DementiaUK
Helping families face dementia

Crisis before care: experiences of community dementia care and support in England





Contents

Executive summary 5

About the research 7

What people told us 8

A diagnosis does not reliably lead to continuing support 8

Support does not keep pace as needs change 11

Unpaid carers provide and organise care without adequate support 13

When support fails 16

What the findings tell us 18

Appendix: methodology and limitations 19

References 22


DementiaUK
AdmiralNurses
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Executive summary

People living with dementia and their families are too often left to hold a complicated health and social care system together. Participants in this research described a lack of support after diagnosis, struggling to obtain help as needs changed, and taking on increasing responsibility for care without adequate professional support.

Dementia UK surveyed 1,196 people affected by dementia about their experiences of dementia care in the community (community care survey). Dementia UK also commissioned a separate survey of 1,200 adults in England, who did not have firsthand experience of dementia, about their expectations of dementia care (public expectations survey). This was supplemented by focus groups and interviews with people living with dementia, current and former unpaid carers, and clinical experts.

Our research with people affected by dementia found that:

A diagnosis did not reliably lead to continuing support.



Many participants described leaving diagnostic services without meaningful follow-up, a clear plan or someone they could turn to. **50%** of respondents to our community care survey said they struggled to access support after diagnosis. Only **36%** knew who to contact when the needs of the person living with dementia changed or increased.

Support often failed to keep pace with changing needs.



People with dementia and families were expected to recognise when help was needed, identify the right service, and pursue a response. Only **9%** of respondents said professional support was typically provided early, before problems became more serious. When needs increased, **41%** experienced delays in getting help, and **37%** received no additional support.

Unpaid carers carried responsibility for providing care and organising it, without dependable support themselves.



They coordinated services, passed information between professionals, and pursued assessments, funding and practical help. **65%** of respondents said families were mostly or entirely responsible for organising professional support. Almost half (**49%**) reported carer exhaustion or breakdown when the needs of the person living with dementia increased.

The public expectations survey presents a different picture of what people believe care **should** provide. **70%** of respondents expected a named professional to support someone living with dementia. Only **12%** thought families should be primarily responsible for organising professional support. Although the surveys asked different questions of different groups, they reveal a substantial gap between public expectation and the experiences reported in this research.

Gaps in support can be particularly difficult for people with young onset dementia (where symptoms develop before the age of 65), whose needs might include support with employment, income, housing and parenting. Participants described services that were designed around older people and did not reflect their age or circumstances. People living alone or without an unpaid carer could also be left without anyone to notice changes, seek help or coordinate care.

Participants described how delays, fragmented services and growing pressure on carers could leave problems unresolved until a crisis occurred. **42%** of survey respondents reported a hospital admission when needs increased. The survey cannot establish how many admissions could have been avoided, but the accounts we heard show how opportunities for earlier help could be missed.

People valued a continuing relationship with someone who understood dementia and their circumstances; support that anticipated and responded to change; and practical and emotional help for unpaid carers. These features mattered because they made care more dependable and reduced the burden of people having to secure and coordinate support themselves.

This report sets out the research findings. An accompanying policy briefing presents Dementia UK's recommendations for change.



About the research

This research explored experiences of community dementia care in England after diagnosis, including what happens when needs change, how care is organised and what contributes to crisis. It brought together two surveys, focus groups, individual interviews and a targeted review of published research and guidance. Evidence was collected between May and August 2026 using the following approaches:

1. Community care survey: an online survey of 1,196 people affected by dementia, from Thursday 28th May-Tuesday 30th June 2026. The respondents included current (**66%**) and former (**28%**) unpaid carers, and people living with dementia (**5%**). Questions were not mandatory, so response rates vary.
2. Public expectations survey: an online survey of a nationally representative sample of 1,200 adults in England, without experience of dementia, to understand what support they would expect following a dementia diagnosis. The survey was conducted by Censuswide from Friday 14th-Monday 17th August 2026.
3. Four focus groups and two interviews with people with lived experience of dementia, with a total of 20 participants. Two of the lived experience focus groups focused specifically on young onset dementia, enabling the research to explore how experiences of community care can differ according to age and life stage.
4. Four focus groups with clinical experts, primarily dementia specialist Admiral Nurses, with a total of 21 participants.

