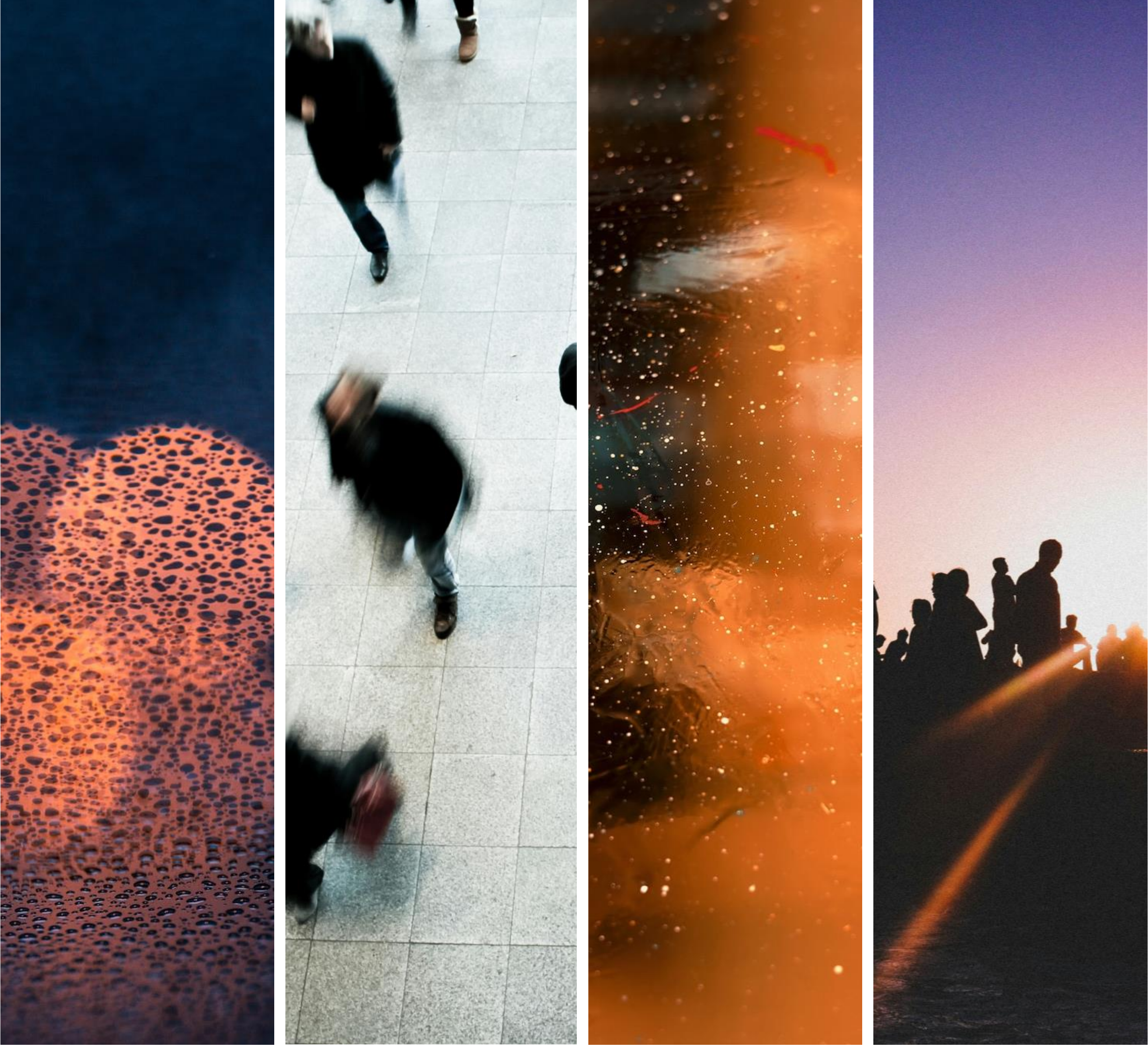

THE LIVED EXPERIENCES OF DEMENTIA

Prepared for Alzheimer's Society by Walnut Unlimited I August 2025

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Alzheimer's Society
It will take a society to beat dementia

WAL NUT
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Introduction from Alzheimer’s Society

Dementia is the biggest health and social care issue of our time. There are currently around one million people with dementia in the UK, and this is expected to rise to 1.4million by 2040. There will be many more people impacted as family members and friends. Its reach extends into every corner of our society.

Yet, despite the scale of dementia, the day-to-day realities of living with dementia often remain hidden or misunderstood. To understand these realities, it is critical that we hear from people living with dementia, and those affected by it.

For a second year, Alzheimer’s Society has commissioned Walnut Unlimited to bring the realities of living with dementia out into the open. You can read our previous report here. This report centres around the experiences of people living with dementia and those who care for them. It reveals the everyday challenges that people face, from navigating complex health and care systems, to coping with stigma and the personal impact of caring for a loved one.

Whilst this report tells a story of challenges, it is one with resilience and hope. Over 3,000 people affected by dementia responded to our survey, because like us, they recognise that their voices and experiences are a powerful tool for change. It can help policymakers, service providers and communities identify what is working, what isn’t and where real improvements can be made.

We invite readers from all sectors to engage with these findings, to reflect on what they reveal, and to act. Local and national leaders across England, Wales and Northern Ireland should embrace the opportunities afforded by upcoming health and care reorganisation. They can do so by putting dementia and the people affected by it at the heart of redesign, helping to reduce the stigma and poor experiences, and to create a future where dementia no longer devastates lives. Real change is possible, if we are willing to listen.

> *“Sharing the realities of living with dementia is vital because it breaks down stigma, fosters empathy, and reminds people that behind the diagnosis is a person with dignity, emotions, and a story. I hope it changes the way society sees dementia—from fear and misunderstanding to compassion and inclusion. By speaking openly, we can push for better support, challenge stereotypes, and create a world where those with dementia are truly seen and valued”*
>
> **Member of the lived experience advisory group**

Background and Methodology

THE AIM

Walnut Unlimited carried out a second wave of the '*Lived Experience*' research, on behalf of Alzheimer's Society, to help them profoundly improve the lives of those living with dementia and their carers, by providing support, amplifying their voices and influencing decision-makers to make positive changes.

RESEARCH OBJECTIVES

The key objectives of the current research were:

1. To gain a rich and strong understanding of the experiences of people living with and affected by dementia at each stage of the journey and at key points of transition, including accessing health and social care services and, where appropriate, track how this has evolved in the last 12 months
2. To reliably represent the views of people living with dementia and those close to them, in terms of their perceptions of dementia services, what needs to improve and what is working well
3. To identify clear and impactful insights around objectives 1 + 2, producing a persuasive case for change and influencing decision-makers, which is focused around 3 key priority areas for Alzheimer's Society: diagnosis, social care and treatments & interventions.

METHODOLOGY

Quantitative

A 15-minute **online survey** with people living with dementia and people who know or care for someone living with dementia.

Wave two was based on the same approach as the baseline survey conducted in 2024. Core tracking questions were retained from wave 1 (results from the previous survey can be found here). Additional questions on social care and treatments were added for the current wave.

Fieldwork took place between 27th February and 26th March 2025.

Broad regional quotas were set, and other demographic quotas, such as age and gender were monitored closely to maintain a consistent approach to wave one.

Weighting has also not been applied to maintain a consistent approach with wave one.

Background and Methodology

The sample consisted of adults aged 16+. 3,487 participants completed the survey:

- 2,803 in England
- 405 in Wales
- 279 in Northern Ireland

The sample consisted of people with varying experiences of dementia:

- Those living with dementia (74)
- Those who know someone close to them living with dementia (2,605)
- Those who care for someone living with dementia (808)

Most of the sample was sourced from Walnut's panel partners. A boost sample for people living with dementia was also sourced and contacted by Alzheimer's Society's by promoting on their dementia support forum.

It should be remembered that a sample was interviewed and not the entire population. Consequently, all results are subject to sampling tolerances, meaning that not all differences are statistically significant.

All aspects of the research were conducted in accordance with the MRS Code of Conduct as well as ISO 20252 and ISO 27001, the international standards for market research and information data security.

All findings shown cover England, Wales, and Northern Ireland combined unless otherwise stated.

Key sub-group reporting is included throughout, covering experience with dementia, age, dementia stage, disability, location and ethnicity.

Unless otherwise stated, we have used 'people' or 'general public' to refer to a person or people living in England, Wales and Northern Ireland who have some level of experience with dementia and dementia services including those living with, know someone or care for someone.

Where percentages do not add up to 100, this may be due to computer rounding, the exclusion of "don't know" categories, or multiple answers.

METHODOLOGY

Qualitative

15 **in-depth online interviews** were carried out with individuals who took part in the quantitative stage of the research. Interviews were 45 minutes – 1 hour long.

Fieldwork took place between the 12th and 30th May 2025.

The objective of the qualitative stage was to further explore the lived experiences of both those living with dementia (7) and individuals who are caring for people living with dementia (8). The sample was demographically diverse in terms of gender, regions and diagnosis.

STRENGTHS & LIMITATIONS

Quantitative

The quantitative survey benefits from a robust sample size that is representative of the three nations served by Alzheimer's Society.

The survey was offered in both English and Welsh languages, and there was an option to complete the survey via telephone. A progress bar was displayed throughout alongside written encouragement to ensure respondents felt comfortable enough to give honest and detailed answers. At the end of the survey, all respondents were thanked and signposted to Alzheimer's Society contact page and support line.

An advisory group was also set up and run by Walnut, including unpaid dementia carers and those living with dementia, to input into the discussion guide design and analysis stages of the research to ensure experiences were captured in a sensitive and representative way.

Qualitative

The qualitative interviews were conducted by trained interviewers going at the pace of the participants, reminding individuals at multiple points of their right to skip questions they did not feel comfortable answering. All participants were asked if any accommodations or adjustments were required beforehand.

Within the group of people living with dementia (7) we included several participants who were actively involved with organisations such as Alzheimer's Society, Age UK, or Dementia NI.

The individuals that we spoke with were confident communicators, who find it easier to advocate for themselves. The insights shared from this group in the qualitative stage therefore reflect the perspectives of these specific individuals and may not be representative of the breadth of experiences of everyone living with dementia, including those less able to speak up or express their needs.

This limitation relates specifically to people living with dementia themselves, not to those of carers or family members (8).

It is important to remember when reading this report that dementia is a highly individual condition, and experiences can differ widely from person to person.

Executive summary

Too many people affected by dementia experience stigma and have poor experiences with diagnosis and care

Findings from this report can be used by national governments and health and care systems to inform policy and practice solutions that can help improve the experiences of people affected by dementia, and to reduce stigma. There have been signs of a positive shift in attitudes towards government and health services, with a significant increase in positivity felt towards them in the last 12 months in terms of how they prioritise dementia. However, the stigma attached to a dementia diagnosis is still felt, and satisfaction with healthcare and social care support available is relatively low (fewer than half are satisfied with the support available).

The diagnosis experience can be negative for some and barriers to access remain.

Only a third reported a positive experience with the diagnosis process and there has been a significant increase in those who do not feel that their experience was positive in the last 12 months.

The diagnosis process is often perceived as stressful, difficult and that it takes too long, preventing people accessing the care they need.

Responses suggest that people want a diagnosis earlier, as well as more information about how a diagnosis can help and the subsequent support which would become available. This would help to encourage more people to seek professional help.

Social care support can be a lottery with mixed experiences and ability to access.

Only a third find social support easy to access and even fewer know who to contact if they need social support.

Satisfaction with the current support available is relatively low. In-home care is meeting the needs of fewer people with dementia compared to those in a care home, with family and friends often trying to plug the gap.

People want more support, specifically for those caring for people with dementia, with many not feeling respected as a carer by professionals or not receiving support that is available. The negative impact felt by this is crossing into many aspects of unpaid carers lives.

Whilst experiences of treatments and interventions are positive, access can be difficult.

Satisfaction with the availability of healthcare is relatively low, and less than one in three believe dementia healthcare is easy to access.

The majority of people who have been offered any drug and/ or non-drug treatments have found them beneficial.

Despite this, access to these types of treatments is varied, with over a third of those with dementia not having been offered a non-drug treatment, and one in five not having been offered a drug treatment.

THE LIVED EXPERIENCES OF DEMENTIA

Section 2: A view of the impact of dementia and the current experience of dementia services

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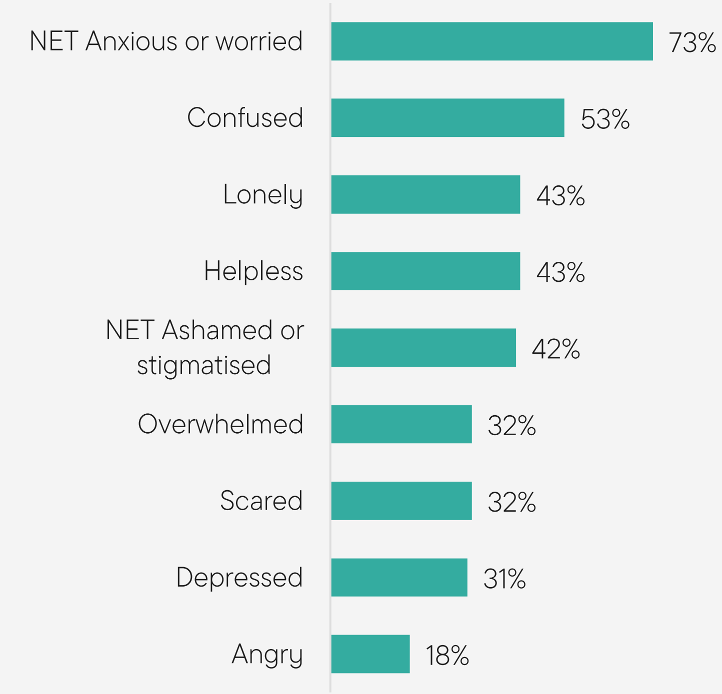
What is the impact of dementia?

Many feel anxious or worried living with dementia symptoms



C2. How does it make you feel to live with symptoms of dementia?
Base: All Living with dementia (74)

Fig 2.1. How does it make people feel living with dementia symptoms among those living with dementia

Many people living with dementia told us they have felt anxious or worried living with the symptoms of dementia (73%).

Over half of those living with dementia feel confused (53%).

Around two in five people living with dementia feel lonely (43%), and a similar proportion feel helpless (43%).

Stigma is still impacting people living with symptoms of dementia, with two in five (42%) indicating that they have felt ashamed or stigmatised.

