healthwatch
Kirklees & Calderdale

Understanding Experiences of Dementia Care and Support in Kirklees and Calderdale

What people living with dementia and their families told us about in Kirklees and Calderdale

July 2026

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Summary and Key Findings

Dementia affects thousands of people across Kirklees and Calderdale and has a significant impact on individuals, families and carers.

In 2025, Baroness Casey's review of adult social care highlighted concerns about the experiences of people living with dementia, including delays in diagnosis, fragmented support, variation in care, poor coordination between services and limited awareness of research opportunities. The review also highlighted that too many people continue to struggle to navigate complex systems and access support at the right time.

To understand whether people in Kirklees and Calderdale were experiencing similar issues, Healthwatch undertook a piece of work exploring experiences of dementia diagnosis, treatment, support and ongoing care.

We heard from more than 130 people through surveys, face-to-face conversations, existing Healthwatch feedback and intelligence provided by organisations supporting people affected by dementia.

While many people shared examples of excellent care and support, particularly from Admiral Nurses, Dementia Hubs, support groups and individual healthcare professionals, many also described a pathway that felt confusing, fragmented and difficult to navigate.

Key Findings

- Many people experienced delays in obtaining a diagnosis and felt concerns were initially dismissed as part of normal ageing.
- Families often recognised changes long before services responded.
- People frequently described receiving a diagnosis without clear information about what would happen next.
- Many felt there was no clear pathway following diagnosis.
- Support after diagnosis was inconsistent and often depended on a person's ability to navigate the system.
- Carers frequently felt unsupported and overlooked.
- Communication between services was often poor.

- Access to social care and respite services was a significant concern.
- Hospital care generated some of the strongest feedback, with examples of both excellent and poor practice.
- Community support groups and Dementia Hubs were consistently praised.
- Mixed feedback about how and when to access Admiral Nurses
- Very few people were informed about opportunities to participate in dementia research or clinical trials.
- People repeatedly called for a named contact or navigator to help coordinate support.

Introduction

Dementia is one of the most significant health and social care challenges facing the UK.

For many people, dementia affects every aspect of daily life. It can impact independence, relationships, physical health, emotional wellbeing and finances. The effects are often felt not only by the person living with dementia but also by their families, friends and carers.

Healthwatch Kirklees and Healthwatch Calderdale wanted to understand whether people locally were experiencing similar issues.

This report explores people's experiences of:

- Recognising symptoms
- Seeking help
- Receiving a diagnosis
- Accessing treatment and support
- Navigating services
- Planning for the future
- Participating in research
- Caring for someone with dementia

What We Did

This project took place between April and June 2026.

Unlike some Healthwatch projects, we did not undertake a large-scale social media promotion campaign. Instead, we took a more targeted and relationship-based approach to hear directly from people with lived experience of dementia and those supporting them.

We gathered evidence through:

Survey responses

A dedicated dementia pathway survey completed by people living with dementia, carers and family members.

Face-to-face engagement

Healthwatch staff and volunteers spoke with people through community groups, outreach activity and engagement events.

Existing Healthwatch feedback

We reviewed feedback previously shared with Healthwatch through enquiries, outreach activity and community engagement.

Stakeholder intelligence

We gathered insight from organisations supporting people living with dementia and carers, including:

- Royal Voluntary Service
- Kirklees Admiral Nurse Team
- Community dementia support groups

Together, these sources provided insight from more than 130 people affected by dementia.

Who We Heard From

The demographic information presented below relates only to people who completed the survey.

Demographic information was not routinely collected during face-to-face engagement, Healthwatch enquiries or when stakeholder organisations shared intelligence. Therefore, the demographics shown should not be considered representative of everyone who contributed to this project.

Survey Respondents

We received 68 completed survey responses.

- 85% were family members or carers supporting someone with dementia.

- 6% were people living with dementia.
- 59% lived in Kirklees.
- 36% lived in Calderdale.

Most respondents were aged over 50 and 62% identified themselves as unpaid carers.

The majority of survey respondents identified as White British. Further work may be needed to understand the experiences of some underrepresented communities.

Findings

The dementia journey often starts long before diagnosis

Many people described noticing changes months or years before receiving a diagnosis.

Of those we spoke with, the largest proportion – 60% - first noticed signs or symptoms of dementia more than two years ago.

Memory problems were the most common concern and the catalyst for seeking help, but people also described changes in behaviour, personality, communication and the ability to manage everyday tasks.

A common theme was that concerns were initially dismissed as part of normal ageing.