The experiences shared during the focus groups and interviews helped us understand what the survey findings meant in people's daily lives, including the effect of gaps in care on independence, relationships, physical and mental health and confidence in the future.

We identified recurring themes across participants' accounts, survey responses and published evidence. The findings provide insight into the experiences of those who took part. The community care survey was self-selecting and should not be read as representative of everyone affected by dementia. Full details of the methods and limitations are provided in the appendix (p19).

What people told us

Across the research, people described three related problems:

- A diagnosis did not reliably lead to continuing support
- Care did not keep pace as needs changed
- Unpaid carers took on growing responsibilities without adequate help themselves

A diagnosis does not reliably lead to continuing support.



A dementia diagnosis is life-changing, but many participants said it did not mark the beginning of continuing care. They described leaving diagnostic services without meaningful follow-up, a clear plan or a professional who remained involved. When they needed help, they faced a network of services with no clear responsibility for connecting the different parts.

What people experienced

People described the period immediately after diagnosis as one of grief, uncertainty and practical confusion.

People wanted to understand what the diagnosis meant, what might change and where to turn for help. Some received little information or advice. Others were given more written material than they could absorb at the time, without opportunities to return to it through a conversation with someone who understood their situation.

> **"I walked away with virtually nothing except the certainty that I had dementia. Other people get piles of literature, which of course they're too traumatised to look through."** Focus group participant living with dementia

> **"The whole experience has been a nightmare with no support at the beginning, no follow-up, no consultation, no nothing."** Community care survey respondent

Where services did exist, they were spread across memory clinics, general practice, community health and mental health teams, hospitals, local authority social care, care providers and voluntary organisations. Each could have different eligibility rules, referral routes and records.

> **"The services are not unified [...] You get passed from one place to another without any real help."** Community care survey respondent

People often did not know which service dealt with which need, or who remained responsible once one service had discharged them.

> **So many different people and organisations were involved that I didn't know who to contact for what. It was very confusing being so fragmented."** Community care survey respondent

Health and social care did not always share information, families had to explain the person's history repeatedly, or messages were lost between services.

This was particularly difficult during transitions, including hospital discharge, changes in care packages, moves into a care home and at the end of life. Families described delays, conflicting advice and nobody taking responsibility for making the different parts work together.

> **In my dad's final weeks, he was in hospital, and it took us two-and-a-half weeks to get him discharged to palliative care at home. There was a lot of back and forth with different practitioners coming in, different teams. They weren't talking to each other, so we had a lot of conflicting information."** Family carer focus group participant

The effort required to navigate care also shaped who could obtain help. For example, those living alone or without relatives to notice changes and speak on their behalf could be much easier to miss.

> **If someone is living alone and doesn't have that family network of support, they're going to slip through the gaps."** Admiral Nurse interview participant

The available support is also often not tailored to individual need. For people with young onset dementia, fragmented care can be compounded by services that do not recognise their circumstances. Participants also described encountering professionals with limited understanding of young onset dementia, age-based eligibility barriers and services designed primarily for older people. Support did not always reflect that people might still be working, physically active, supporting children or meeting significant financial and housing commitments.

> **No support for family being young onset [...] For my dad, he was in his 50s [...] And the support groups that my parents received were for people who were above 65."** Family carer focus group participant

Some accounts also highlighted support that did not reflect the person's cultural or religious needs.