> *"It's really difficult sometimes. I was very organised - I knew exactly where things were, I would be able to just locate something easily. Now, if I'm looking for something and it's like a mountain to climb"*
>
> **A person living with dementia**
>
> *"I think we've got to take the scariness out of the word dementia and Alzheimer's. People are very scared to hear that. Because they hear all the old myths and stories of it...But we need to take the fear out of it. We need to show positives."*
>
> **A person living with dementia**

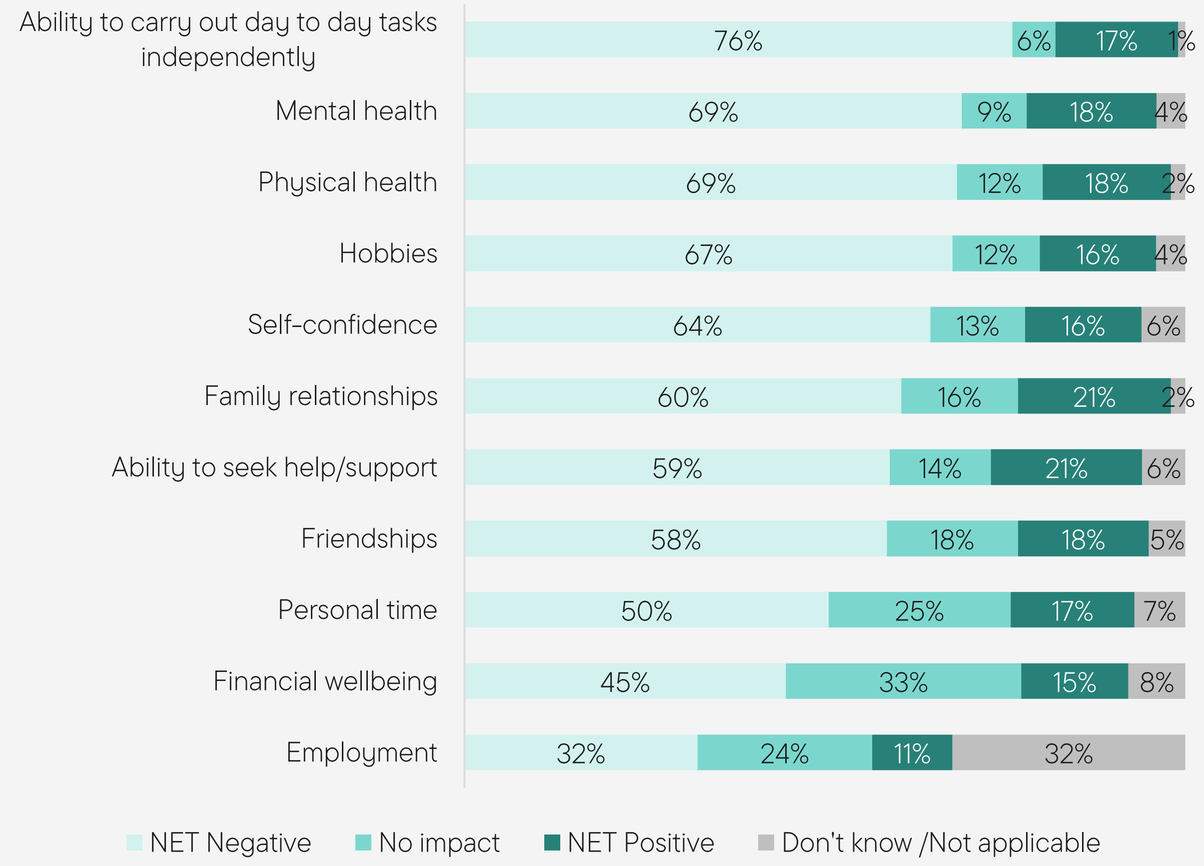
The overall impact of living with the symptoms of dementia is negative for the majority and is felt across almost every aspect of their lives.

Many people living with dementia or who know someone living with dementia say that they or the person living with dementia has experienced a negative impact on their ability to carry out day to day tasks independently (76%).

People also reported a negative impact on their physical health and their mental health (both 69%).

Many also say they have experienced a negative impact on their hobbies (67%), their self-confidence (64%) and their family relationships (60%).

The majority of those living with dementia have experienced a negative impact on their daily lives



C1. What impact has dementia had on the following areas of your/the person's life)?
Base: All respondents (3,487)

Fig 2.2. Impact of living with dementia on different aspects of their life (total sample – all with a dementia diagnosis or who know/care for someone with dementia)

> *"I have no time to spend on myself or see friends and family. It has dominated my life. It also had an impact on my mental health due to the constant worrying and lack of time to look after myself."*
>
> **Carer for someone living with dementia**

The impact is also felt by those who care for someone living with dementia.

Seven in ten (70%) who care for someone living with dementia have experienced a negative impact on their daily lives as a result of caring for someone.

Just under half (46%) say that they spend less time doing the activities that they enjoy. Many unpaid carers have also experienced a negative impact on their mental health (37%) or physical health (24%).

For some though, caring for the person living with dementia has been a positive experience as they feel closer to the person who they are caring for (39%) or they feel a sense of fulfilment (33%).

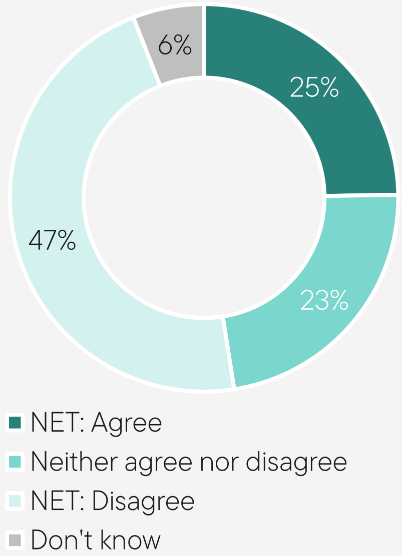
Some carers have experienced a negative impact on their physical and mental health

E6. Which, if any, of the following statements describe your experience of caring for someone with dementia/ knowing someone close to you with dementia? Base: All who care for someone living with dementia (808)

Fig 2.3. Impact on those caring for someone living with dementia (among people who care for someone with dementia)

Do people feel dementia is a priority for government and health services?

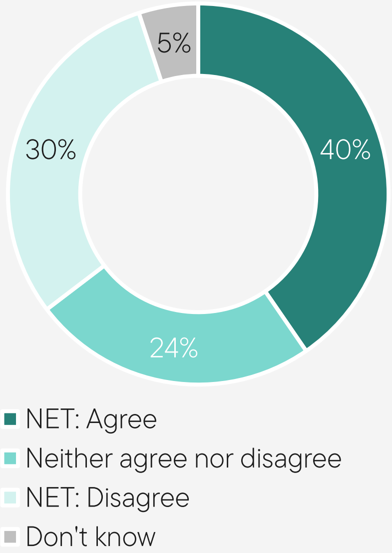
Only a minority agree that government considers dementia a priority



B1_3. The Government/Executive considers dementia a priority (To what extent do you agree or disagree with the following statements?) Base: All respondents (3487)

Fig 2.4. Agreement that government considers dementia a priority (total sample)

Only a minority agree that health services consider dementia a priority



B1_4. The NHS/Health service considers dementia a priority (To what extent do you agree or disagree with the following statements?) Base: All respondents (3,487)

Fig 2.5. Agreement that health services consider dementia a priority (total sample)

People have a relatively negative view of public administration and health services in terms of dementia care.

Only one in four (25%) people believe that government considers dementia a priority. This has increased since 2024 (up by 9 percentage points), which is likely a reflection of the change in the UK Westminster Government, however, it remains the minority of people who think governments are prioritising dementia.

Those aged over 65 (14%), those with experience of late-stage dementia (16%), people with a disability (19%) and people living in a rural area (21%) are even less likely to agree that government considers dementia a priority.

Furthermore, **only two in five (40%) believe that health services consider dementia a priority**. While this figure has increased 6 percentage points since the baseline survey, it remains the minority of people who believe health services are prioritising dementia.

Agreement that health services consider dementia a priority is even lower amongst over 65s (32%), people with experience of late-stage dementia (35%), those with a disability (37%) and those living in a rural area (38%).

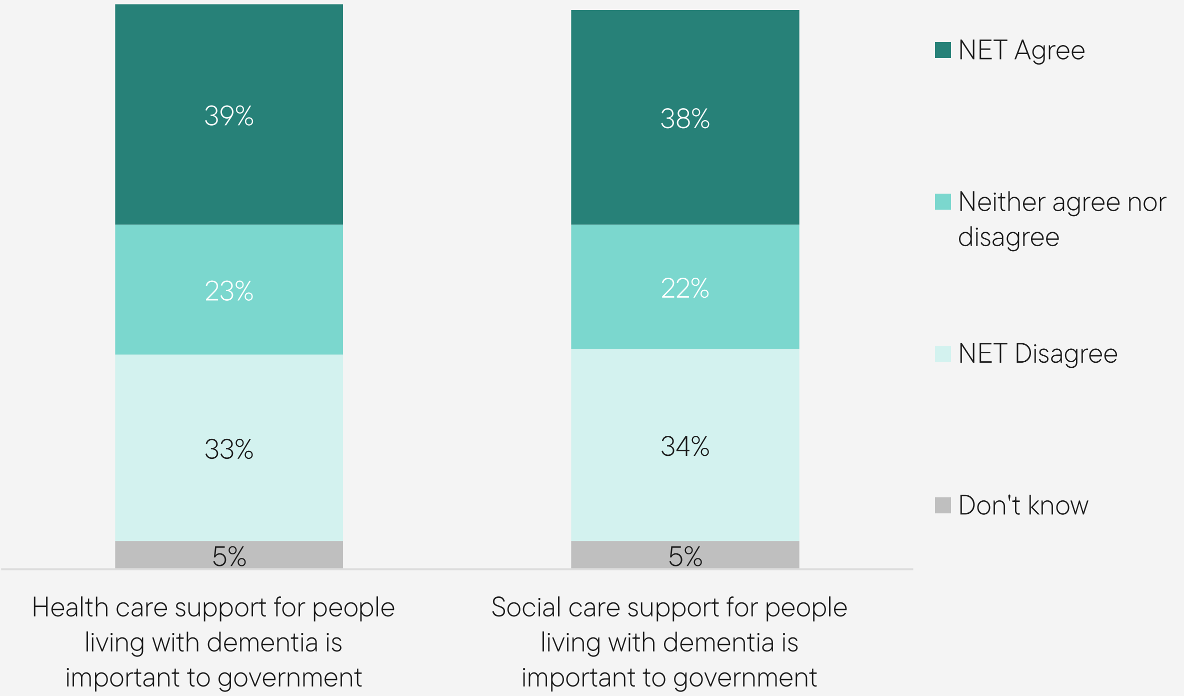
Two in five people (39%) think that healthcare support for people living with dementia is important to government. There are signs of a positive shift in attitudes, as this has increased since 2024 (up by 10 percentage points). However, it remains the minority of the public who believe healthcare support for dementia is important to governments in England, Wales and Northern Ireland.

People who have experience of late-stage dementia (29%), people with a disability (32%) and those living in a rural area (34%) are even less likely to think that healthcare support is important to government.

It is also the minority (38%) of people who think that social care support for people living with dementia is important to government.

Those who have experience of late-stage dementia (28%), people with a disability (32%) and those living in a rural area (34%) are even less likely to think that social care support is important to government.

A minority think that healthcare or social care support is important to governments



B1. To what extent do you agree or disagree with the following statements?
Base: All respondents (3,487)

Fig 2.6. Agreement that health care and social care support are important to government (total sample – all with a dementia diagnosis or who know/care for someone with dementia)

Roger’s Story

Roger is in the **early stages** of living with frontotemporal dementia, he was diagnosed at 53 and lives near the border of Northern Ireland and the Republic of Ireland. He feels **abandoned** by the healthcare system due to the severe shortages of consultants and long waits for diagnosis. His **frustration** stems from a deep sense that the government has **neglected** dementia by “**starving**” the NHS of funding and prioritising funding for other conditions, such as cancer.

Just 30 minutes away across the border, Roger believes that care is **significantly** better with more consultants, quicker diagnoses, and access to specialist nurses. This highlights the stark “**postcode lottery**” in dementia support that he thinks exists. He has **little hope** for future governments, believing that systemic change is needed in the government’s handling of the NHS.

> *“Fifty steps from here, you could be down the road in the Republic of Ireland, and you're treated like a lord down there. Dementia care is so, so much better. Over here, we do feel abandoned.”*

Jackie’s Story

Jackie has been supporting her mother, whose **dementia diagnosis was suggested** by healthcare professionals after a series of hospital stays following two hip fractures. Jackie describes how her family **were not told** of her mother’s suspected dementia initially, only finding out after seeing a symbol of ‘the butterfly scheme’ on the door of her mother’s ward. Jackie describes this experience and subsequent discussions with healthcare professionals on the treatment of her mother as **long, confusing, and emotionally draining.**

Her mother has received health and social care from both Northampton and Cornwall services, and comments on the **stark contrast** between the quality as “**pretty awful**”.

> *“Regardless of whether she has got dementia or not, she deserves dignity and the treatment she got was pretty bad. Listen to patient’s families because they know their relative best.”*

Qualitatively, what are the key takeaways in relation to government and health services and their prioritisation of dementia services?

Perceptions of how government is prioritising dementia are at low levels

Using findings from this report, national governments and health and care systems could build their understanding of the realities of living with dementia, ensuring lived experiences are reflected in policies, services and support available.

People's perceptions are reinforcing their actual lived experiences

There is consistency between perceptions about care in terms of how it's prioritised and understood by government, and their lived experiences. If people think dementia isn't a priority, this reflects in their stories through things like them perceiving their lack of access to a service as a postcode lottery.

Honesty is important to people affected by dementia

Acknowledging the challenges of those living with dementia and caring for someone with dementia in open and honest conversations can humanise the process. It can also help inform people on the challenges people are facing and the possible solutions.

What did people tell us about their experience of dementia support?