One person told us:

"I felt it was just put down to ageing for too long until it became obvious." *(no demographics given)*

Another said:

"Was several years between my dad first going to GP and Alzheimer's diagnosis. Fobbed off as old age numerous times." *(family member, Kirklees)*

This was echoed by Royal Voluntary Service, who told us:

"One of our members waited two years for a diagnosis, as her concerns were not initially taken seriously. Because she is a chatty and outgoing person, her symptoms were attributed to ageing rather than being properly investigated." *(Royal Voluntary Service)*

Many families felt they had to repeatedly advocate for their loved one before action was taken.

"My mother is very deaf so it was difficult to know if she'd heard the questions correctly." *(family member, Kirklees)*

For some people, symptoms were only recognised following a hospital admission or crisis.

"An illness of another kind meaning a long hospital stay where her dementia then came to light very quickly." *(family member)*

The diagnosis wasn't explained to us very much in the hospital. We were given the diagnosis of Korsakoff dementia and left to do the majority of the research and readings of what this illness entails ourself as a family. *(No demographics given)*.

Waiting for answers

Obtaining a diagnosis was often described as a lengthy and frustrating process.

Most people (79%) started with their GP and 72% were referred for an assessment.

More than one quarter of survey respondents waited over a year for a diagnosis, while others were still waiting at the time they completed the survey.

People described delays relating to:

- Referrals
- Memory clinic appointments
- Brain scans
- Follow-up consultations

- Diagnostic assessments

One person told us:

"Mum is 92. We have been waiting for an appointment for best part of 9 months." (*family member, Kirklees)*.

“More information early on as to what help is available to cope with this disease. This would help to get on the referrals waiting lists for help well before the situation gets desperate. Most referrals take far too long when the situation requires quick response. Being proactive is necessary to plan as much ss we can before its too late!” *(family member, Calderdale)*.

Several people felt that deterioration occurred while they were waiting for assessment.

We waiting a long time for the assessment. Within that time we felt there was a decline and contacted for an earlier appointment but this was not possible. We attended the appointment and diagnosis was given and medication. I feel that my relative could have had the medication earlier." *(feedback from Kirklees)*.

Admiral nurses told us that without a formal dementia diagnosis it is difficult for people to access support, practical support in particular and that information and support for people waiting for an assessment/diagnosis could be strengthened

“… it’s possible that services and support is available through Carers Count, Carers Trust etc but perhaps people aren’t signposted to it until the diagnosis is given” *(Admiral Nurses, Kirklees)*

Royal Voluntary Service highlighted that the Memory Clinic is difficult to contact with calls often being unreturned, and socials workers are frequently difficult to get hold of. Things like this can make an already stressful situation even more difficult to deal with.

One person described the lack of support in the following way:

“The way the health service supports those with chronic conditions such as dementia and Parkinson’s is dreadful. All thrown over the fence to social care, which is so unfair. It’s an artificial line. People need care because they’re ill.” *(family member, Calderdale)*

However, some people also described positive experiences where GPs acted quickly and referrals were made promptly.

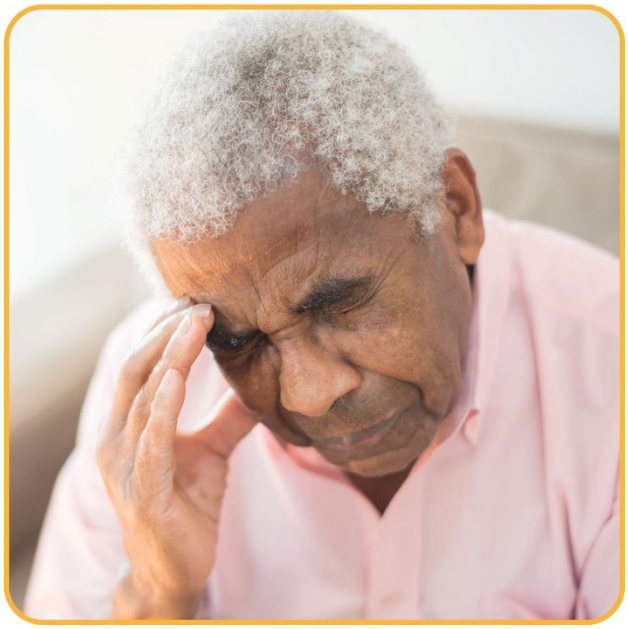
Receiving a diagnosis

Experiences of diagnosis varied considerably.

Some people felt supported, informed and listened to throughout the process.

