extra support, we keep their case open until we’ve achieved what [we are aiming] for. Once that’s in place, you can close the file, and ask would you like a call back in a month or two weeks’ (Case study site 2)

These services, therefore, were aware of the additional specific needs associated with not having family or friends to help navigate services and they developed pathways accordingly, but this was rare.

Support used by people with dementia living alone with no informal support

People with dementia who do not have informal support told us about the support they used, and what support was missing.

Social care support

Many people in our study did not have contact with or support from local authority social care services. For some, this was an active decision, but others were not aware what was available.

A number of people had contacted local authority social care services themselves, but this had not always resulted in appropriate support. Two people declined care after assessments revealed they would have had to contribute to their own care costs.

Martin recognised the importance of earlier intervention, but system/service level tensions arose, as, while Martin's current home was deemed unsafe for him, his needs were not deemed sufficient for the type of housing that was available, and there was no intermediate option:

> [I kept] saying that, yes, I know I'm not that bad yet, but once I am, it's too late to move me. You can't then safely pick me up and put me in a whole new environment where nobody will know me, I won't know them, and I won't know my way around. I need to be moving now while I can still – but they wouldn't have it' (Martin).

Martin had remained in what the social worker had assessed as an unsafe home until he took action himself. In this case, Martin was able to clearly advocate for himself, and found a place in an extra care housing facility through building relationships with staff on open days and through attending activities, but other people without informal carers might not be able to do this.

Several people described problematic interactions with staff. For example, Dorothy invited a friend, who was visiting from Spain, to attend an assessment with her for moral support, but the social worker focused only on the friend, not Dorothy herself, and the resulting assessment report was inaccurate.

> 'He just hadn't taken onboard the fact that I didn't have anyone. I'd said my friend was just here today, normally she's not around… I think he'd actually said in his report that I had her around for support' (Dorothy).

This assessment resulted in Dorothy not receiving social care support.

Only one person described a good social care experience. They were assigned a social worker during the COVID-19 pandemic, and while they are not currently in need of support, they were keen to remain on their radar:

> 'I don't want to shut the door because things move very slowly if you want to start them again' (Ron).

Other support to promote independence

Participants with dementia used various types of equipment and general support to help them in their daily lives. While many of these will also be used more widely by other people with dementia, some have particular importance for people without carers. Many tasks are related to maintaining independence and running a household. Often, they would be done, or at least arranged, by a carer, but this group, living alone without informal care, must organise these themselves.

Most of our participants used some form of reminder to organise their daily lives, and acknowledged that dementia had made them more reliant on routine. Examples

included a whiteboard for daily appointments, a list of things to check before leaving the house, using Alexa to add appointments and reminders to a calendar, a weekly routine for shopping and cleaning, and sticky notes in strategic places. These activities allowed them to maintain independence and helped to prevent future problems by, for example, ensuring they attended medical appointments.

Many people also used outside services not specifically designed for people with dementia, including a community taxi service, delivery of frozen ready meals, dosette boxes for medication, shopping deliveries, cleaners, gardeners, and a laundrette service. Some had medication delivered, although there were mixed feelings about this, as some preferred the opportunity to walk to the pharmacy. Using these services supported our participants to maintain their independence without the presence of a carer. However, not everyone was able to pay for such services.

For some people, neighbours or friends helped with some activities, for example reading mail or checking money, and one woman asked a friend to help put together a series of outfits, as she was concerned about no longer being able to identify stylish clothes.

> ‘I open a cupboard door and I just see too many things and I just don’t know where to start… We’re putting things together that would make an outfit’ (Colette).

Some people had adaptations provided by an occupational therapy service, for example handrails, shower seats, and falls pendants. Others used more readily available technology, such as a one-cup kettle to avoid spillage and Google maps to navigate journeys.

Lots of our participants discussed being aware of what they could no longer do, and had taken steps to ensure that living alone was still safe for them. Several people had stopped using ovens or hobs, with one describing how she had once left the hob on when out all day. This had led to some people opting to use microwaves rather than ovens, or purchase meal delivery services.