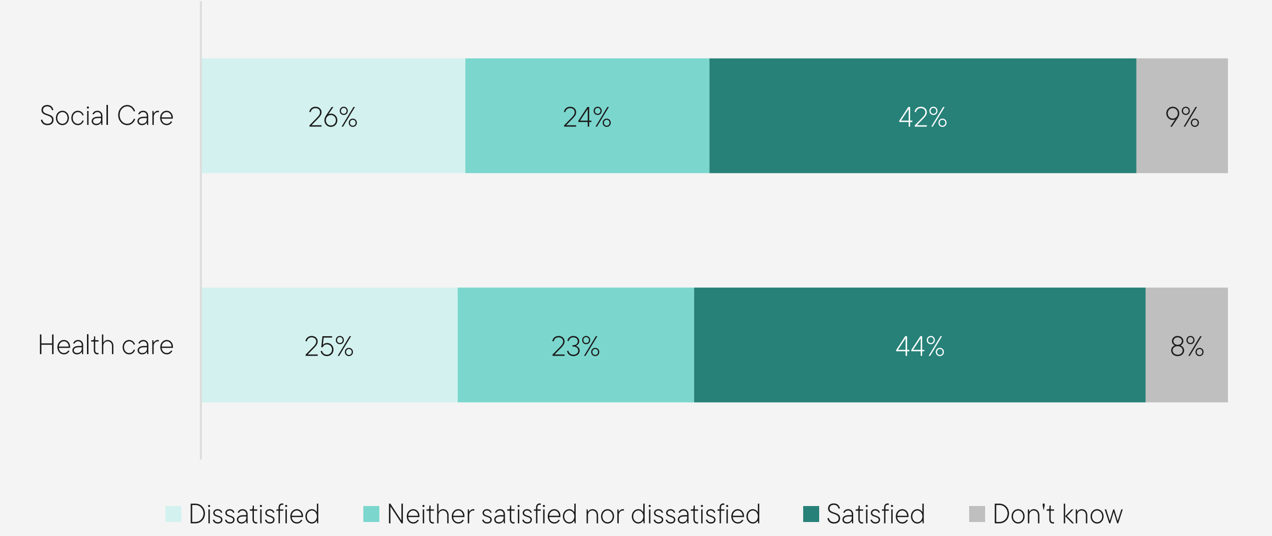
> *"I had a lack of professional support after my diagnosis. I wasn't getting very far with seeing anyone in the NHS. It's not that easy to navigate. I had nothing."*
>
> **A person living with dementia**

There is a lack of consistency in the support available for people living with dementia. One in five people (21%) said that they have not received any support for the person living with dementia.

A quarter of those who know or care for someone with dementia state that they are dissatisfied with the health (25%) and social care (26%) support that is available to those who are living with dementia.

There are even higher levels of dissatisfaction with health care support available among people living in a rural area (27%), those experiencing late-stage dementia (30%), and people with a disability (32%). Likewise, dissatisfaction for social care support available is greater among those with a disability (35%), in late-stages of dementia (33%) and those living in a rural area (29%).

Only a minority are satisfied with health and social care support available to people living with dementia



E16a/b. How satisfied are you with the healthcare support/social care support available for people with dementia?
Base: All who know or care for someone with dementia (3,413)

Fig 2.7. Satisfaction with the support available for people living with dementia (among people who care or know someone living with dementia)

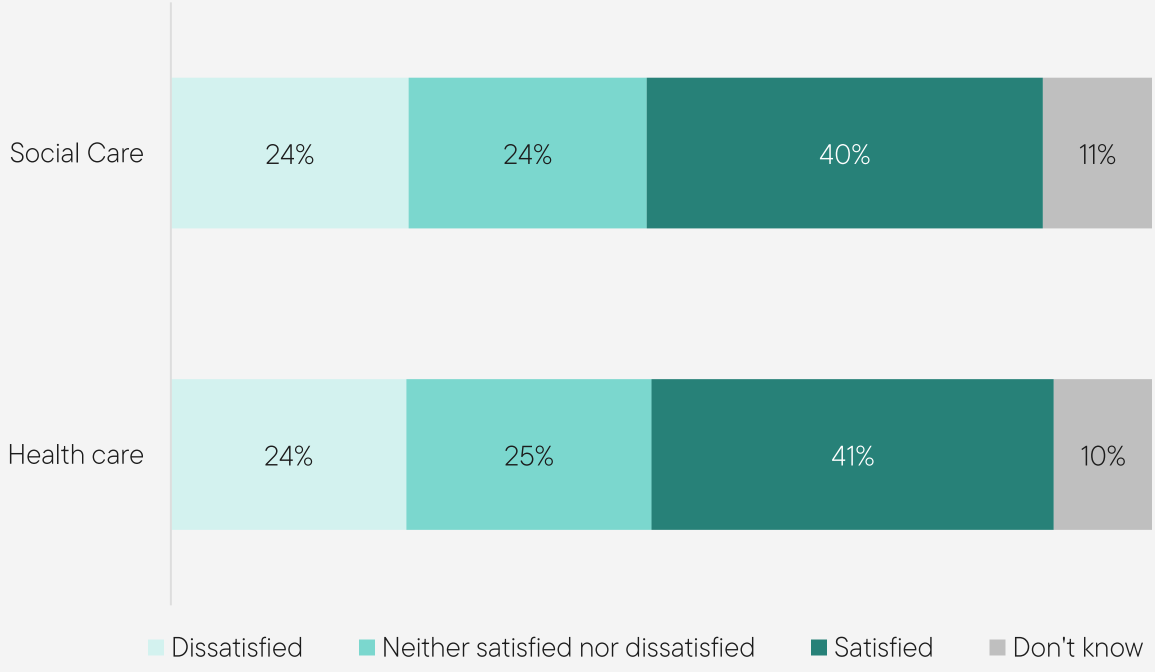
Some unpaid carers are also dissatisfied with the support that is available specifically to them.

A quarter of people who know or care for someone with dementia are dissatisfied with the health (24%) and social care (24%) support that is available to those who care for people living with dementia.

Dissatisfaction with the health care support available to unpaid carers is even higher amongst those with a disability (32%), those caring for someone experiencing late-stage dementia (30%) and people living in a rural area (27%).

Dissatisfaction with the social care support available to unpaid carers is also higher amongst those with a disability (32%), those caring for someone experiencing late-stage dementia (30%) and people living in a rural area (27%).

Only a minority are satisfied with health and social care support available to people *caring* for those living with dementia



E10a/b. How satisfied are you with the healthcare support/social care support available for those who care for people with dementia?
Base: All who know or care for someone with dementia (3,413)

Fig 2.8. Satisfaction with the support available for people caring for someone living with dementia (among those who care or know someone living with dementia)

THE LIVED EXPERIENCES OF DEMENTIA

Section 3: What are the biggest opportunities for improvement for people whose lives are impacted by dementia?

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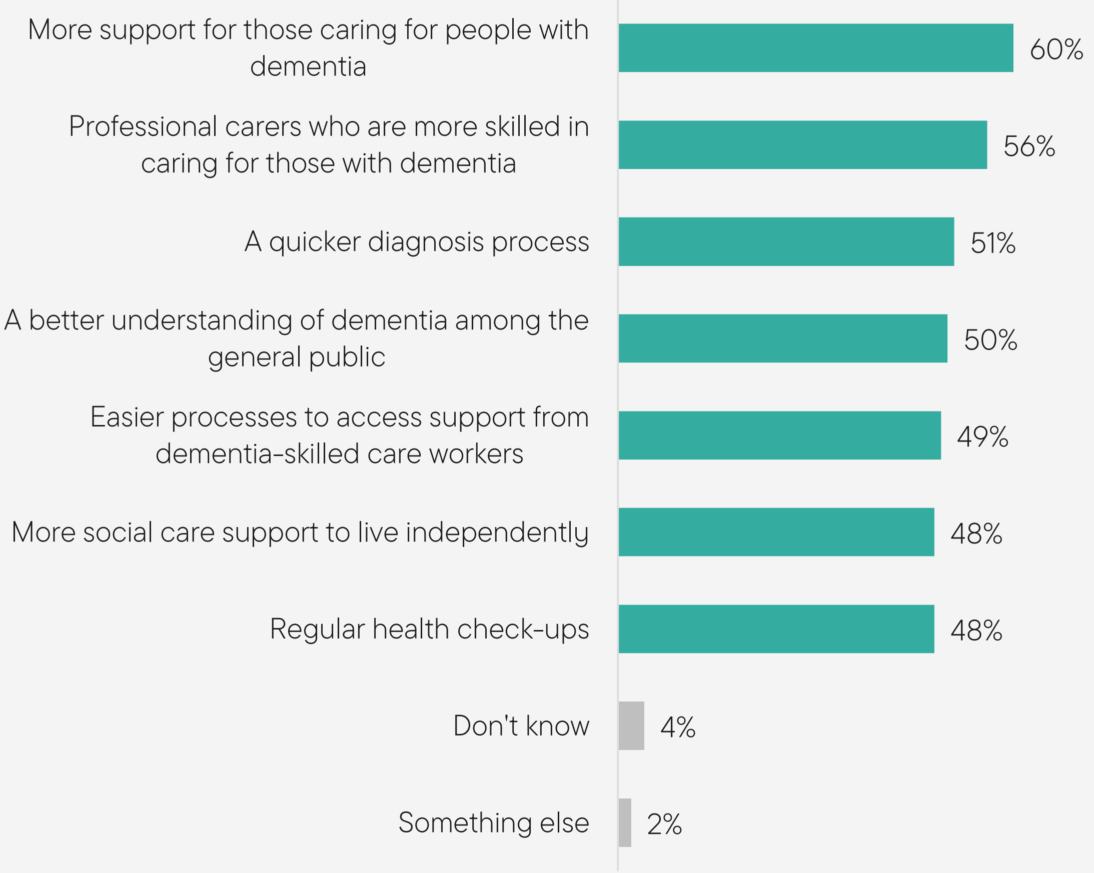
More than half say that professional carers who are more skilled in dementia care would help improve their lives.

Fifty-six per cent of people report that professional carers who are more skilled in caring for those with dementia would help improve the lives of those living with dementia.

Alongside this, six in ten feel that more support for those caring for people with dementia would best help to improve the lives of those living with dementia (60%) and 51 per cent believe a quicker diagnosis process for people living with symptoms of dementia would best help improve their lives.

More support and a quicker diagnosis would help improve the lives of those living with dementia



E17. Overall, what would best help to improve the lives of people living with dementia?
Base: All respondents (3,487)

Fig 3.1. What would best help to improve the lives of people living with dementia (total sample – all who are living with dementia or know or care for someone living with dementia)

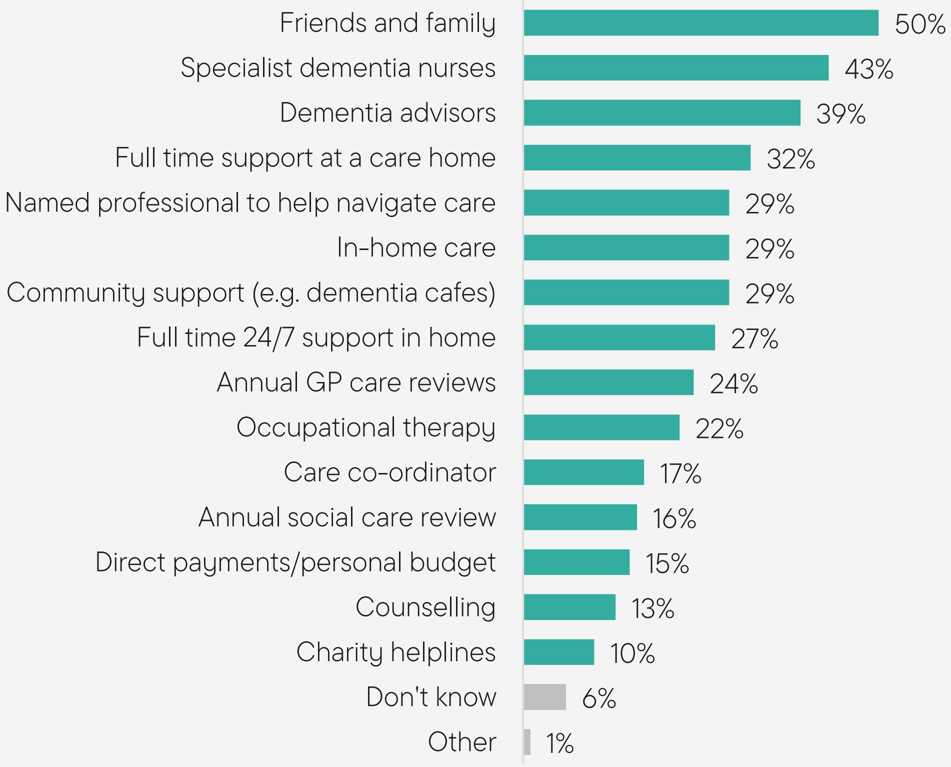
What do people believe are the most helpful sources of support?

Half of the people who know or care for someone living with dementia say that support from friends and family (50%) would be most helpful for those living with dementia.

For others, support from specialist dementia nurses (43%) or dementia advisors (39%) would be most helpful.

One in three identify full time support in a care home (32%) as most helpful.

Specialist dementia nurses and dementia advisors are valuable sources of support



E2. Which, if any, sources of support do you think would be/would have been most helpful
Base: All who know or care for someone living with dementia (3,413)

Fig 3.2. Sources of support that would be most helpful (among those who know or care for someone)

There are three key areas for improvement identified:

1. The diagnosis process
2. Social care support
3. Treatments and interventions

THE LIVED EXPERIENCES OF DEMENTIA

Section 4: People benefit from a dementia diagnosis, but experiences vary and there are barriers to access

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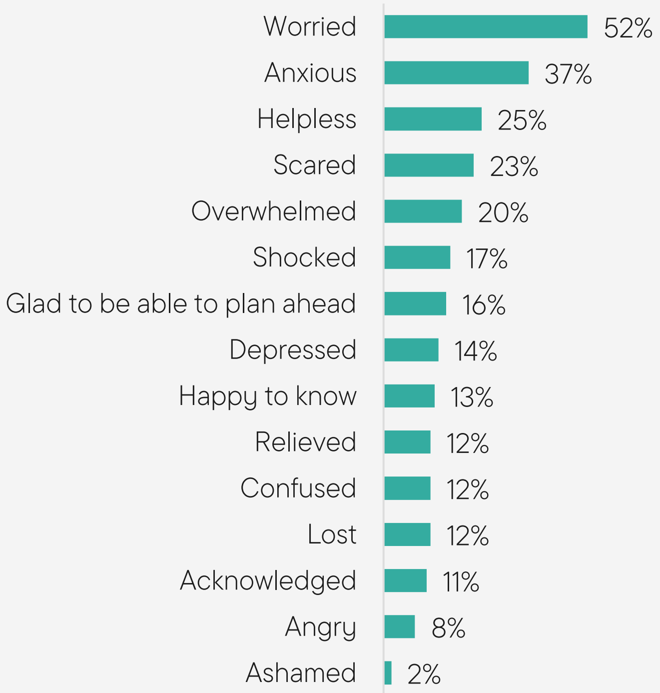
How do people feel about a dementia diagnosis?

Findings suggest there is a need for clearer and more compassionate communication throughout the diagnosis process, and people with lived experience tell us that quicker referrals for diagnosis would help make the diagnosis process smoother

Feeling worried, anxious or helpless are commonly experienced when a dementia diagnosis is received



D7. How did you feel when received an official diagnosis of dementia?
Base: All diagnosed with dementia (2,544)

Fig 4.1. Feelings experienced when official diagnosis of dementia is received (total sample – all with a dementia diagnosis or who know/care for someone with a dementia diagnosis)

Those diagnosed with dementia or know/care for someone with a diagnosis reported that the diagnosis process can be a difficult time. The top six emotions experienced when they received their official diagnosis were negative, including worry (52%), anxiousness (37%) or helplessness (25%).