> **Many of the care homes do not understand the culture of the loved one in terms of food requirements and daily skin and hair care; no training is provided for staff."** Community care survey respondent

What the numbers show

Our survey results reinforce the difficulty of accessing and coordinating support after a dementia diagnosis, and throughout the dementia care pathway. In our survey of people affected by dementia:

- **50%** said they struggled to access support after diagnosis
- Only **36%** knew who to contact when the needs of the person living with dementia changed or increased

In contrast, the wider public expect much more continuity. In our survey of people without experience of dementia:

- **70%** told us they would expect a named professional to support someone living with dementia, and **85%** think this is important

What mattered to people

People wanted a clear and continuing connection to support, even when they did not need intensive help. They valued knowing that somebody understood their situation, could explain which service did what, and would help them reconnect quickly when circumstances changed.

> **"With our Dementia UK [Admiral] Nurse being that point of contact, she was able to navigate that cobweb of different teams and different people that could help support this."** Family carer focus group participant

In the community care survey, we asked people to choose three things would have made the biggest difference during periods of increased need. The most frequently selected answer was 'a named person to help coordinate support', chosen by **51%** of survey respondents.

Participants described contacts who changed repeatedly, did not know their history or could only signpost elsewhere. Instead, the relationships they valued were continuous ones that reduced the need to retell their story, made responsibility clearer and provided a dependable route back into care.

Support does not keep pace as needs change.



Dementia is progressive, and the support a person needs can change substantially over time. Participants described care organised around individual appointments or requests for help, with limited follow-up between them. This left people and their families responsible for recognising changes and securing a response, even when they were unsure what those changes meant.

What people experienced

Many families were discharged from memory services while circumstances were relatively stable and then remained outside formal support for months or years. They were expected to recognise that a change required professional attention, know which service could help and make the request themselves. Information given at diagnosis was often out of date or forgotten by the time it became relevant.

> **"People often receive some support immediately after diagnosis, although even that varies enormously. Then we often see them 12, 18 or 24 months later. By that point they've completely lost track of who does what, who they should contact, where they should go for support."** Admiral Nurse focus group participant

When people did ask for help, the response could be too slow for a progressive condition. Participants described long waits for assessments, equipment, specialist referrals, care packages, funding decisions and hospital discharge. During those waits, the person's cognition, mobility or physical health could deteriorate and the pressure on the carer could grow.

> **"The support you do get is hard to organise and takes months, when you haven't got months. The system is too slow."** Community care survey respondent

Annual dementia reviews through primary care should offer a regular opportunity to discuss how the person is living, review physical and mental health and medication, consider the carer's wellbeing, and identify new risks or support needs.[i] Yet many participants did not know a review was available, had not received one, or experienced it as a brief administrative exercise. Reviews conducted by text message or limited to medication and blood pressure did not necessarily explore how dementia was progressing or whether life at home remained safe and sustainable.

> **"The GP I've seen most over the last few years called me in for an annual dementia review, partly because I'd prompted him. He said, 'Well, what do we talk about?' I've had one annual review in 12 years."** Focus group participant living with dementia

Planning for the future showed a similar pattern. Families said professionals did not initiate conversations about future care, emergency arrangements and end of life wishes until the person was admitted to hospital or was already very unwell. At that stage, the person might no longer be able to communicate their preferences and relatives had to make difficult decisions under pressure. Previous Dementia UK research found that only **14%** of bereaved dementia carers said an advance care plan had been in place.[ii]

> **"I meet a lot of people towards the end of their lives and end up having some really difficult conversations [...] I get to the point where I'm asking, 'What would they have wanted?' The family say, 'We don't know. We never had those conversations.' Those conversations need to happen much sooner."** Clinical expert focus group participant

What the numbers show

Community care survey respondents were much more likely to describe professional support as a response to requests for help or a crisis, than as something provided before problems became serious:

- Only **9%** said support is typically provided early, before problems become more serious
- **11%** said support is regular but mostly responds to arising problems
- **35%** said support is usually available only when they ask for help
- **33%** said support is mainly provided during crisis situations

When the needs of a person living with dementia change or increase, the system is slow to react. **63%** of people surveyed found it difficult to access or coordinate support when needs increased.