Often, this fluctuated over time.

> ‘At the moment I’m lucky enough to recognise… whether I’m capable of doing things on certain days, like… if I was having an iffy day, I wouldn’t even attempt any financial stuff’ (Martin).

Missing support

Participants identified several areas where support would be useful, but was not easily available or accessible for them. Organisation and coordination were the areas where participants felt they were most in need of additional support.

Amina was particularly concerned about safety, and would have appreciated someone to help with safety issues around the house, like making sure the doors were locked. Several participants mentioned help with organisation, for example of cupboards, or household paperwork.

> ‘I know I need to throw out a lot of stuff, but it’s the selection of what I need from that requires a good cognitive function, which I haven’t got, and I don’t know anyone who can do it on my behalf’ (George).

Minor tasks were causing disproportionate difficulty when nobody was available to help.

> ‘I do need a new TV. I can afford one, but how am I going to do it?’ (George)

Several people mentioned that it would be useful to have help with IT, managing finances, filling in forms, or administrative tasks, for example applying for council tax exemption or a disabled person’s railcard. In some cases, system changes had significantly impacted what people were able to do independently. Robert, for example, used to walk to the council offices for help to complete his council tax exemption form. Then he was told he had to do it online. Unable to do this, the council sent him a paper form to complete, but this then caused problems.

> ‘I’ve posted something back and they claimed they never received it…. I think if you haven’t done this form in 28 days, you’ve got to pay council tax’ (Robert).

Without someone else to help, Robert was left navigating council bureaucracy alone, potentially ending up in debt.

None of the participants had found a satisfactory solution to these dilemmas – they were relying on ad hoc help with individual tasks from neighbours, or other members of groups they were part of. One person mentioned a personal assistant, but had been unable to secure this.

> ‘I know a couple of people have had a personal assistant. It would be useful to get that a couple of hours a week just to help me, but when I’ve mentioned it to social services, they’ve been really dismissive of that. Within my own area, it’s very much unless you want someone to wash and dress you, they’re not interested’ (Dorothy).

Several of these tasks are connected to people maintaining their independence, and would usually be done by another member of the household, or even a distant family member. However, this group have nobody, and are therefore at risk of these tasks being neglected until a crisis brings them to the attention of statutory services. This raises issues around support for self-funders without access to informal care.

Several of our participants felt they were potentially missing out because they did not have an informal carer to advocate for them, partly because there were assumptions from professionals about what family would do. For example, Dorothy tried to arrange a lasting power of attorney (a legal document that allows the owner to appoint another person to make decisions on their behalf should they lose capacity). She contacted a dementia charity's advice service set up for this purpose, but because she did not have a carer, they were unable to help.

'I said to one of the advisers, what happens when someone's in this situation, you know, how can that be arranged? I think she was a bit embarrassed because she realised there wasn't any provision, and she just went "oh well, you don't have to worry about that now", and I thought well if you don't worry about it now when you're… able to put those arrangements in place, then it's too late later on. So, it's frustrating' (Dorothy)There was also a recognition that people fall through the cracks, and receiving support often requires chasing, which people with no carers weren't always in a position to do.

> There's a large gap where people have no help, or they have no help offered to them like people with a family would, because the family, if they didn't get the help, they would jolly well be on the phone' (Elizabeth).

Many participants felt neglected by services, or felt professionals assumed there would always be a carer involved, and therefore did not know how to deal with people who had no family involvement. For some people, this was about a lack of understanding of what people without carers need, exacerbated in this case by assumptions about and within a minority ethnic community.

> 'I find it difficult, I think people don't understand it from an ethnic minority point of view, they think you've got issues, mental health issues… they think you might be a danger to society and I don't know what. But I need, I am wanting more to step out of my comfort zone asking for help, but no-one is willing to help, they don't seem to understand what help I need. They think it is just you creating more problems' (Amina).