For some though, receiving a diagnosis can act as a positive step as it allows people to start planning ahead (16%), gives them a sense of relief that they know their diagnosis (12%), or makes them feel acknowledged (11%).

> *"When I came out of the diagnosis, our heads were swirling because we didn't expect it. The two of us broke down in tears because we were convinced that I wasn't going to see Monday morning."*
>
> **A person living with dementia**
>
> *"I felt that they really listened to me. It had been niggling in my mind that this is just more than mild cognitive impairment"*
>
> **A person living with dementia**

What are the benefits of a diagnosis?

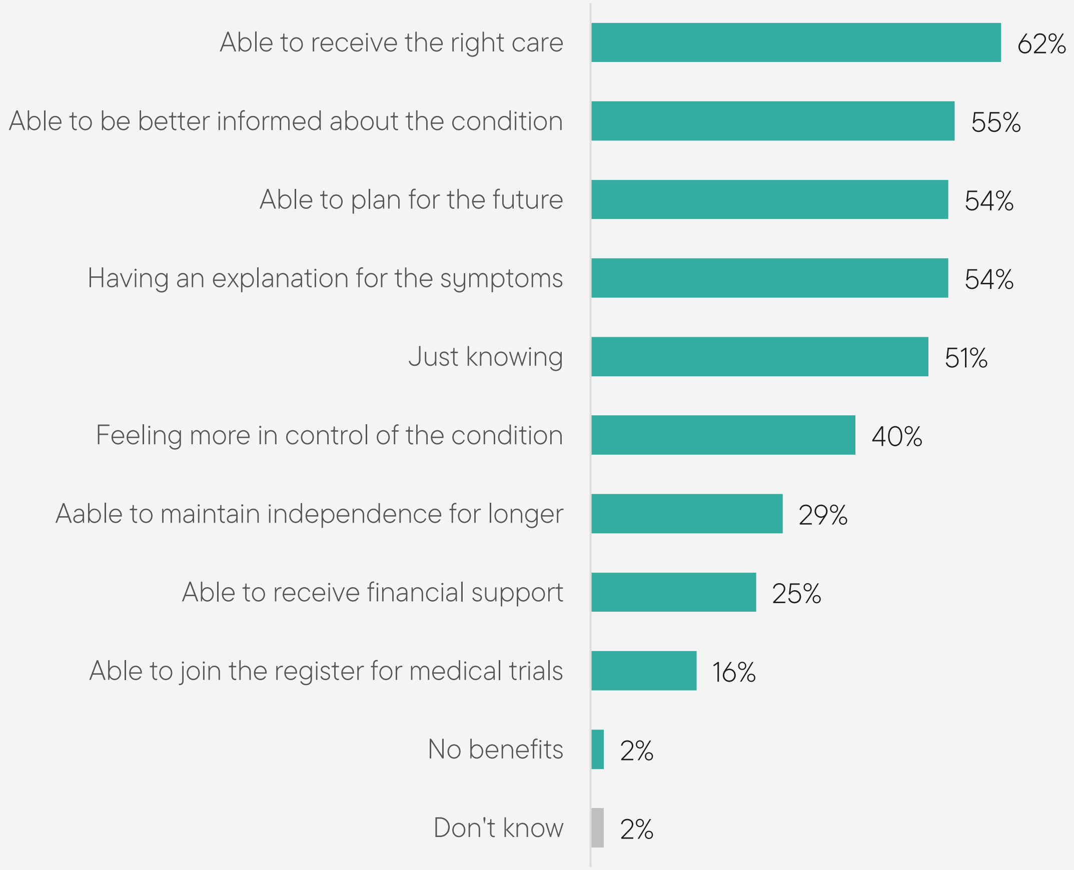
What do people believe are the benefits are of receiving a diagnosis?

The benefit of receiving a diagnosis is well understood, with only 2 per cent of respondents not thinking there is any benefit at all.

The main benefits are that those living with dementia will be able to receive the right care (62%) and that they feel better informed about the condition (55%).

Over half say that a diagnosis allows them to plan for the future (54%), and the same number of people told us that they would benefit from an explanation for the symptoms. For half (51%) of the public, the benefit is simply 'just knowing'.

Almost everyone sees a benefit to receiving a diagnosis



D14. What do you think the benefits are of receiving a diagnosis?
Base: All respondents (3,487)

Fig 4.2. The perceived benefits of getting a dementia diagnosis (to total sample – all who are living with dementia or know or care for someone living with dementia)

Experience of the diagnosis process

The overall experience of getting a dementia diagnosis is not positive for everyone and many find the process stressful.

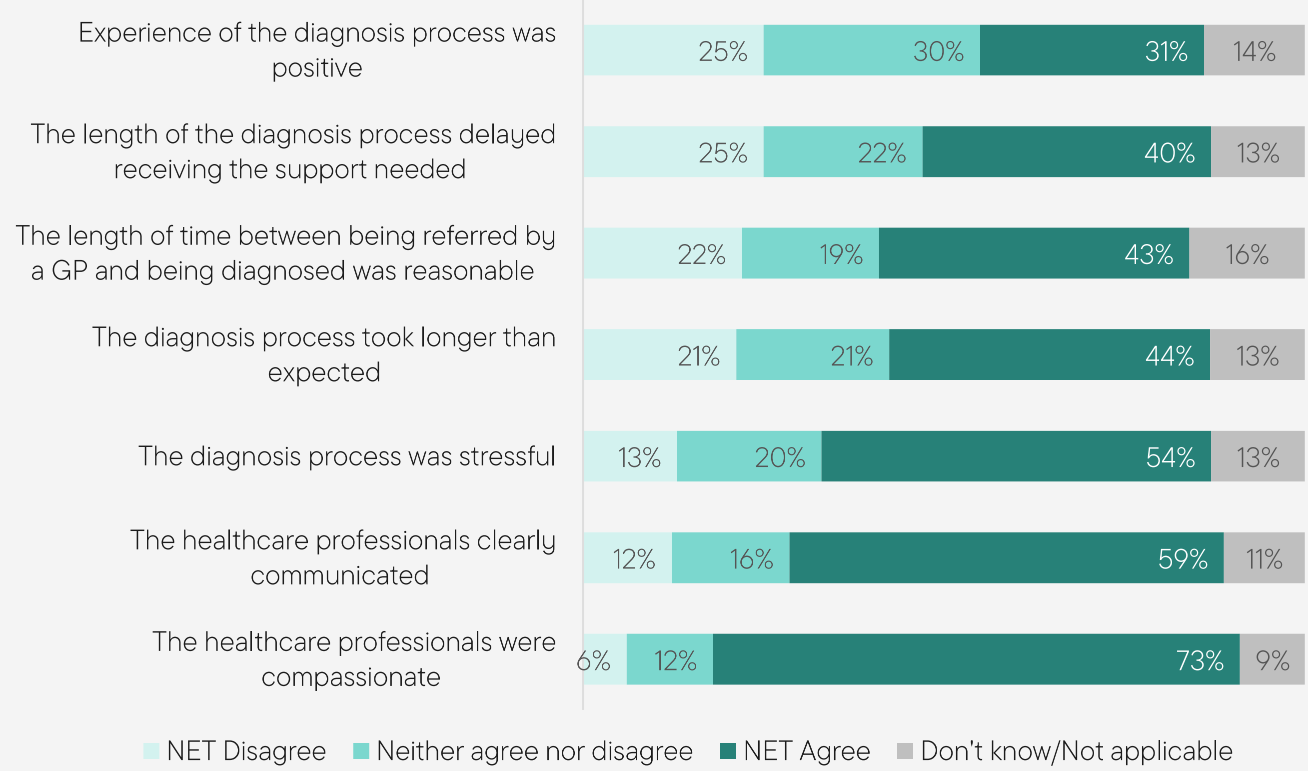
Three in ten people with a diagnosis say that their experience of the diagnosis process was positive (31%). People experiencing late-stage dementia (21%) and those living in rural areas (28%) are even less likely to have had a positive experience of the diagnosis process.

Many also found the diagnosis process stressful (54%), and the more firsthand experience someone has with dementia, the more stressful it becomes. The research shows that people living with dementia (72%) and those caring for someone (63%) felt this more strongly.

The diagnosis process also takes too long for some.

Two in five (40%) say that the length of the diagnosis process delayed them receiving the support they needed, and a similar proportion (44%) say that the diagnosis process took longer than they expected.

Only a minority agree that the experience of the dementia diagnosis process was positive, and the length of the process is delaying receiving the support needed



D9. Thinking about the experience of getting a diagnosis, how much do you agree or disagree with the following statements. Base: All diagnosed with dementia (2,544)

Fig 4.3. Levels of agreement with statements regarding the diagnosis process (total sample – all with a dementia diagnosis or who know/care for someone with a dementia diagnosis)

People are not always told what type of dementia they have during the diagnosis process.

Less than half were told what type of dementia they had *and* were given further information about it. Almost one in seven (15%) were told what type they have, but were not given any further information, and 12 per cent were not told what type of dementia they had.

Many of those diagnosed with dementia also found the diagnosis process difficult, with 37 per cent mentioning it was difficult compared to only a quarter (26%) who found the process easy.

The top issues making the diagnosis process difficult for people are long waiting times to see a healthcare professional (52%) and seeing lots of different healthcare professionals (41%).

One in three also say they experienced difficulties with communicating their symptoms (36%), while others had issues with healthcare professionals not understanding their symptoms (18%) or a misdiagnosis (12%).

Long wait times and seeing lots of different professionals make the diagnosis process difficult

D13. What made it difficult getting a diagnosis? Base: All who found diagnosis process difficult (953)

Fig 4.4 Aspects that made it difficult getting a diagnosis

Elizabeth’s Story

Elizabeth, living with **dementia** and **mild cognitive impairment**, found the diagnostic process at the memory clinic **overwhelming** and confusing. She has **little family alive** and had to navigate the diagnosis process alone. She only secured an appointment at short notice, after a long wait, and knows others who had to wait so long that they **deteriorated** before getting a diagnosis, sometimes missing the chance to benefit from **medication**.

She describes the process as “**impersonal**” and “**anxiety-inducing**”, involving **unfamiliar** tests with little explanation. Elizabeth is also frustrated by the “**postcode lottery**” in dementia care. Though told the average wait in Sheffield is 4–6 weeks, she worries delays will grow. **Post-diagnosis**, she received little support and had to find information herself, this caused her great distress as she had no one to **process** the diagnosis with.

> *“They just tell you to sit in a room, fill in some paperwork, and do tests you don’t understand. It’s confusing and it puts you on edge straight away. It’s hard to know what’s going on or what to expect.”*

Kenneth’s Story

Kenneth lives with young onset **Lewy body dementia** and **Parkinson’s;** he was diagnosed at 48. His diagnosis process was long and complex. Originally his symptoms of dementia were **dismissed** due to his age, with many other conditions having to be ruled out before dementia was considered.

He describes the diagnosis process as “**cold** and **distressing**”. At the memory clinic, the consultant spoke mainly to his wife, making him feel **ignored**. He also gave an **unsolicited** life expectancy of five years, which Kenneth found deeply upsetting, especially as he has already **outlived** this life expectancy. After the diagnosis, he had to actively **seek out** further support, when he would have expected to be contacted. This negative experience of the diagnosis process was **deeply upsetting** to Kenneth, he believes it could have done **great damage** to his mental health if it was not for the support of his wife.

> *“I was told I was too young for dementia, no one listened. Then at the memory clinic, they spoke to my wife instead of me. It was like I didn’t even matter. They told her to get my affairs in order - she was terrified.”*

What prevents people from seeking a diagnosis?

There remains a perceived stigma attached to a dementia diagnosis.

Those who have not seen a healthcare professional about their symptoms and do not have an official diagnosis feel scared, worried or apprehensive, which has prevented them from seeking professional help. One third say they have not seen a professional due to being scared (35%), while others said they feel apprehensive about speaking to a healthcare professional (31%). Women are particularly likely to say they feel apprehensive (35%).

Three in ten (29%) are worried about the impact of diagnosis on aspects of daily life. This figure is significantly higher for those who are ethnically diverse (49%) and those who care for someone with dementia (39%).

For some though, they have not seen a healthcare professional about a diagnosis because they feel ashamed (18%) or they are worried about what their friends or family would say (21%), suggesting that a perceived stigma around the condition remains.

Stigma around a diagnosis remains, with fear, worry and apprehension acting as barriers for those who haven't sought professional help

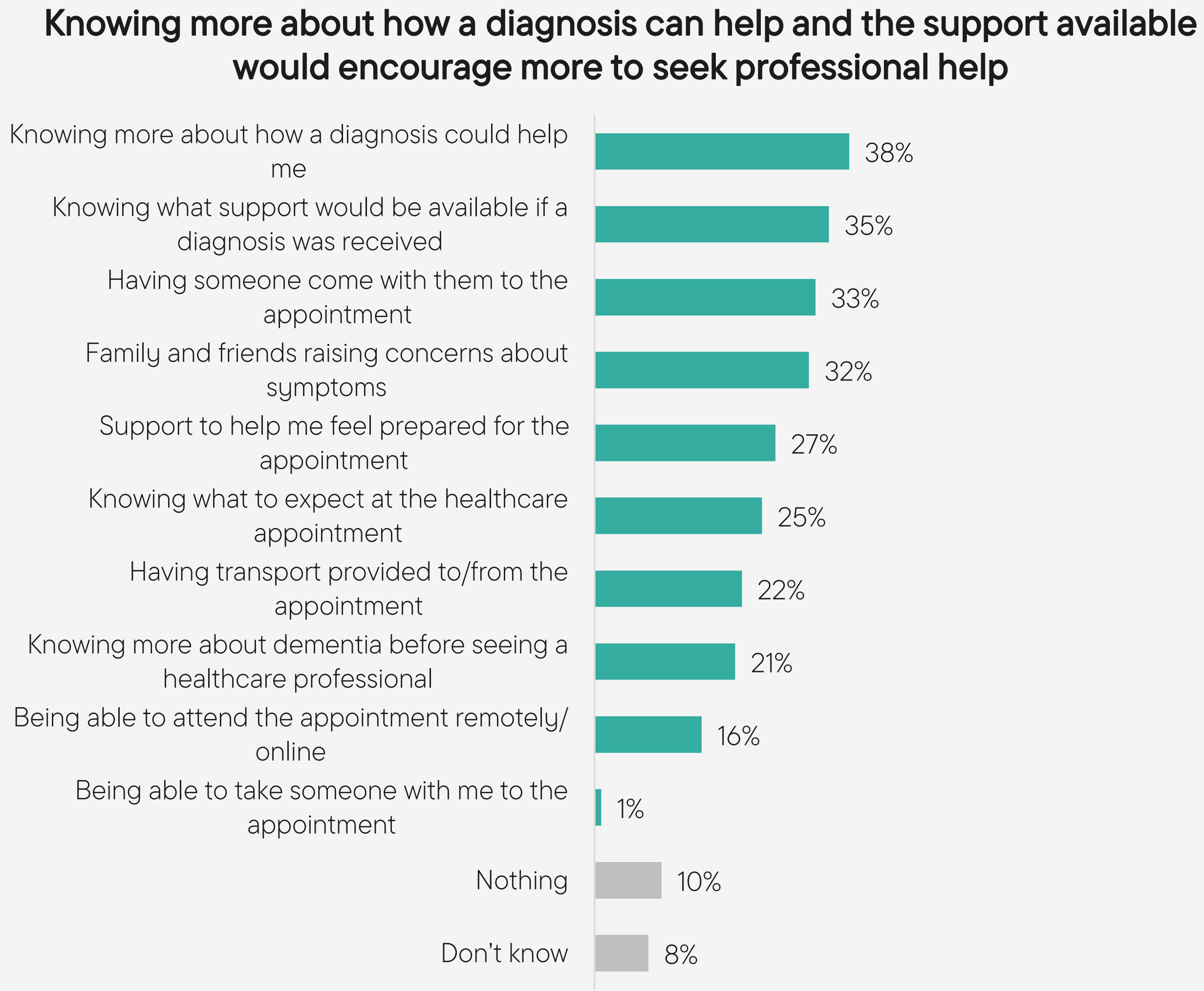
D1. Which of the following reasons describes why you/the person has not seen a healthcare professional about your/their suspected dementia symptoms. Base: All who have not seen a healthcare professional (516)

Fig 4.5. Reasons for not seeing a healthcare professional amongst those who do not have an official dementia diagnosis

What would encourage those without a diagnosis to see a healthcare professional?