When asked what happened when support needs changed or increased:

- Only **12%** said support was provided quickly
- **41%** experienced delays in getting help
- **37%** received no additional support
- **33%** said the situation reached crisis point

Together, these responses show that increasing need did not reliably lead to timely additional support.

What mattered to people

People valued contact that continued beyond diagnosis and could be adjusted as needs changed. They did not expect constant intensive intervention. They wanted support to remain in the background, with regular check-ins and a quick route to advice when something changed. Information needs to be staged, repeated and discussed with a trusted person as circumstances change, rather than delivered once at diagnosis.

When asked to choose three changes that would have made the biggest difference to their experience, **39%** selected 'earlier and more proactive support', making it the joint second most popular choice.

> **"The important thing is that the planning continues throughout the dementia journey and evolves as the person's needs change."** Clinical expert focus group participant

Meaningful reviews mattered because they could connect different parts of a person's life, such as dementia symptoms, physical health, the carer's situation and plans for the future. Participants wanted conversations that looked ahead as well as recording what was happening on the day, with advance care conversations initiated compassionately, at the right pace, while the person living with dementia could participate.

The person living with dementia and the family carer should both be invited to and heard in these conversations, with appropriate adjustments for communication needs and decision-making support. A meaningful review should also trigger actions with named owners and timescales, not simply record concerns.

Unpaid carers provide and organise care without adequate support.



Unpaid carers described carrying two responsibilities: providing day-to-day care and making the wider system work. As dementia progressed, both could become more demanding. Yet support did not consistently reflect the carer's own health, wellbeing, employment, finances or ability and willingness to continue.

What people experienced

The pressure extended far beyond caring itself. In the absence of clear professional responsibility, families were expected to coordinate care while grieving ongoing losses, making difficult decisions and trying to preserve their relationship with the person they love. They contacted general practice and social care, found providers, applied for funding, arranged equipment, coordinated appointments, monitored whether services arrived and challenged decisions when the person's needs were not recognised.

> **"I organised everything myself. But carers shouldn't have to become coordinators for the whole system."** Family carer focus group participant

Participants described the constant telephone calls, repeated explanations and uncertainty about who could help as mentally exhausting. This work sat alongside employment, childcare, household responsibilities and the carer's own health conditions.

> **"The pressure of now having to coordinate everything for Mum… was just too much and I have struggled to cope."** Community care survey respondent

Carers were not consistently identified by services or told that they could register as a carer with their GP. A formal carer's assessment could help establish how caring affected their health and daily life, but participants described not being offered one, waiting a long time or completing an assessment that led to no further action. An assessment on its own did not relieve pressure if practical support remained unavailable.

> **"I received a carer's assessment and heard nothing afterwards. This was over two years [ago]."** Community care survey respondent

Support also needed to change over time. A carer who was coping shortly after diagnosis could be providing near-continuous care several years later. Training offered only at the beginning did not necessarily prepare somebody for later changes in mobility, continence, behaviour, communication, frailty or end of life care. Families wanted opportunities to revisit information and talk about new problems as they arose.

> **"Family carers are increasingly expected to support people living with dementia through complex and evolving needs, often undertaking tasks that would traditionally be carried out by trained healthcare professionals. They are expected to understand and respond to a wide range of physical and cognitive changes, often without specialist training or support."** Admiral Nurse focus group participant

These accounts highlight the limits of information and training alone. As needs became more complex, families also needed access to professionals who could assess the situation, provide clinical advice and help arrange appropriate care.

Many carers said practical and emotional help was missing. Respite could be difficult to obtain or unknown to the family. Counselling and bereavement support, where available, was not always tailored to the grief, uncertainty and relationship changes associated with dementia. Legal and financial information were complicated, and carers often learned about rights, benefits, powers of attorney or funding routes by chance.