This was not only a perception of people with dementia. Our service audit demonstrated that commissioners did not usually collect information about this group so they were hidden in the commissioning processes, and that some services did not cater to people without a carer so they could be hidden from monitoring and delivery systems too.

Discussion

People with dementia can and do live successfully on their own. However, without informal support to contact and navigate services, they are at risk of not getting the

support that they need to continue to live alone well as their needs increase. Our research showed that there is currently no consistent mechanism for local authorities to collect data about the number of, and which, people with dementia live alone without informal support, so they are often hidden in commissioning arrangements, and services do not always meet their needs. Some actions by services can help this group, for example providing supported handovers and keeping case files open longer to check in with people regularly, but given that data is not always collected about living and caring arrangements, services do not always know who needs this.

People with dementia who live alone without informal support are often resourceful and have adopted many ways to maintain their independence. However, there is a risk of inequity as not everyone has the resources to fund useful paid support (for example cleaners, taxis, frozen meal deliveries), meaning people without such financial resources may find themselves unable to maintain living independently for so long. Also, and, as services often assume there is a carer, little thought is given to the needs of someone with dementia navigating bureaucracy alone. Our research reiterates the risks for people with dementia living alone, highlighted by Miranda-Castillo, Woods, Galboda et al. (2010) and others, but goes further to demonstrate the specific risks faced by those living alone with no informal support. This also demonstrates yet again the significant reliance by services on informal carers (CF/Pathway Touchpoint, 2024, Ponnala et al., 2020).

There are two related issues here that specifically affect people without informal support. One is around living independently, and the activities that are involved in that, both practical (such as housekeeping) and administrative (paying council tax, buying a train ticket) – tasks which might usually be done by informal carers (Ponnala et al., 2020) and for which there is often therefore little formal support available.

The other significant issue is around coordination, the 'orchestrator in the background' role often played by carers (Edwards, 2014, p. 176), but in this case is taken on by the person with dementia themselves. Services often have precarious funding arrangements, meaning regular changes, and it can be tricky for someone with dementia living alone without carers to resolve issues if something goes wrong, potentially leading to further calamity.

Our research highlights the potential problems caused by services assuming a carer will be present, particularly as people with dementia and carers may have different requirements at different times. A recent review of information needs of people with dementia and caregivers (Soong et al., 2020) identified only one study (Edelman et al., 2006) which separated the needs of people with dementia and carers, and found that while there was an overlap in need for information about things like understanding dementia, managing medication, and communication difficulties, people with dementia 'were more concerned about service-related topics such as where to find

support groups for people with memory loss' (Soong et al., 2020, p. 11). Although not specifically addressed in our research, the assumption of carer support seems likely to affect people's access to diagnosis. This could be addressed by support services with flexibility to include the pre-diagnosis stage.

It is worth noting that, although this study focuses on people with dementia who have no informal support to access or navigate care, this does cover two distinct scenarios, which we did not analyse separately: those with no family at all; and those with family who were unable to provide this type of informal care, due to, for example, incapacity, ill health, or other caring responsibilities. This distinction matters for both policy and practice. It is important that any attempts to identify people with 'no informal carer' do not restrict this designation to only those with 'no family at all', as this risks overlooking those who have relatives who cannot either advocate for the person or act in that 'orchestrator' role. Future research should examine whether these two groups differ in their needs or in their access to formal support.

The Care Act (2014) gives statutory rights to assessment regardless of people's financial situation (Department of Health, 2014, section 6). However, if, after a financial assessment, a person does not meet the threshold for council funding, they are considered self-funders, and must pay for care from their own resources. There is often little support available to arrange this care (Baxter et al., 2021) which may have a particularly negative impact for those without informal carers.