Others described receiving little explanation about:

- What type of dementia had been diagnosed
- What support was available
- What treatment options existed
- What would happen next



One respondent told us:

"Very surprised to be told no follow up, here's a leaflet and details of charity." *(family member, Calderdale)*

Someone else also spoke about the lack of follow up:

"Been told got vascular dementia that's it, go to doctors. No reviews just left to get on." *(Survey respondent)*

Another said:

"It seemed to take a long time to get referred then I had to wait for the assessment. However, once diagnosed I was rather inundated with offers of support for my father and I was over whelmed as I have mental health problems my self. I was confused as to whose role it was to do certain things. It became clearer once I had met everyone though. I think information outlining what role social services have in helping me care for my father and what to expect of the psychiatrist and the CMHT [community mental health team] would be useful. Also information about how long the CMHT are likely to be involved would be useful as I expected them to be involved in the longer term and this isn't the case." *(no demographics given)*

Many people described diagnosis as the point at which support should have begun, but instead felt it marked the end of professional involvement.

For many people (62%) their relatives/carers were asked to give views as part of the dementia assessment.

But it was patient and carer's understanding of the assessment process that was more uncertain – only 38% told us they felt it was clearly explained; 25% felt it was 'somewhat' explained.

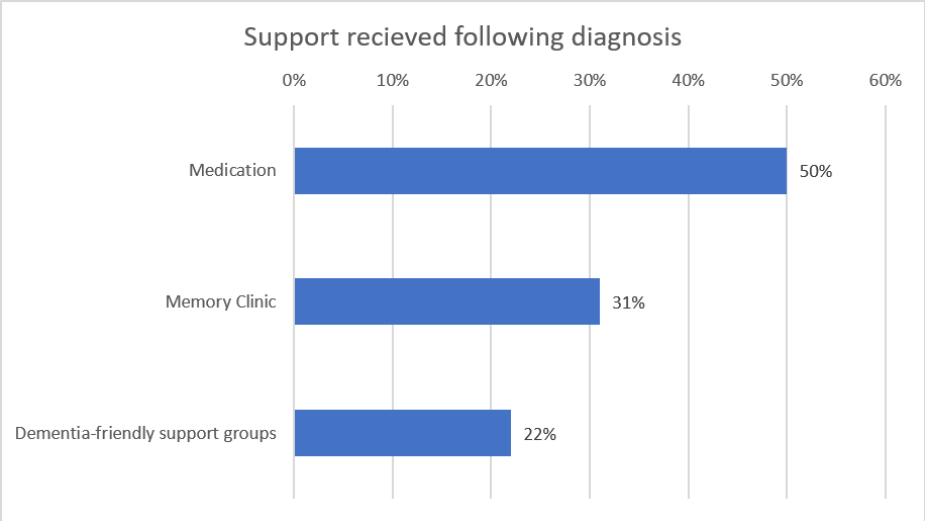
Another person said to us:

"Once they receive their diagnosis, they throw loads of information at you, and it's so overwhelming. So, by the time you have digested what is going on, you have completely forgotten everything you were told, and don't know where to turn". (Family member, Calderdale).

Life after diagnosis – "what happens now?"

The strongest message throughout this project related to what happened after diagnosis. Many people described feeling lost, overwhelmed and unsure where to turn.

Most people told us they were prescribed medication 50%; 31% got support from the Memory Clinic and 22% from dementia-friendly support groups.



Medication was the most reported form of support following diagnosis. However, only around one-third received support from a Memory Clinic, and fewer than one-quarter accessed dementia-friendly support group

Comments included:

"There is NO pathway following diagnosis." (*person with dementia, Calderdale)*

"We were given the diagnosis then left to deal with it without any further information or help." *(family member, Calderdale)*

"There should be a joint constructive plan of action/support package put together." *(person with dementia, Calderdale)*

Royal Voluntary Service reported similar concerns:

"A key issue raised by many of our members is the lack of a clear and easy-to-understand pathway. People often feel overwhelmed by information and unsure of what steps to take next." (*Royal Voluntary Service)*

Many people told us they only discovered support through chance conversations, online searches or recommendations from other carers.

One person told us:

"I only found support services in the community by chance." *(feedback from a face-to-face discussion)*

Another shared a similar experience:

"We as a family have had to track down key people and departments - nothing was offered to us in hospital or during discharge arrangements and we are still finding it difficult getting the right workers in place now mum has been placed in a care home." *(family member, Kirklees)*

Royal Voluntary Service told us about the difficulties some people experience when trying to find reliable, up-to-date information about the support available:

"Websites, including council listings, are often out of date. Some members have attempted to attend groups listed online, only to find they are no longer running, which can be very discouraging" *(Royal Voluntary Service, Kirklees)*

The evidence suggests that support is often available, but people need more help to find it.

Services making a difference

People highlighted a number of services that made a significant difference to their lives.