> **"Something that came up time and time again was the need for counselling, for the family members to be able to offload and talk to somebody about what was happening, their fears and the living grief."** Family carer focus group participant

Peer support and voluntary organisations sometimes filled these gaps. Carers described learning from others who had faced similar decisions, feeling less isolated and gaining practical knowledge that reduced stress. However, not knowing that a service existed remained a major barrier.

> **"The best support I received came from a support group. Finding people living through something similar made an enormous difference. Being able to learn from other people's experience reduced my stress enormously and helped me become a much better carer."** Family carer focus group participant

What the numbers show

Our survey of people affected by dementia shows that in most cases, the responsibility for organising support is falling to families and unpaid carers rather than professionals. This contrasts with public expectations and the needs of families who are trying to navigate a complex and unfamiliar system in difficult circumstances.

What people without experience of dementia told us they expect (community care survey)	What people affected by dementia told us they experience
Only **12%** think families should be primarily responsible for organising professional support.	**65%** said families were mostly or entirely responsible.
68% think professionals should be primarily responsible for organising support.	Only **9%** said professionals were primarily responsible.
69% expect regular checks of carers' health, wellbeing and capacity.	**49%** of carers reported breakdown or exhaustion.

These findings come from separate samples and questions. The paired figures illustrate the gap between public expectations and reported experiences; they are not direct like-for-like comparisons.

Almost half (**49%**) of respondents to the community care survey reported carer exhaustion or breakdown when the needs of the person living with dementia increased. The survey did not distinguish between exhaustion and a complete breakdown in the caring arrangement. Participants' accounts nevertheless describe the substantial physical and emotional strain of caring without adequate support.

What mattered to people

Carers wanted professionals to recognise their contribution and their needs as individuals. They valued clear information, practical advice, emotional support, respite and training relevant to the care they were providing. They also wanted assessments to lead to practical help. When asked to choose three changes that would have made the biggest difference to their experience, **39%** selected 'more support for carers', making it the joint second-most popular choice.

> **"If support was clearer at that stage [post-diagnosis], registering carers immediately, making sure carers knew where support was, connecting them with services – it would make a huge difference."** Clinical expert focus group participant

For families affected by young onset dementia, this included peer support with people at a similar life stage, counselling informed by the particular experience of young onset dementia, and advice about employment, finances, housing and supporting children.

People also wanted professionals to ask whether the caring arrangement remained safe and sustainable, rather than assuming a relative would continue caring indefinitely. For people without an unpaid carer, the findings point to the importance of not making access to care depend on having somebody else available to notice changes, coordinate services or argue for help.

When support fails

The three findings describe different parts of the same experience. A person loses contact with support after diagnosis; their needs change without regular follow-up; services respond slowly or separately; and relatives take on more care and coordination. This can continue until the situation becomes unsafe or the carer can no longer manage. At that point, a crisis response may replace the planned community support that was missing.

Crisis and hospital admission

Participants described crises involving falls, infections, delirium, distress, changes in behaviour, the person with dementia leaving their home and getting lost, police attendance and sudden loss of mobility. These events may require urgent medical care, and hospital admission is sometimes necessary. The concern raised by participants was that services often became fully involved only at this stage, even where problems had been developing for weeks or months.

> **"At the moment, they're picked up when people turn up at A&E or end up in hospital, which is the wrong way round."** Clinical expert focus group participant

When community services could not agree responsibility, arrange support quickly or respond outside normal hours, families described calling 999 because there appeared to be no other safe option. Once the person was in hospital, unfamiliar surroundings, disrupted routines and long waits could increase confusion and reduce mobility.

People living with dementia have a higher risk of hospital admission than people without dementia, even after differences in physical health are taken into account.[iii] Across the UK, almost one million A&E visits each year are made by people living with dementia, and emergency admissions make up most inpatient activity involving dementia.[iv]

Community care survey respondents also reported substantial use of urgent and hospital care when needs increased:

- **42%** reported a hospital admission
- **39%** visited A&E
- **36%** reported an emergency GP appointment or NHS 111 contact

These figures record what happened, not why each event occurred, so they cannot identify how many admissions were avoidable.