The lack of appropriate support for people with dementia without informal carers may exacerbate existing inequalities. In the UK, people in Black and minority ethnic groups are more likely to be unsure about how to access dementia services (Moriarty et al., 2011). Black and South Asian people are more likely to have a younger age at diagnosis, to survive for less time after diagnosis, and to die younger than White people (Mukadam et al., 2023) and may encounter more difficulties with a lack of culturally appropriate service provision without support from informal carers. Lesbian, gay, bisexual and transgender older adults are less likely to have children and support from a 'conventional family' than heterosexual older adults (Guasp, 2011), and experience inequities in relation to health and care, particularly in social care environments (Kneale et al., 2021), meaning they can fear accessing care as a result of previous discrimination (Fredriksen-Goldsen et al., 2018).

With nobody other than the person with dementia themselves having full oversight, there is a risk that people living alone with no informal support will fall into the gaps between services. There are particular risks when a service ends, or is no longer suitable. Supported handovers and not closing cases for this group can be helpful, but rely on information about living arrangements being logged, which, in many cases, it is not.

One reason we know little about the needs of people with dementia who live alone without carers is that people with dementia have often been excluded from research where there is no carer to facilitate their involvement (Brooks et al., 2017), and there is therefore a lack of evidence for this group (Polack et al., 2025). Our research has demonstrated that it is eminently possible to involve people with dementia directly in research, as both participants and advisers, and we would encourage other researchers to seek to involve this group to better represent their needs in future research.

Limitations

Our service audit covered local authority commissioners in two English regions. While there is no reason to suspect the regions themselves are atypical, we did have a considerably higher response rate in one region. Commissioners in the other suggested that our lower response rate may be due to high staff turnover. However, there was no indication that either region had adopted a regional approach to this group of people, that data were collected about this group or that services were tailored to this group.

For our interviews with people with dementia, we recruited those with a diagnosis of dementia (reported by either themselves or the participant-identifying organisation). We did not assess dementia severity, but only recruited people who had the capacity to consent to taking part in an interview. This necessarily meant Work Package 2 excluded the views of people with dementia living alone without informal care who did not have capacity to consent to taking part in an interview. We ensured that professional participants in Work Package 3 case studies could draw on a range of experience of working with people with more severe cognitive impairment (who still lived alone with no informal carer), and the findings from this section reflect this. Many of our participants did not have social care support.

Conclusion

People with dementia can and do live alone even when they have no informal support to contact and navigate services by adopting a range of strategies to maintain their independence, and taking advantage of more general, often paid for, services where possible, but this can create inequity for those who are unable to identify and navigate general services or pay for such support. The most significant types of support our interviewees with dementia were missing was practical support particularly with administrative tasks, and coordination of care. Commissioners and service providers do not track this group, so they are not reflected in commissioning decisions, meaning that there are very few specific services tailored to the different needs of this group, resulting in further inequity. Those services that did cater for people with dementia living alone (whether or not they had informal carers) had modified services to better support these

particular clients by including supported handovers to other services, keeping client cases open, and providing regular check-ins, but without all dementia services logging people's living situation routinely, they might miss opportunities to provide essential and personalised support that will help people to maintain their independence and wellbeing for as long as possible.

References

Aspinal, F., Willcox, A., Murphy, D., Sanders, T., & Brooks, J. (2023). Living alone with dementia-managing without informal support to contact and navigate services: A mixed methods protocol. *Journal of Long-Term Care*, 135-141.

Baxter, K., Wilberforce, M., & Birks, Y. (2021). What skills do older self-funders in England need to arrange and manage social care? Findings from a scoping review of the literature. *The British Journal of Social Work*, *51*(7), 2703-2721. https://doi.org/10.1093/bjsw/bcaa102

Bernard, S., Aspinal, F., Gridley, K. and Parker, G. (2010). *Integrated services for people with long-term neurological conditions: Evaluation of the impact of the National Service Framework. Final report* University of York. http://php.york.ac.uk/inst/spru/pubs/1787/

Brooks, J., Savitch, N., & Gridley, K. (2017). Removing the 'gag': Involving people with dementia in research as advisers and participants. *Social Research Practice*, 3-14.

Carnero-Pardo, C. (2014). Should the mini-mental state examination be retired? *Neurología (English Edition)*, 29(8), 473-481.