For those who do not have a diagnosis of dementia, many would be more likely to see a healthcare professional if ahead of the initial appointment they knew more about how a diagnosis could help them (38%) or if they knew more about what support would be available to them if a diagnosis was received (35%).

Others without a diagnosis would like more support or information for the initial appointment; either by having someone come to the appointment with them (33%), support to help them feel prepared for the appointment (27%) or knowing more about what to expect at the appointment (25%).


Knowing more about how a diagnosis can help and the support available would encourage more to seek professional help

D2. What, if anything, would make you/the person more likely to see a healthcare professional about dementia symptoms? Base: All who have not seen a healthcare professional (516)

Fig 4.6. What would make people more likely to see a healthcare professional amongst those who do not have an official dementia diagnosis

What are the key takeaways in relation to the dementia diagnosis process from both the quantitative and qualitative phases?

Diagnosis experience

People's experience of the diagnostic process can be negative, and people find it stressful.

Clear communication

People can feel apprehensive or fearful speaking to healthcare professionals. They also want more information on the diagnosis process and dementia, including potential tests and scans and the reasons why these are conducted.

Information and support

Findings suggest that more logistical and emotional support would encourage more people to seek professional help for dementia. People also want more information on dementia generally, which could reduce anxiety and confusion.

THE LIVED EXPERIENCES OF DEMENTIA

Section 5: People often rely on friends and family for support, and access to and the experience of social care needs to be improved

Alzheimer's Society

It will take a society to beat dementia

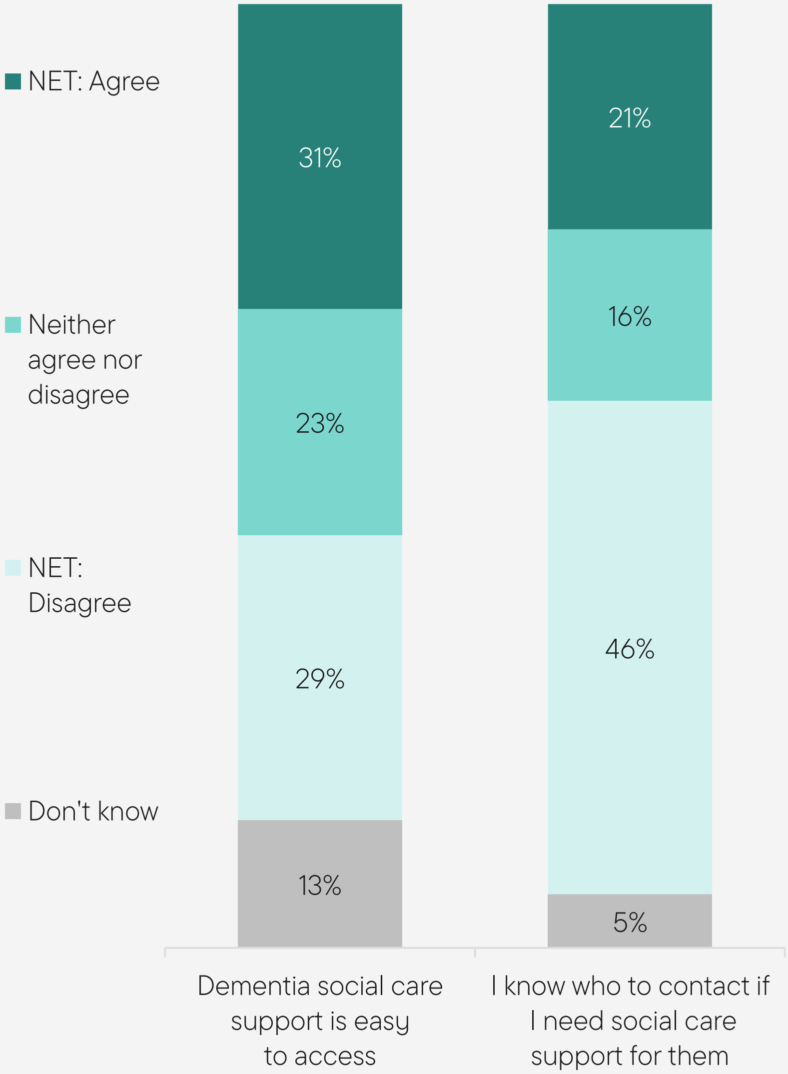
WAL NUT

Part of Accenture Song

How accessible is social care support?

Access to social care for individuals living with dementia is inconsistent with the ability to access social care in the first place being an obstacle for many.

Accessing social care support can be challenging



E9. To what extent do you agree or disagree with the following statements?
Base: All who know or care for someone with dementia (3,413)

Fig 5.1. Agreement with statements about social care support asked amongst all who know/care for someone with dementia

Of those who know or care for someone living with dementia, just three in ten (31%) agree that social care support for dementia is easy to access.

There was even lower agreement amongst those with experience of the early stages of dementia (18%), people from an ethnically diverse background (18%) and those who live in urban areas (22%).

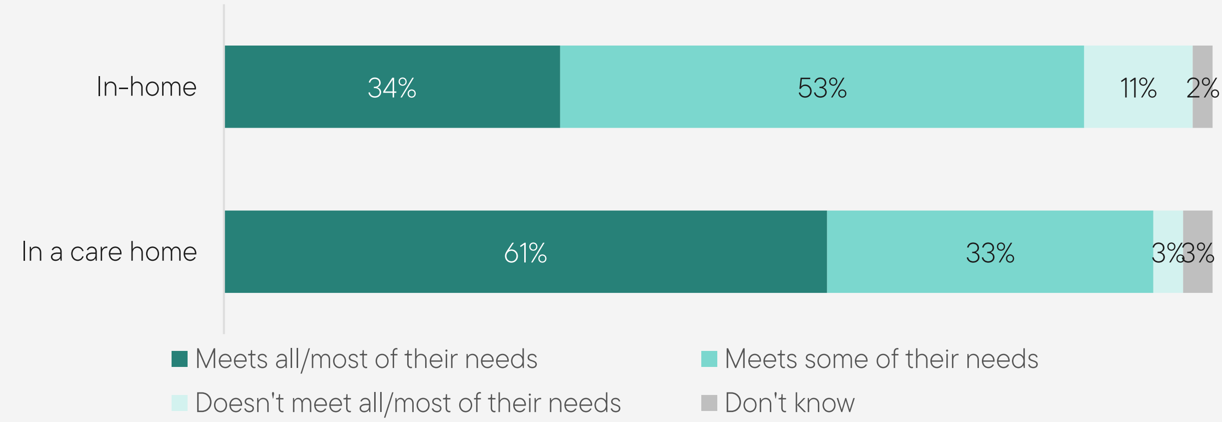
Nearly half (46%) don't know who to contact if they need social care support for the person they know or care for.

This was even higher amongst those from an ethnically diverse background (62%), those with experience of early-stage dementia (60%) and those living in an urban area (58%).

Experience of social care received

Quality of care is felt to be more comprehensive and complete in care homes than from in-home professional carers by those who know or care for someone living with dementiaa. One third (34%) believe the support received from professional in-home carers meets all or most of their needs compared to three-fifths (61%) of those who receive care in a care home.

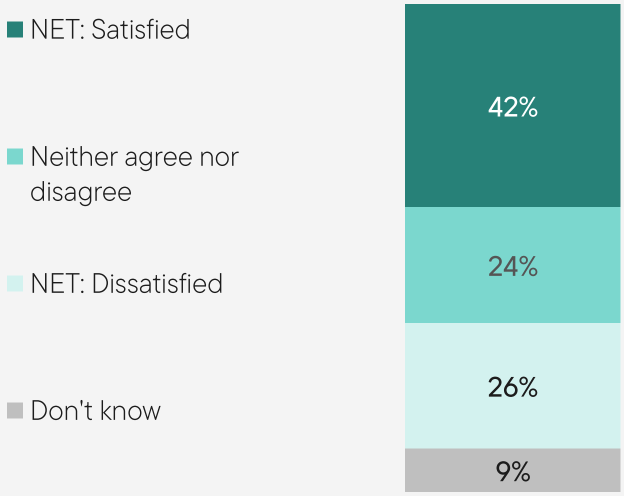
Professional care home support meets the needs of the majority



ES1/2. Do you feel that the support that they receive from professional carers in-home/in the care home meets/met their needs?
Base: All who know or care for those who receive social care support in-home (829)/in a care home (382)

Fig 5.2. Degree of needs met from professional carers in-home or in a care home (among people who care or know someone living with dementia in-home or in a care home)

Only a minority are satisfied with the social care support available



E16b. Now thinking overall about your experiences with dementia. How satisfied are you with the social care support available for people with dementia? Base: All who know or care for someone with dementia (3,413)

Fig 5.3. Satisfaction with social care support, amongst those who know or care for someone with dementia.

Many are not satisfied with social care support.

Just over two in five (42%) who know or care for someone say they are satisfied with the social care support available for people living with dementia. Yet, a quarter (26%) say they are dissatisfied.

People with a disability (35%) and those with experience of late-stage dementia (33%) are more likely to be dissatisfied.

Phillip's Story

Phillip lives with **young onset dementia** and describes the social care system as difficult to **navigate,** especially for younger individuals. He notes that many people are **unaware** of how to access free support or avoid seeking help due to **negative perceptions** of social care, often shaped by stories of poor treatment and neglectful staff.

While Phillip has benefited from home adaptations provided by an occupational therapist, he expresses frustration that he is not eligible for government-funded **residential care.** Phillip believes there is an urgent need for the government to **reassess** the services available to those living with young onset dementia, as too many people are left without vital support.

> *"There are 70,000 of us with young onset. We're not a small number, but we're treated like we don't fit anywhere."*

Rose's Story

Rose lives **alone** with dementia and has no family support. After calling Age UK, she used the Sheffield Directory to find a **local support group**, which she now attends weekly and finds deeply **valuable** as a space to feel **understood**. Ideally, she would attend more groups, but her mobility issues means she is reliant on social care support to help her. Currently she can not find **free resources** and so would have to **pay for support**. Rose considers this out of the question, despite how beneficial attending groups may be, as she is prioritising **saving** for a **care home** over all other needs.

With no family to look after her she has been financially planning for her deteriorating health in recent years. Rose's story demonstrates how, without family support and with limited **affordable social care** options, some people living with dementia are under extreme **financial** strain, having to make difficult decisions **alone.**

> *"I'd rather have some nice people in to help me, but I just can't afford it. I have to be pragmatic whilst I'm still insightful and make sure it is all sorted."*

How does social care make a difference?

Many with dementia rely *solely* on their friends and family for support.

Over half (54%) who know or care for someone say that the person they know with dementia relies solely on their friends or family for support, rather than any other help. This figure is significantly higher for those who are ethnically diverse (61%).

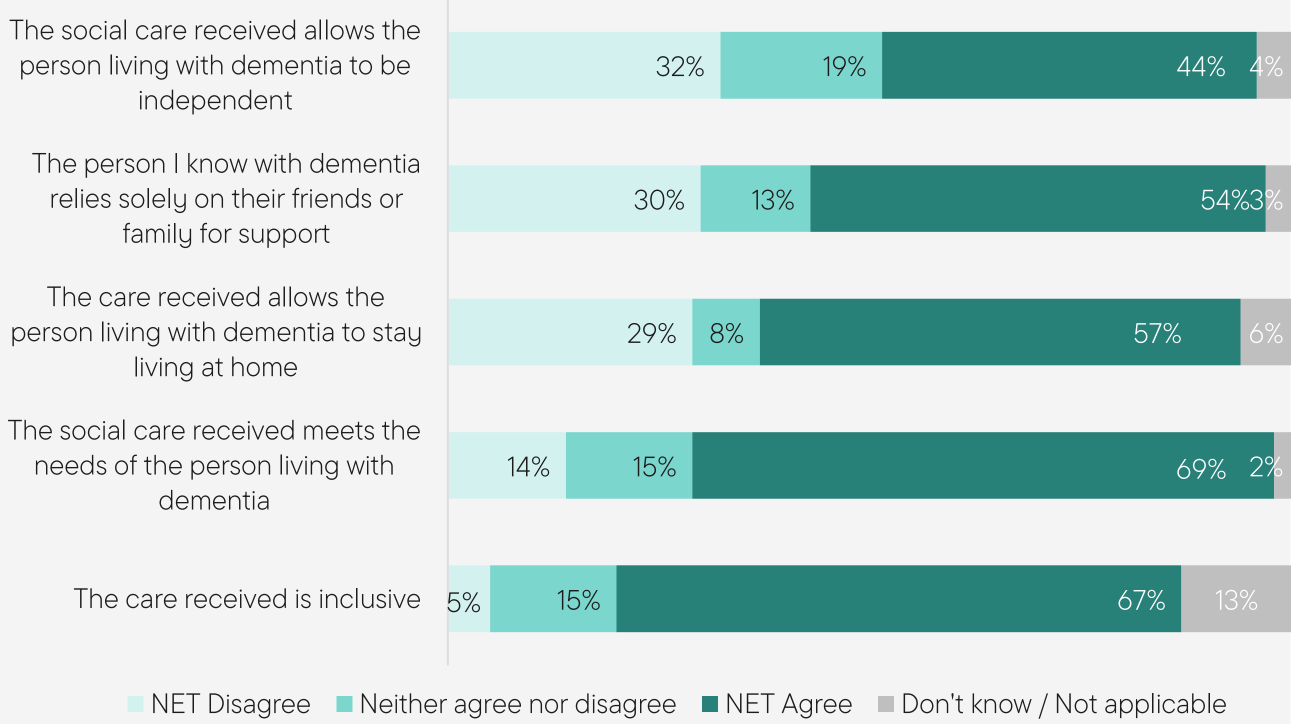
Social care doesn't allow the majority of those living with dementia to be independent.