The qualitative evidence nevertheless shows repeated situations in which earlier attention, quicker coordination or support for the carer might have widened the options before emergency care became necessary.

> **"There are lots of situations where someone ends up in hospital simply because services haven't worked together quickly enough to organise the right support."** Admiral Nurse focus group participant

Carer exhaustion and breakdown

Carer exhaustion was the closely connected consequence. When professional support was absent or fragmented, unpaid carers became the main source of continuity. They monitored the person, filled gaps between services and carried responsibility through the night as well as the day. Many said they kept going because they believed there was nobody else who would help the person.

"There were times when I really struggled mentally. But I kept thinking, 'If I stop, who's going to help her?'" Family carer focus group participant

People described disturbed sleep, anxiety, depression, physical injury, financial pressure and having to reduce or leave paid work. Some felt they had to cry, complain or prove how exhausted they were before services took them seriously. Others feared stepping back because doing so could leave the person they loved at risk.

"My stress levels were through the roof."
"I'm exhausted most of the time."
"I have had to ring the Samaritans for support when I was desperate."

Community care survey respondents

Almost half of respondents (**49%**) reported carer exhaustion or breakdown when needs increased. These accounts illustrate the strain behind that finding, including the impact on carers' mental health and the difficulty of continuing when they felt there was nobody else to take responsibility.

Other research reinforces the scale of unmet need. Dementia Carers Count found that **52%** of dementia carers received no support and **71%** did not receive the support they needed.[v] **78%** said they had reached crisis point because of their caring responsibilities and **72%** often or very often felt unable to continue to provide care.[vi]

Carer breakdown can itself lead to emergency service use, admission to hospital, emergency respite or a rapid move into a care home. The two consequences reinforce each other: a stressed caring arrangement increases the risk of crisis, while crisis can make the caring arrangement still harder to sustain.

Although not every crisis can be prevented, this research shows that the system often leaves the assessment and management of risk with the person and family until choices have narrowed. Earlier contact, clearer responsibility and support that recognises carers' limits were the features most often missing before the crisis.

What the findings tell us

The central finding of this research is that people living with dementia and their families too often carry responsibility for connecting services, recognising changes and securing help. When professional support is absent, delayed or fragmented, that responsibility grows.

People described needing three closely connected features of care they could depend on: a continuing relationship with someone who understood dementia and their circumstances; support that anticipated and responded to changing needs; and dedicated help for unpaid carers.

A named contact can help to coordinate care and provide a dependable route to advice and support. However, being given a name or a list of organisations was not enough. A named contact needs enough authority and persistence to coordinate action, follow up referrals and remain accountable, not merely provide another signpost or telephone number. People valued relationships that reduced the need to repeatedly explain their history and helped them obtain the care they needed.

Continuing support also needed to adapt. Participants wanted opportunities to discuss changes, revisit information and plan ahead, with access to more specialist help when their circumstances required it. Support needed to reflect the person's age, life stage, preferences and wider health and care needs.

Carers wanted to be involved and listened to, with attention to their own health, wellbeing and choices. Their contribution could not be assumed to continue indefinitely. The experiences described also raise concerns about people who do not have an unpaid carer to notice changes, pursue help or organise support.

The evidence cannot establish that every crisis could have been prevented. It does, however, show how gaps in support can leave people facing increasingly difficult circumstances with fewer options. Participants' accounts make clear the value of care that remains connected to people over time, responds when their needs change and shares responsibility rather than leaving them to manage alone.

The accompanying policy briefing sets out Dementia UK's recommendations in response to these findings.

Appendix: methodology and limitations

Purpose and scope

The research was conducted between May and August 2026. It explored people's experiences of community dementia care in England, with particular attention to the period after diagnosis, changes in need, crisis and the role of unpaid carers. It combined quantitative and qualitative methods so that broad patterns could be considered alongside detailed accounts of how care felt and worked in practice.