CF/Pathway Touchpoint (2024) *The economic impact of dementia*. Alzheimer's Society. https://www.alzheimers.org.uk/sites/default/files/2024-05/the-annual-costs-of-dementia.pdf

Cheung-Cook, T., Joddrell, P., Harrison Dening, K., Sobers, T., Walpert, M., & Wolverson, E. (2025). The Psychosocial Needs of People With Dementia Living Alone: A Narrative Synthesis Systematic Review. *Dementia 0*(0). https://doi.org/10.1177/14713012251363090

Citizen Network. (2025). Citizen network: Map of ISFs in England. https://citizen-network.org/library/map-of-isfs-in-england.html

Clare, L., Martyr, A., Gamble, L., Caulfield, M., Charlwood, C., Ward, J., Hulme, C., Prina, M., & Oyebode, J. (2025). *Living alone with dementia: a neglected inequality*. DeNPRU Exeter report 2025 (Version 1). University of Exeter. https://hdl.handle.net/10871/140650

Clare, L., Martyr, A., Henderson, C., Gamble, L., Matthews, F. E., Quinn, C., Nelis, S., Rusted, J., Thom, J., Knapp, M., Hart, N., Victor, C. (2020). Living alone with mild-to-

moderate dementia: Findings from the IDEAL cohort. *Journal of Alzheimer's Disease, 78*(3), 1207–1216.

de Witt, L., & Ploeg, J. (2016). Caring for older people living alone with dementia: Healthcare professionals' experiences. *Dementia, 15*(2), 221–238. https://doi.org10.1177/1471301214523280

DEEP. (2016). Involving people with dementia as members of steering or advisory groups. The Dementia Engagement and Empowerment Project (DEEP). https://www.dementiavoices.org.uk/wp-content/uploads/2016/03/DEEPGuidance_involvingpeoplewithdementiainadvisorygroups.pdf

Department of Health (2014) *Care and Support Statutory Guidance. Issued under the Care Act 2014*. https://assets.publishing.service.gov.uk/media/5a7f6122e5274a2e87db57f9/23902777_Care_Act_Book.pdf

Duane, F., Brasher, K., & Koch, L. (2011). Living alone with dementia. *Dementia, 12*(1), 123–136. https://doi.org/10.1177/1471301211420331

Edelman, P., Kuhn, D., Fulton, B. R., & Kyrouac, G. A. (2006). Information and service needs of persons with Alzheimer's disease and their family caregivers living in rural communities SAGE Publications. *American Journal of Alzheimer's Disease & Other Dementias®*, *21*(4), 226-233. https://doi.org/10.1177/1533317506290664

Edwards, M. (2014). Distance caregivers of people with alzheimer's disease and related dementia: A phenomenological study. *British Journal of Occupational Therapy, 77*(4), 174. https://doi.org/10.4276/030802214x13968769798719

Eichler, T., Hoffmann, W., Hertel, J., Richter, S., Wucherer, D., Michalowsky, B., Dreier, A., & Thyrian, J. R. (2016). Living alone with dementia: Prevalence, correlates and the utilization of health and nursing care services. Journal of Alzheimer's Disease, 52(2), 619–629. https://doi.org/10.3233/JAD-151058

Evans, D., Price, K., & Meyer, J. (2016). Home alone with dementia. *SAGE Open, 6*(3) https://doi.org/10.1177/2158244016664954

Falzarano, F. B., Cimarolli, V. R., Minahan, J., & Horowitz, A. (2022). Long-distance caregivers: What are their experiences with formal care providers? *Clinical Gerontologist, 45*(5), 1273–1284. https://doi.org/10.1080/07317115.2020.1783043

Folstein, M. F., Folstein, S. E., & McHugh, P. R. (1975). "Mini-mental state": a practical method for grading the cognitive state of patients for the clinician. *Journal of psychiatric research*, *12*(3), 189-198.