Just over two in five (44%) who know or care for someone think that the social care received allows the person they know living with dementia to be independent, and this is significantly higher for those who are ethnically diverse (63%). One third (32%) disagree with this.

However, social care does allow many of those with dementia to stay living at home.

Nearly three in five (57%) feel that the care received by the person they know living with dementia allows them to stay living at home.

For many, social care does not allow the person living with dementia to be independent however it does meet their needs



E8b. To what extent do you agree or disagree with the following statements?
Base: All who know or care for someone with dementia (3,413)

Fig 5.4. Levels of agreement with statements regarding social care support, amongst all who know or care for someone with dementia.

Karen's Story

Karen supports her 92-year-old grandfather who was **diagnosed with dementia** within the last 2 years. While she doesn't think of herself as a formal carer, she plays a consistent role visiting him, providing financial support, arranging transport and sending him quality meals to improve his day-to-day life. Her grandfather **lives alone and receives drop-in social care** at home from the NHS to aid with taking medication, food and personal care needs.

Karen **expresses concern over the limited and impersonal nature** of the social care support, feeling that day-to-day tasks such as using the toilet and food preparation are sometimes handled by professional **carers who seem fatigued and detached.** She wishes they would **treat him more than a client** and try and build a good relationship with him by being conversational and asking questions.

She believes the current care system **lacks community-based solutions** that provide support above and **beyond basic needs**, to enrich lives like her grandfather's, such as local day centres that offer meaningful activities like painting.

> *"I would tell them to treat him more than a client, but someone who they actually get to know, and get a good relationship with him. I think that would be important. And try and have a good conversation with him."*

Qualitatively, what are some of the key takeaways in relation to access and experience of social care for those living with dementia?

Support for people in earlier stages of dementia

People who are living in the earlier stages of dementia experience difficulties with accessing social care support, and the experience isn't always inclusive of their needs leaving them feeling overlooked and poorly supported.

Care for those without family

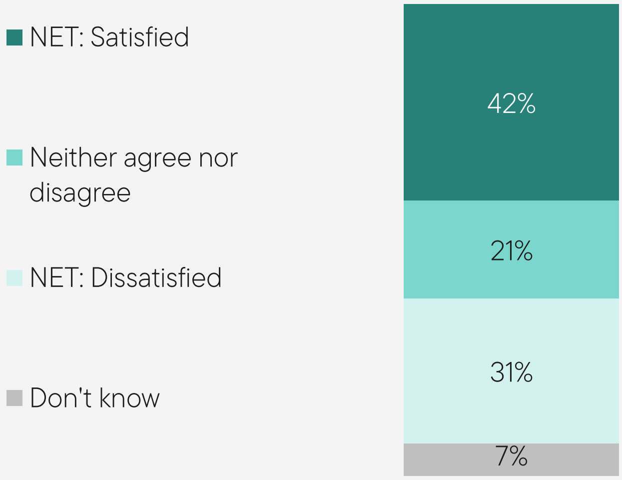
Not all people living with dementia have wider family and friend support networks, which impacts on access and awareness of affordable and ongoing social care support. They want their needs to be considered in the development and delivery of social care support.

Training professional carers

There is a need for greater training for professional carers of those with dementia above the physical care tasks, to include interpersonal skills such as empathy, communication and trust building. This ensures rapport is developed with the individuals they care for, especially if they do not have family or friends who live close by.

What is the experience of social support for carers?

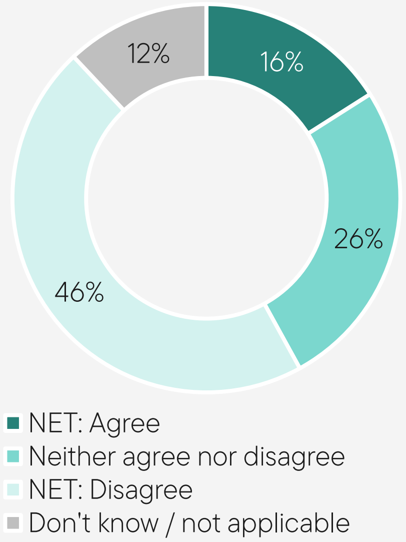
Many unpaid carers are not satisfied with the social care support available to them



E10b. How satisfied or dissatisfied are you with the social care support available for those who care for people with dementia? Base: All who care for someone with dementia (808)

Fig 5.6. Satisfaction with social care support for unpaid carers, amongst those who care for someone with dementia.

Many unpaid carers don't feel respected as a carer by social care professionals



E9b_3. I feel respected as a carer by social care professionals (To what extent do you agree or disagree with the following statements around social care?) Base: All who care for someone with dementia (808)

Fig 5.7. Agreement with feeling respected in their role by social care professionals, amongst unpaid carers

For many unpaid carers, the current experience of social care support specifically available to them is not satisfactory.

Just over two in five (42%) are satisfied with the social care support available for those who care for people with dementia, compared to one third (31%) who said they are dissatisfied with this.

Many unpaid carers also don't feel respected in their role by social care professionals.

When unpaid carers were asked if they feel respected as a carer by social care professionals, nearly half (46%) disagreed, and only one in six (16%) agree that they feel respected as a carer.

Those from an ethnically diverse background (7%), those caring for someone in the early stages of dementia (7%) and those living in an urban area (8%) were even less likely to agree that they feel respected as a carer by social care professionals.

Steve's Story

Steve cared for his grandmother, who was diagnosed with Alzheimer's, for over five years. He also cares for his wife and child, which placed an **additional strain on his time and mental health** during this time. He faced significant emotional and practical challenges during his caring journey, including a **lack of training or information** about dementia from health services and **minimal early-stage support** for carers, receiving just a leaflet.

He feels there is a need for more **social hubs in his local community,** as well as online, for advice and to allow for much needed connection and collaboration. Steve thinks there should be better awareness, communication, and support for family carers from the NHS, noting that existing resources often **focus solely on the patient** rather than those providing care.

> *"I think there should be a bit more advertising, more for the people caring for them – that there is support out there for them, you know, this is a number you can ring for free"*

Hazel's Story

Hazel has supported **both her mother-in-law and father-in-law with dementia** and has recently started caring for her husband now that he has started developing symptoms of dementia.

When she was supporting her mother-in-law and father-in-law, she **wasn't sure who to contact for support.** She considered calling social services but was concerned that they would think she couldn't look after them and was **worried about being judged** for the questions she asked. She also faced struggles with her **mental health** but was worried that if she told her GP that they would put the person she was caring for in a home.

> *"If there is a sort of local clinic or somebody you could go to off the record to discuss your worries with them and say 'how do I do this and that', that would be really helpful"*

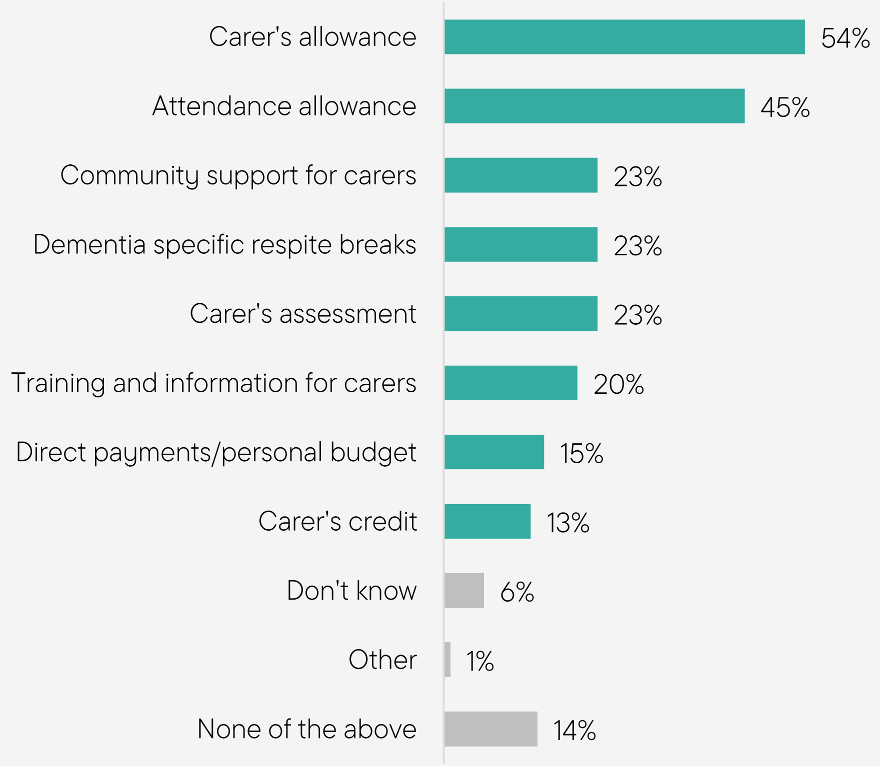
Some unpaid carers are not aware of any types of support that are available to them. One in seven (14%) state this is the case for them.

The most commonly known types of support are carer's allowance and attendance allowance but there remains inconsistencies, with around half of unpaid carers still not aware of these types of support.

More than half of unpaid carers (54%) are aware of carer's allowance, which is the type of support most widely known among unpaid carers. Attendance allowance is the second most widely recognised form of support, with just under half of unpaid carers (45%) aware.

There are similar levels of awareness for community support, dementia specific respite breaks and carer's assessment, with around a quarter (23%) of unpaid carers aware of these. The least known forms of support are direct payments (15%) and carer's credit (13%).

Carer's allowance and attendance allowance are the most known types of support for unpaid carers



E4. Are you aware of the following areas of support available for carers of those with dementia? Base: All who care for someone with dementia (808)

Fig 5.8. Awareness of the support available for carers of those with dementia, amongst unpaid carers

Of unpaid carers who are aware of the support available to them, many do not actually receive *any* support.

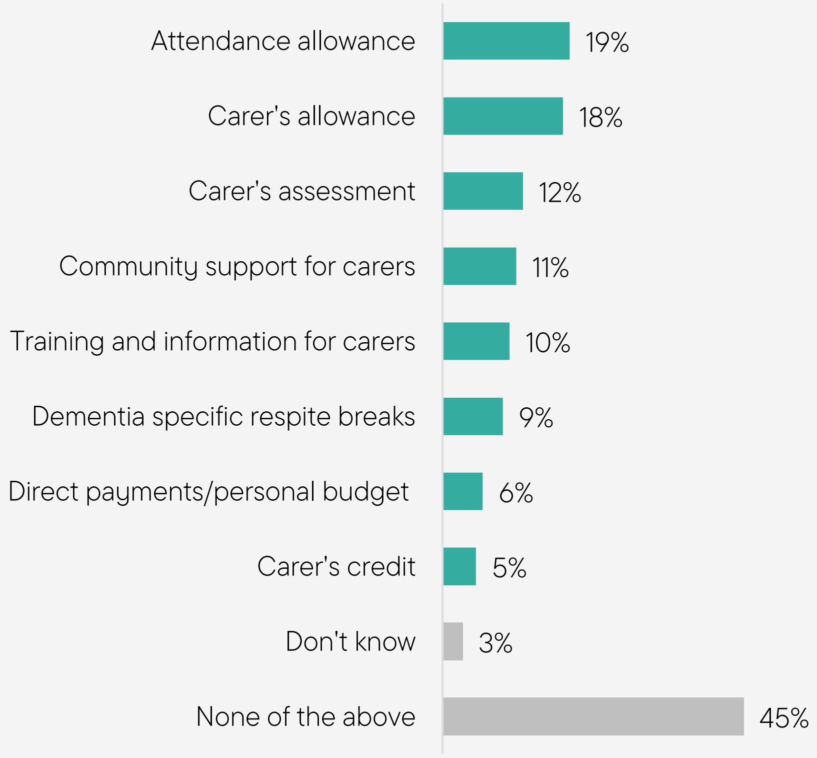
Just under half (45%) do not receive any support that is available to them.

Attendance allowance is the type of support most widely received, but it is not universal.

Amongst unpaid carers who are aware of the support available, one in five (19%) receive the attendance allowance, and a similar proportion (18%) receive the carer's allowance. Even fewer unpaid carers have received a carer's assessment (12%) or any community support (11%).

> *"All I got was a leaflet off the doctor, it just helps with what the person will go through in stages, but it doesn't help the person who's caring. There's not things in place for the carer if things get too much."*
>
> **Carer for someone living with dementia**

Many unpaid carers do not receive any form of support



E5. Have you received any support available for carers of those with dementia from the following sources?
Base: All carers who aware of support for carers (641)

Fig 5.9. Types of carer support received, amongst unpaid carers who are aware of support for them

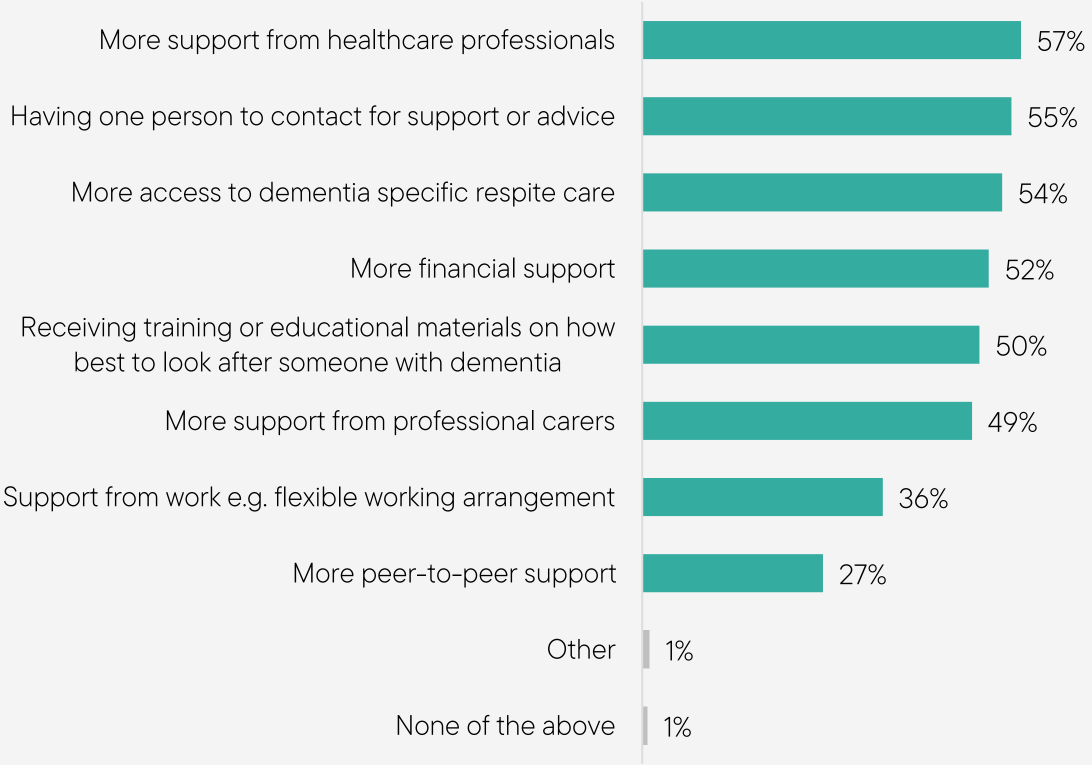
Unpaid carers would like more support from professionals and a single named contact for advice or support.