Community care survey

Dementia UK circulated an online survey through its Campaign Network from Thursday 28th May-Tuesday 30th June 2026. There was an open invitation to respond. A total of 1,196 people completed the survey. Of these, **66%** currently supported or cared for a person living with dementia, **28%** had previously done so, **5%** were living with dementia and **1%** reported no direct personal experience. Questions were not mandatory, so the number answering each question varied.

The survey combined closed questions with open-text responses. Closed questions covered changing needs, who organised support, how and when professional help was provided, experiences of crisis, difficulties accessing or coordinating care, knowledge of who to contact and the changes respondents thought would have helped most. Open-text responses provided examples and context. Percentages in this report use the valid response base for the relevant question and may not sum exactly to 100 because of rounding or because respondents could select more than one answer.



Public expectations survey

Censuswide conducted a second online survey for Dementia UK from Friday 14th-Monday 17th August 2026. It involved a nationally representative sample of 1,200 adults in England without firsthand experience of caring for somebody living with dementia. The survey asked what support people would expect following a diagnosis, who should organise professional support, the importance of a named professional and the point at which professional care should begin.

Focus groups and interviews

Four clinical focus groups involved 21 participants. Nearly all were current Admiral Nurses or clinical leaders who had previously worked as Admiral Nurses. Discussions explored where people fall through gaps, the causes of crisis, barriers to earlier help, experiences of annual review and advance care planning, transitions between services, and the support required by family carers.

Four lived experience focus groups involved 18 participants, including people living with dementia and current or former family carers. Two additional interviews were held with two participants unable to attend a group. Two of the focus groups were for people affected by young onset dementia. Discussions covered experiences after diagnosis, navigating health and social care, changes in needs, what had worked well, what had been missing and what participants most wanted from support.

Literature review and analysis

A targeted review of published research, national data, guidance and previous Dementia UK evidence was used to place the primary research in context. Survey results were summarised descriptively. The qualitative material was reviewed thematically, and themes were compared across lived experience accounts, clinical evidence, survey comments and the literature. Particular weight was given to findings that recurred across more than one source.

Limitations

The community care survey was not a representative sample of everybody affected by dementia. It was circulated through Dementia UK's Campaign Network, mailing list and other networks, and people who chose to respond may have been more engaged with dementia services or more motivated by particularly positive or negative experiences. The survey was online, which may have made participation harder for people who are digitally excluded. Most respondents were current or former carers; people living with dementia made up **5%** of the sample. The findings therefore provide strong insight into family experience but should not be read as a complete account of the views of all people living with dementia.

The public expectations survey was nationally representative, but it asked hypothetical questions of people without firsthand caring experience. It shows what the public expects from the system, not what respondents had personally received. Comparisons between the two surveys are informative but should be interpreted carefully because the questions and samples were different.

Focus groups and interviews were designed to explore experiences in depth, not to estimate how common each experience is. Participants were self-selecting and the clinical sample was mainly drawn from Admiral Nursing, so other professional perspectives may be under-represented. The research did not include enough participants for reliable comparisons by ethnicity, income, geography, type of dementia or other characteristics. Furthermore, the focus groups did not include care home residents and those with advanced dementia. Their experiences may differ substantially and could inform future research.

Important inequalities may therefore be visible in individual accounts without being measurable in the study.

The literature review was targeted rather than systematic. It supported interpretation of the findings but did not assess every study of community dementia care.

Finally, the survey records whether events such as hospital admission or carer breakdown occurred; it cannot by itself establish that they were caused by gaps in support or would have been prevented by a different response. The qualitative evidence helps explain possible pathways to crisis, but causal claims remain appropriately cautious.



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DementiaUK
Helping families face dementia

If you're caring for someone with dementia or if you have any other concerns or questions, call or email our Admiral Nurses for specialist support and advice.

Call 0800 888 6678 or email helpline@dementiauk.org
Open Monday-Friday, 9am-9pm
Saturday and Sunday, 9am-5pm

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