Fredriksen-Goldsen, K. I., Jen, S., Bryan, A. E. B., & Goldsen, J. (2018). Cognitive impairment, alzheimer's disease, and other dementias in the lives of lesbian, gay, bisexual and transgender (LGBT) older adults and their caregivers: Needs and competencies. *Journal of Applied Gerontology, 37*(5), 545. https://doi.org/10.1177/0733464816672047

Growdon, M. E., Harrison, K. L., Steinman, M. A., Hunt, L. J., Stone, R. I., Tran, T., ... & Portacolone, E. (2026). Medication management among older adults living alone with cognitive impairment. *JAMA Internal Medicine*. https://doi: 10.1001/jamainternmed.2026.1562 Guasp, A. (2010). *Lesbian, gay & bisexual people in later life*. Stonewall. https://www.ageuk.org.uk/bp-assets/globalassets/shropshire-telford--wrekin/original-blocks/our-services/useful-links/stonewall-lesbian-gay-and-bisexual-people-in-later-life.pdf

Kneale, D., Henley, J., Thomas, J., & French, R. (2021). Inequalities in older LGBT people's health and care needs in the United Kingdom: a systematic scoping review. *Ageing and Society*, *41*(3), 493–515. https://doi:10.1017/S0144686X19001326

Local Government Association (2026) Introduction to adult social care: briefing pack for chief executives. https://www.local.gov.uk/parliament/briefings-and-responses/introduction-adult-social-care-briefing-pack-chief-executives

Lowers, J., Brus, K., Smith, C., Kavalieratos, D., Hepburn, K., & Perkins, M. M. (2025). "How do You Take that Much Time for One Person's Life?" Experiences of Dementia Caregivers Who are Not Immediate Family. *Journal of Applied Gerontology*, *44*(1), 166-175. https://doi.org/10.1177/07334648241265197Ministry of Housing, Communities and Local Government. (2025). *English Indices of Deprivation*. https://www.gov.uk/government/statistics/english-indices-of-deprivation-2025

Miranda-Castillo, C., Woods, B., Galboda, K., Oomman, S., Olojugba, C., & Orrell, M. (2010). Unmet needs, quality of life and support networks of people with dementia living at home. *Health and Quality of Life Outcomes, 8*(1), 132. https://doi.org/10.1186/1477-7525-8-132

Miranda-Castillo, C., Woods, B., & Orrell, M. (2010). People with dementia living alone: What are their needs and what kind of support are they receiving? *International Psychogeriatrics, 22*(4), 607–617. https://doi.org/10.1017/S104161021000013X

Moriarty, J., Sharif, N., & Robinson, J. (2011). *SCIE research briefing 35: Black and minority ethnic people with dementia and their access to support and services. (research briefings)*. Social Care Institute for Excellence. https://kclpure.kcl.ac.uk/ws/portalfiles/portal/13501330/SCIE_briefing.pdf

Mukadam, N., Marston, L., Lewis, G., Mathur, R., Rait, G., & Livingston, G. (2023). Incidence, age at diagnosis and survival with dementia across ethnic groups in England:

A longitudinal study using electronic health records. *Alzheimer's & Dementia*, *19*(4), 1300–1307. https://doi.org/10.1002/alz.12774

Needham, C., & Hall, P. (2023). *Social care in the UK's four nations: Between two paradigms*. Policy Press.

NHS England. (2025). *Primary Care Dementia Data, December 2025. Official Statistics.* https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/december-2025

NHS England. (2026). *Primary Care Dementia Data, February 2026. Official Statistics.* https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/february-2026

Office for National Statistics. (2020). *Living longer: Implications of childlessness among tomorrow's older population*. https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/livinglonger/implicationsofchildlessnessamongtomorrowsolderpopulation

Office for National Statistics. (2022). *UK population by ethnicity and local authority 2021*. https://www.ethnicity-facts-figures.service.gov.uk/uk-population-by-ethnicity/national-and-regional-populations/regional-ethnic-diversity/latest/#ethnic-diversity-by-local-authority