Further support from healthcare professionals is the top action identified by unpaid carers to improve carer support, with more than half (57%) reporting this as a need. A similar proportion (55%) believe having one named person to support or advise them could improve the support available to carers. Half (49%) would generally like more support from professional carers.

Further financial support and greater access to dementia specific respite care is also needed.

Over half (54%) also believe that better access to dementia specific respite care would improve the support available to unpaid carers, and a similar proportion (52%) think additional financial support could help.

Carer support could be improved through further support from professionals, respite care, training and financial assistance



E11. How could support for carers of people with dementia be improved?
Base: All who know or care for someone with dementia (3181)

Fig 5.10. Ways carer support could be improved, amongst those who know or care for someone with dementia

What are the key takeaways in relation to social care support that is available to unpaid carers of those living with dementia?

Support and guidance for unpaid carers

Unpaid carers would like earlier support and greater training, practical support and guidance to help reduce stress and to support them in their caring role. Some also want spaces within communities to share their experiences.

Increased signposting

Some carers only have a healthcare professional as their main point of contact and want healthcare professionals to be equipped to refer or direct them to appropriate financial and social support services.

Single named contact

People caring for people living with dementia say that a single named contact to coordinate care would help facilitate access to support such as offering advice and signposting to services available.

THE LIVED EXPERIENCES OF DEMENTIA

Section 6: People are not always given access to existing treatments and interventions for dementia, but they could provide benefits

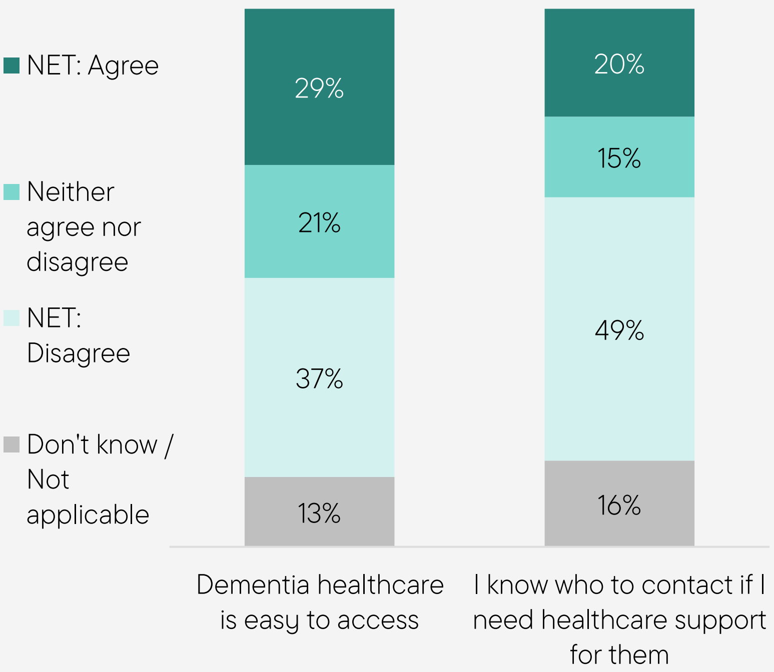
Alzheimer's Society
It will take a society to beat dementia

WAL NUT
Part of Accenture Song

How accessible is healthcare support?

Overall, the findings show that the outcomes from treatments and interventions are positive. However, accessing treatments and healthcare support can be difficult for some.

Dementia healthcare accessibility is mixed



E9a. To what extent do you agree or disagree that Dementia healthcare was/is easy for [them] to access.
Base: All who know or care for someone with dementia (3,413)

Fig 6.1. Agreement with statements about healthcare support, amongst all who know/care for someone with dementia

Those who know or care for someone with dementia have mixed experiences when it comes to accessing healthcare support.

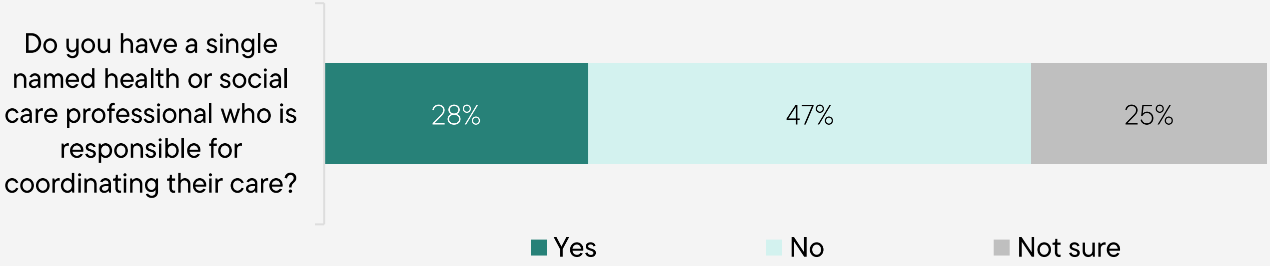
Three in ten (29%) agree that dementia healthcare support is easy to access.

Those who live in urban areas (20%) or from an ethnically diverse background (18%) are less likely to think that dementia health care is easy to access.

When it comes to knowing who to contact for healthcare support for the person they know or are caring for, only one fifth (20%) agree that they know who to contact.

> *"Sometimes it's like trying to get blood from a stone. It's just really hard trying to get through all the red tape and trying to get through people."*
>
> **A person living with dementia**
>
> *"There is so many people that need help. The waiting list is so long, I had a friend who called up and he was 17th in a queue."*
>
> **A person living with dementia**

Access to care coordinators vary



ES3. Do/Did you have a single named health or social care professional who is responsible for coordinating their care?
Base: All know or care for someone with dementia receiving social or healthcare support (1,991)

Fig 6.2. Whether or not those who know or care for someone with dementia have a care coordinator, asked amongst those who have received health or social care support

Not everyone has access to a care coordinator.

Care coordinators are single named health or social care professionals who are responsible for coordinating the care of someone diagnosed with dementia. Their role includes providing information on how to access services and developing a care and support plan. While almost three in ten (28%) who know or care for someone have a single named health or social care professional who coordinates the care for the person they know with dementia, nearly half (47%) say they do not.

Those who know or care for someone with early-stage dementia (46%), living in urban areas (41%) or higher social grades (35%) are more likely to have a single named health or social care professional.

> *"We did have a carer who was our single named contact. Whilst he couldn't help with a lot of things, he had gone through similar experiences which was sometimes helpful."*
>
> **Carer for someone living with dementia**
>
> *"We had a named social worker who I met several times, and we went through the care plan together with her. She did what she could, and she was at the end of the phone when I needed her. She was useful to have there, and develop a care plan, but things don't often go to plan"*
>
> **Carer for someone living with dementia**

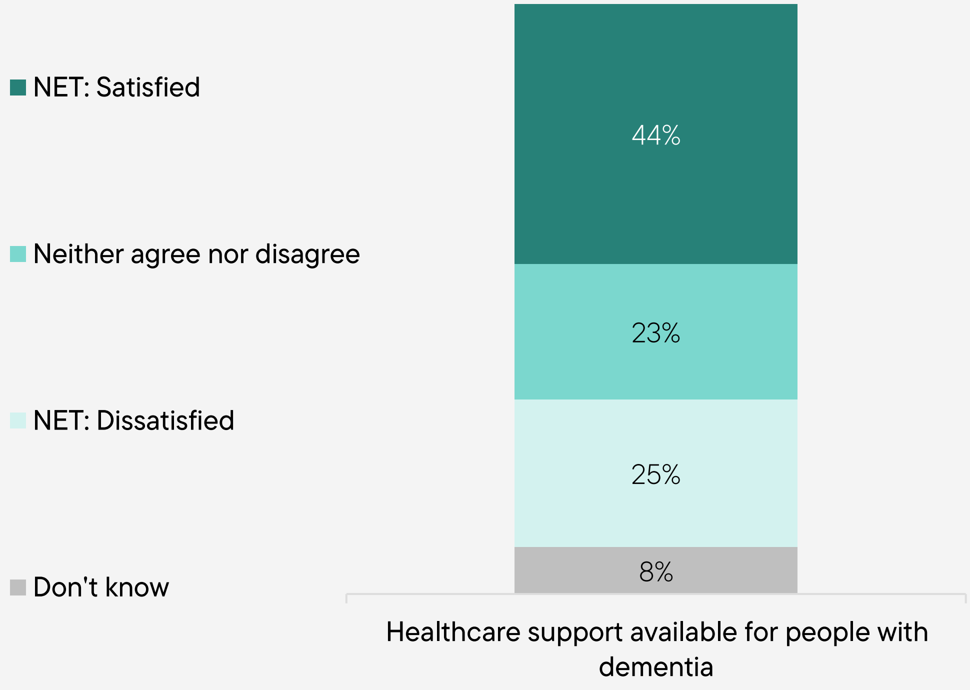
Experience of healthcare support received

Satisfaction with healthcare support is relatively low.

Less than half (44%) of those who know or care for someone say they are satisfied with the healthcare support available for those living with dementia, and a quarter (25%) say they are dissatisfied.

Satisfaction is lower amongst those aged 65+ (31%), those with a disability (36%), those caring for someone with later stage dementia (39%) and those who live rurally (41%).

Satisfaction with healthcare support for people living with dementia is relatively low



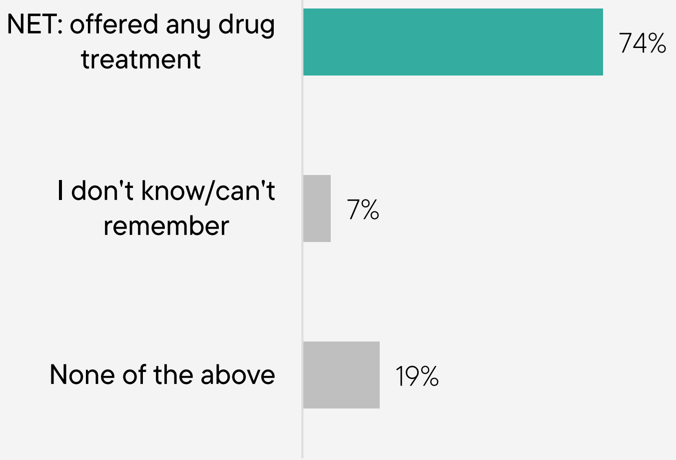
E16a. Now thinking overall about your experiences with dementia. How satisfied are you with the healthcare support available for people with dementia? Base: All who know or care for someone with dementia (3,413)

Fig 6.3. Satisfaction with healthcare support, amongst all who know or care for someone with dementia.

Accessibility of treatments and interventions

**NOTE: low base sizes on this page– interpret with caution*

The majority have been offered access to drug treatments



ET1. Have/Had you been offered any of the following drug treatment for dementia? *Question includes Donepezil, Galantamine, Rivastigmine and Memantine.*
Base: All living with dementia (74*)

Fig 6.4. Whether those who are living with dementia have been offered drug treatments

Most have been offered drug treatments.

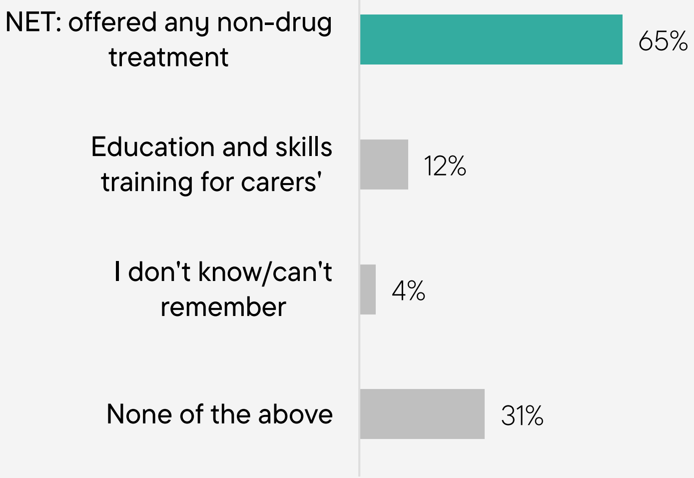
Three quarters of those living with dementia say they have been offered some sort of drug treatment such as Donepezil, Galantamine, Rivastigmine or Memantine.

A fifth say they have not been offered one of these drug treatments.

Fewer people have been offered a non-drug treatment.

Two-thirds (65%) of those living with dementia have been offered non-drug treatments, such as cognitive stimulation therapy, group reminiscence therapy, cognitive rehabilitation therapy or occupational therapy. A third (31%) have not been offered one of these non-drug treatments.

Access to non-drug treatments is less common



ET3. Have/Had you/they been offered any of the following non-drug treatments for dementia? *Question includes cognitive stimulation therapy, group reminiscence therapy, cognitive rehabilitation therapy or occupational therapy.*
Base: All living with dementia (74*)

Fig 6.5. Whether those who are living with dementia have been offered non-drug treatments.