These included:

- Admiral Nurses
- Dementia Hubs
- Memory Clinics

- Carers organisations
- Dementia cafés
- Community support groups
- Volunteer-led initiatives

One respondent said:

"The Dementia Hub has been very responsive whenever any concerns have been raised and has provided ongoing support throughout." *(feedback from a face-to-face discussion, Calderdale)*

Another told us that the 'Home from Home' group in Kirkheaton is "a success and people who have lost their relatives still keep coming along for the social contact and friendship" (Volunteer, Kirklees)

People consistently valued having access to someone who understood dementia and could offer practical advice, emotional support and guidance.

Another person said:

"I don't know what we would have done without the support from memory lane cafe, they are an incredible support group for people and their families living with dementia". (Family member, Calderdale).

The Kirklees Admiral Nurse Team highlighted that people are automatically referred to the Dementia Hub following diagnosis unless they opt out and that people with more complex needs may be referred for specialist Admiral Nursing support.

One person told us the referral may not be needed immediately, and there should be the option to process the diagnosis and seek support after.

Experiences of carers

The impact of dementia on carers was evident throughout this project.

Many carers described:

- Emotional strain
- Exhaustion
- Anxiety
- Isolation
- Difficulty navigating services
- Lack of respite opportunities

One person told us:

"The lack of help, support and information led to me having a breakdown." *(family member, Kirklees)*

Another said:

"Ask the carers how they're doing." (*family member, Kirklees)*

Several people also highlighted difficulties balancing caring responsibilities with work and family life.

One suggested wanting "respite for two weeks so I could organise the house and get my work completed as I am self employed. but day care is most helpful in the longer term." *(no demographics given)*

People wanted more practical support, training, information and regular wellbeing checks.

Access to respite care

Many carers told us that having regular breaks from caring responsibilities was essential to maintaining their own wellbeing. However, people described difficulties accessing respite services, short breaks and emergency support.

While concerns about respite were raised across both areas, they were particularly prominent in Calderdale.

One respondent told us:

"Barely any access to respite in Calderdale. My dad was placed first in Huddersfield then Bradford then Burnley..."(*family member, Calderdale)*

Others spoke about long waits for assessments, difficulties accessing social workers and uncertainty about how to arrange respite support.

People frequently described reaching crisis point before support became available. Several carers felt that better access to respite services could help

people remain living independently for longer while also protecting carers' wellbeing.

When things go wrong

The most concerning experiences often occurred when people's needs became more complex or when a crisis developed. Families described difficulties accessing timely support, particularly when behaviour changed suddenly or when a person's needs increased rapidly.

Some felt there was no clear response available when situations became urgent.

46% told us the support they were offered only partly met their need, and 36% said it didn't at all.

One person told us:

“I seem to remember that at one point I was told if things got really bad (I thought they were!), then to ring 999. Surely that’s isn’t the best idea for frightened dementia sufferers - crisis management needs to properly cover this situation.” *(family member, Kirklees)*

"For any families without someone who understands the system, I dread to think how they cope” *(family member, Kirklees)*

Others described being passed between organisations, each directing them elsewhere for help.

These experiences often left families feeling alone at the point they most needed support.

One person said:

“The social worker changed frequently and some clearly didn’t understand dementia.” *(family member, Kirklees)*

Hospital care and treatment

Hospital care generated some of the strongest feedback.

People shared examples of excellent care from individual staff members who understood dementia and adapted their approach accordingly.

However, others described experiences where dementia was not adequately recognised or understood.

Themes included:

- Lack of dementia awareness
- Poor communication
- Difficult discharge experiences
- Failure to make reasonable adjustments
- Carers having to advocate repeatedly

One person told us:

"Hospitals are unsafe for people with dementia and staff do not know how to interact with people with dementia." *(feedback from a face-to-face discussion)*

Another said:

"When she was admitted to hospital, the staff there were unaware that she had dementia and did not make allowances for her cognitive impairment." *(family member, Kirklees)*

Several families felt hospital environments could be particularly distressing for people living with dementia.

Research and clinical trials

Baroness Casey's review highlighted concerns regarding poor awareness of dementia research and clinical trials. Our findings suggest that this issue also exists locally.

Only a small number of survey respondents said they had been informed about opportunities to participate in research.

Of those who answered, 83% were not told about opportunities to take part in dementia research or clinical trials, and 58% said they would have been interested with 28% not sure.

Of the 4 who were offered, 2 chose to take part in research and/or clinical trials.

However, most said they would have liked more information. This suggests there may be opportunities to improve awareness and discussion of dementia research, particularly as new treatments continue to emerge.