Office for National Statistics. (2024). *Household composition by age.* https://www.ons.gov.uk/datasets/RM057/editions/2021/versions/3

Office for National Statistics. (2025). *Estimates of the population for the UK, England, Wales, Scotland, and Northern Ireland (mid-2024).* https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/datasets/populationestimatesforukenglandandwalesscotlandandnorthernireland

Pearson, C., Brunner, R., Porter, T., & Watson, N. (2020). Personalisation and the promise of independent living: Where now for cash, care and control for disability organisations across the UK? *Scandinavian Journal of Disability Research, 22*(1), 285. https://doi.org/10.16993/sjdr.742

Polack, S., Bell, G., Silarova, B., Hebditch, M., Tingle, A., Sommerlad, A., Portacolone, E., Sykes, K., & Tabet, N. (2025). Non-Pharmacological Interventions for People With Dementia Who Live Alone: A Systematic Review. *International Journal of Geriatric Psychiatry*, *40*(3), e70059. https://doi.org/10.1002/gps.70059

Ponnala, S., Block, L., Lingg, A. J., Kind, A. J., & Werner, N. E. (2020). Conceptualizing caregiving activities for persons with dementia (PwD) through a patient work lens. *Applied Ergonomics, 85* https://doi.org/10.1016/j.apergo.2020.103070

Portacolone, E., Nguyen, T. T., Bowers, B. J., Johnson, J. K., Kotwal, A. A., Stone, R. I., ... & Covinsky, K. E. (2023). Perceptions of the role of living alone in providing services to patients with cognitive impairment. *JAMA network open*, *6*(8), e2329913.

Samsi, K., & Manthorpe, J. (2013). Everyday decision-making in dementia: Findings from a longitudinal interview study of people with dementia and family carers. *International Psychogeriatrics, 25*(6), 949–961. https://doi.org/10.1017/S1041610213000306

Soong, A., Au, S. T., Kyaw, B. M., Theng, Y. L., & Tudor Car, L. (2020). Information needs and information seeking behaviour of people with dementia and their non-professional caregivers: A scoping review. *BMC Geriatrics, 20*(1) https://doi.org/10.1186/s12877-020-1454-y

Soto, M., Andrieu, S., Gares, V., Cesari, M., Gillette-Guyonnet, S., Cantet, C., Vellas, B.& Nourhashémi, F. (2015). Living alone with alzheimer's disease and the risk of adverse outcomes: Results from the plan de soin et d'Aide dans la maladie d'Alzheimer study. *Journal of the American Geriatrics Society (JAGS), 63*(4), 651–658. https://doi.org/10.1111/jgs.13347

Spencer, L., Ritchie, J., O'Connor, W., Morrell, G., & Ormston, R. (2013). Analysis in practice. In J. Ritchie, J. Lewis, C. McNaughton Nicholls & R. Ormston (Eds.), *Qualitative research practice: A guide for social science students and researchers*. Sage.

Waugh, F. (2009). Where does risk feature in community care practice with older people with dementia who live alone? *Dementia, 8*(2), 205–222. https://doi.org/10.1177/14713012091032

Wood, R. Y., Giuliano, K. K., Bignell, C. U., & Pritham, W. W. (2006). Assessing cognitive ability in research: use of MMSE with minority populations and elderly adults with low education levels. *Journal of Gerontological Nursing*, 32(4), 45-54.

York Minds and Voices. (2021). *The pros cons and particular needs of those living alone with dementia and those living with a care partner*. Dementia Enquirers. https://dementiaenquirers.org.uk/wp-content/uploads/2021/05/minds-and-voices-in-york_report.pdf

[i] Join Dementia Research: https://www.joindementiaresearch.nihr.ac.uk/
[ii] DEEP Network: https://www.dementiavoices.org.uk/
[iii] https://determind.org.uk/
[iv] SPSS statistical analysis platform: https://www.ibm.com/products/spss-statistics
[v] NVivo qualitative data analysis software: httpfxs://lumivero.com/products/nvivo/