Experience of treatments and interventions

NOTE: low base sizes on this page– interpret with caution

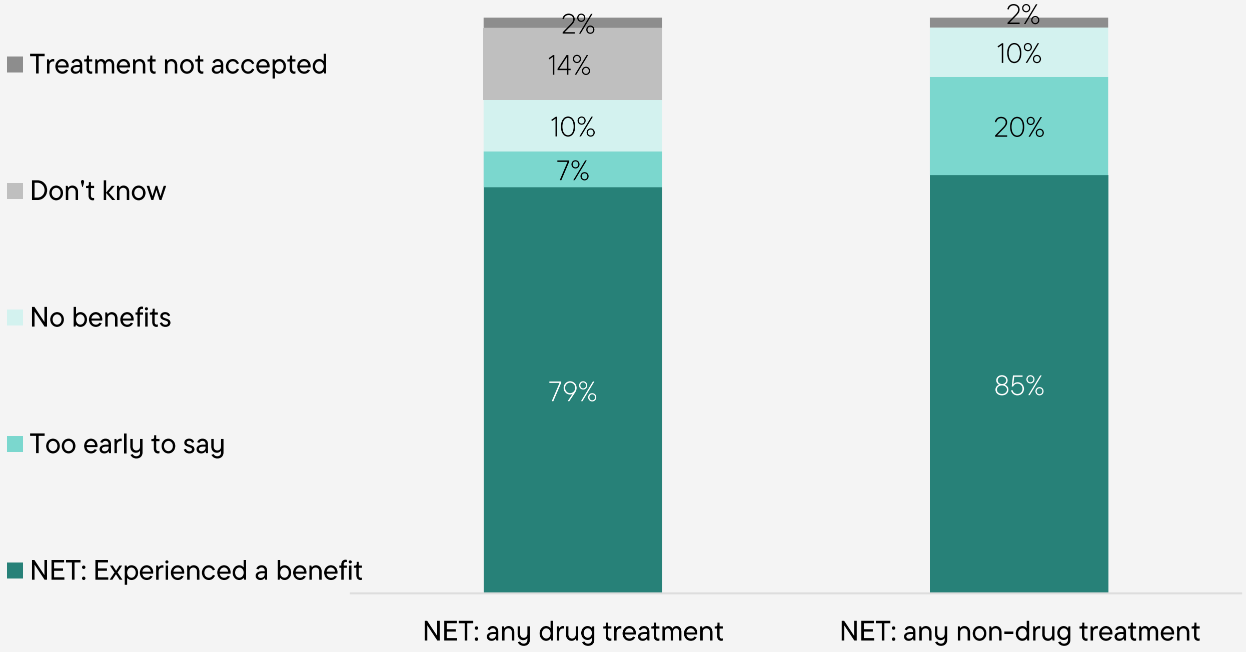
Most have experienced some benefit from treatments.

While non-drug treatments are less likely to be offered, they are just as likely to be reported as beneficial as drug treatments.

Four in five (79%) people living with dementia have experienced benefits from a drug treatment they took, while 7 per cent stated it was too early to say and only 10 per cent felt they experienced no benefits. Most did accept the drug treatment that was offered, with only 2 per cent saying that they did not accept the treatment offered.

Over four in five (85%) said they experiences a benefit from non-drug treatment, one in five said it was too early to say and 10 per cent said they experienced no benefit. As with drug treatments, most accepted the non-drug treatment they were offered.

Many experience benefits from both drug and non-drug treatments



ET2. To what extent do you feel you/they experienced benefits from the following drug treatments?
NOTE: those who answered 'A drug treatment was offered but I don't know what it was called' at ET1 were not asked if they experienced benefits
Base: Those living with dementia who have been offered each drug treatment (42*)
ET4. To what extent do you feel you/they experienced benefits from the following non-drug treatments?
NOTE: those who answered 'A non-drug treatment was offered but I don't know what it was called' at ET1 were not asked if they experienced benefits
Base: Those living with dementia who have been offered each non-drug treatment (41*)

Fig 6.6. Benefits of any drug or non-drug treatments that have been taken by those living with dementia.

Judith's Story

Judith, who is living with Alzheimer's, takes **Memantine** to help **combat** the effects of "brain shrinkage and white spots". While she is unsure how much the medication has helped, she **remains optimistic** and believes it is important to consistently try new medication.

She actively **engages** in non-drug treatments. These include a walking class with Age UK to prevent falls, Tai Chi, gardening, and balance exercises. Judith emphasises the importance of staying **motivated and involved**, finding both the social and physical elements of these treatments useful.

> *"Have to get involved to keep yourself going. I have to have the motivation to do things, but if you haven't got the motivation to do things, it's a very slippery slope.*

Frederick's Story

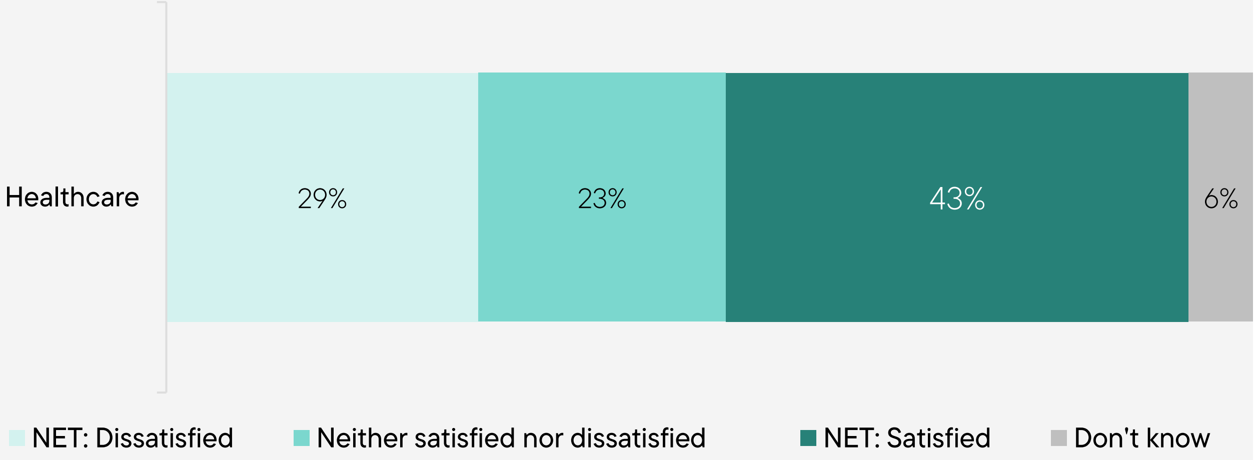
Frederick, diagnosed with young onset Lewy Body dementia and Parkinson's, has been prescribed **Memantine** and **Rivastigmine**. He finds these treatments beneficial and believes they have slowed his decline. He also participated in an NHS-run 16-week **Cognitive Stimulation Therapy** (CST) programme.

However, the activities were not suited to him as most participants were much **older**, making the sessions **less engaging** and **relevant** for his needs. The lack of services for those with young onset makes Frederick feel that his needs are **not considered**. Frederick stresses the need for more funding for non-medical treatments for those with **young onset.**

> *"The activities in the therapy group weren't suited to me because I was too young compared to the others. It didn't really stimulate my brain or feel relevant, but it was good to try"*

Experience of healthcare support for unpaid carers

Satisfaction with health and social care support for unpaid carers is mixed



E10a. How satisfied or dissatisfied are you with the healthcare support available for those who care for people with dementia?
Base: All who care for someone with dementia (808)

Fig 6.7. Satisfaction with health and social care support for unpaid carers of people with dementia, amongst carers of people with dementia

A third are dissatisfied with health care support for unpaid carers.

Satisfaction amongst unpaid carers with health care support specifically available to them is mixed, with three in ten expressing dissatisfaction with healthcare support (29%). At the same time, around two in five are satisfied, showing that experiences are mixed.

> *"I think the thing that's missing… is support for [unpaid] carers, so that the burden doesn't fall on carers. There's got to be something in there to support carers, that would have to be the biggest thing. And listening to people, listening to what people are saying.*
>
> **A person living with dementia**

What are the key takeaways in relation to healthcare treatments and interventions?

People benefit from drug and non-drug treatments

There are benefits for people living with dementia who are able to access drug and non-drug treatments, where appropriate. Drug and non-drug treatments can support both clinical and care needs, with people reporting their crucial role in maintaining motivation, wellbeing and quality of life.

People want age-appropriate support

People with young-onset dementia may not always have the same experience of non-drug interventions where they are not relevant to their age and experiences. The people we spoke to felt that their needs should be reflected in the development and delivery of interventions to ensure they are age appropriate.

Available support

We understand that some of the lived experience stories within this report may cause you concern but rest assured Alzheimer's Society are here to help you.

Alzheimer's Society offers a range of dementia support services.

From a listening ear on the phone to a visit in person and opportunities to connect with others, Alzheimer's Society will be there for you no matter what, again and again and again.

You can call the Dementia Support Line on 0333 150 3456 to get personalised information, support and advice.

You can also visit alzheimers.org.uk/get-support for more information.

THE LIVED EXPERIENCES OF DEMENTIA

Section 7: Appendices

Alzheimer's Society
It will take a society to beat dementia

WAL NUT
Part of Accenture Song

Sample profile

Figure 7.1: Unweighted sample profile

Sample profile (unweighted)		Total Sample	Living with dementia	Know someone living with dementia	Care for someone living with dementia
	TOTAL		74	2,605	808
Nation	England	2,803	65	2,175	563
	Wales	405	4	256	145
	Northern Ireland	279	5	174	100
Stage of dementia	Early stage	424	23	291	110
	Middle stage	876	29	610	237
	Late stage	1,159	0	908	251
Gender	Male	1,437	42	1,069	326
	Female	2,044	32	1,531	481
	In another way	3	0	2	1
Age	16 to 24	212	0	185	27
	25 to 34	689	2	533	154
	35 to 44	528	1	415	112
	45 to 54	575	7	452	116
	55 to 64	532	13	353	166
	65 to 74	548	22	393	133
	75 to 84	372	26	256	90
	85 or older	31	3	18	10
Socio-economic grade	AB	1,340	n/a*	1,012	328
	C1	865	n/a*	664	201
	C2	478	n/a*	368	110
	DE	707	n/a*	546	161
Area	Urban	2,377	n/a*	1,813	564
	Rural	1,021	n/a*	779	242
Ethnicity	White	3,009	n/a*	2,299	710
	Ethnically diverse background	394	n/a*	297	97

**Questions not asked to those living with dementia to minimise overall survey length for this group*

Socio-economic definitions

Figure 7.2: Guide to socio-economic definitions

The grades detailed below are the socio-economic definitions, as used by the Institute of Practitioners in Advertising, and are standard on all surveys carried out by Walnut Unlimited.

Social class		Occupation of Chief Income Earner
A	**Upper Middle Class**	Professionals such as doctors, surgeons, solicitors or dentists; chartered people like architects; fully qualified people with a large degree of responsibility such as senior editors, senior civil servants, town clerks, senior business executives and managers, and high-ranking grades of the Services.
B	**Middle Class**	People with very responsible jobs such as university lecturers, hospital matrons, heads of local government departments, middle management in business, qualified scientists, bank managers, police inspectors, and upper grades of the Services.
C1	**Lower Middle Class**	All others doing non-manual jobs; nurses, technicians, pharmacists, salesmen, publicans, people in clerical positions, police sergeants/constables, and middle ranks of the Services.
C2	**Skilled Working Class**	Skilled manual workers/craftsmen who have served apprenticeships; foremen, manual workers with special qualifications such as long-distance lorry drivers, security officers, and lower grades of Services.
D	**Working Class**	Semi-skilled and unskilled manual workers, including labourers and mates of occupations in the C2 grade and people serving apprenticeships; machine minders, farm labourers, bus and railway conductors, laboratory assistants, postmen, door-to-door and van salesmen.
E	**Lowest levels of subsistence**	Those on lowest levels of subsistence including pensioners, casual workers, and others with minimum levels of income

Statistical reliability

Overall sample

The respondents in the survey are only a sample of the those in England, Wales and Northern Ireland who have experience of living, knowing or caring for someone with dementia. We cannot, therefore, be certain that the figures obtained are exactly those we would have if everybody in England, Wales and Northern Ireland who have some experience of dementia had been interviewed (the ‘true’ values). We can, however, predict the variation between the sample results and the ‘true’ value from the size of the samples on which the results are based and the number of times that a particular answer is given.

The confidence with which we can make this prediction is usually chosen to be 95% – that is, the chances are 19 in 20 that the ‘true’ value will fall within a specified range. The table below illustrates the predicted ranges for different sample sizes and percentage results at the ‘95% confidence interval’, assuming an infinite population.

Figure 7.3: Guide to statistical reliability

Statistical reliability – 95% confidence			
Size of sample on which survey result is based	**Approximate sampling tolerances applicable to percentages at or near these levels**		
	10%/90%	**30%/70%**	**50%/50%**
50 interviews	8.4	12.8	14.0
100 interviews	5.9	9.0	9.8
250 interviews	3.7	5.7	6.2
500 interviews	2.6	4.0	4.4
74 interviews *(e.g. living with sample)*	6.8	10.4	11.4
2,605 interviews (*e.g. know someone sample)*	1.2	1.7	1.9
808 interviews (*e.g. caring for sample)*	2.1	3.2	3.5

For example, on a question where 70% of the people in a sample of 808 respond with a particular answer, the chances are 95 in 100 that this result would not vary by more than plus or minus 3.2 percentage points from a complete coverage of the entire population using the same procedures.

Comparing percentages between subgroups

When results are compared between separate groups within a sample, different results may be obtained. The difference may be "real", or it may occur by chance (because not everyone in the population has been interviewed).

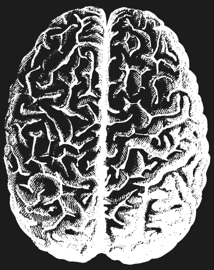
To test if the difference is a real one - i.e. if it is "statistically significant", we again have to know the size of the samples, the percentage giving a certain answer and the degree of confidence chosen. If we assume the "95% confidence interval", the differences between the two sample results must be greater than the values given in the table below.

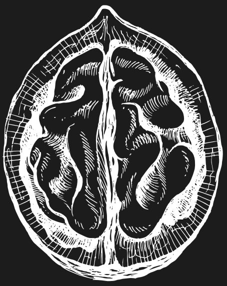
Figure 7.4: Guide to statistical reliability when comparing subgroups

Statistical reliability when comparing subgroups – 95% confidence			
Size of samples compared	Differences required for significance at or near these percentages		
	10%/90%	30%/70%	50%/50%
100 and 50	10.3	15.7	17.1
100 and 100	8.4	12.8	13.9
250 and 250	5.3	8.0	8.8
500 and 100	6.5	9.9	10.8
500 and 250	4.6	7.0	7.6
500 and 500	3.7	5.7	6.2
1,000 and 250	4.2	6.4	6.9
1,000 and 500	3.2	4.9	5.4
1,000 and 1,000	2.6	4.0	4.4
2,000 and 100	6.1	9.2	10.1
2,000 and 250	4.0	6.0	6.6
2,000 and 500	2.9	4.5	4.9

For example, when comparing the results between a sample group of 2,000 and a sample group of 500, where 30% give a particular answer, a difference of approximately 4.5 percentage points is required for it to be considered statistically significant.

Part of **Accenture** Song





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