Inequalities and additional barriers

Several inequalities emerged through the project.

People without advocates

The strongest inequality related to advocacy.

Many respondents felt they successfully navigated services because they had supportive family members, healthcare knowledge or previous experience.

People without these advantages may struggle to access support.

People with language and communication difficulties

We heard examples where language barriers created difficulties during assessment and diagnosis.

People also called for clearer communication and less use of jargon.

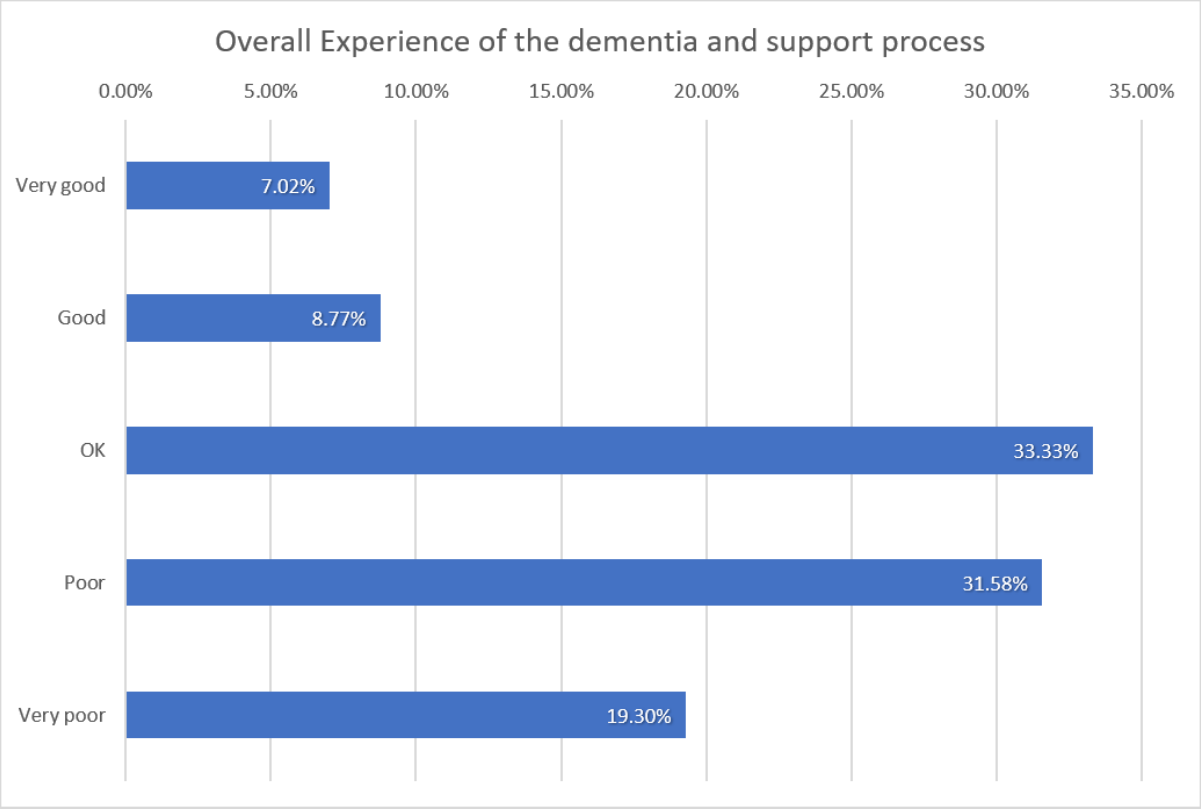
Hearing and sensory impairments

Some people described difficulties participating fully in assessments because of hearing or sensory impairments.

Working carers

Several carers reported difficulty accessing support groups and services because many operate during standard working hours.

Overall experience



Half of respondents (50.9%) rated their overall experience as poor or very poor. Only 15.8% rated it as good or very good, while a third (33.3%) described their experience as OK.

Conclusion

People shared examples of excellent care, compassion and support throughout this project. Dementia Hubs, Admiral Nurses, support groups, volunteers and many individual professionals are making a significant difference to people's lives.

However, positive experiences were often dependent on individuals rather than a consistently coordinated system.

Too many people described delays, poor communication, fragmented services and uncertainty about where to turn for help.

Although many themes were consistent across Kirklees and Calderdale, concerns about access to respite care were particularly evident in feedback from Calderdale carers.

The strongest message from this work is clear.

People need a clearer pathway after diagnosis, better support for carers, improved coordination between organisations and a named point of contact who can help them navigate what can be a complex and overwhelming journey.

Recommendations

South West Yorkshire Partnership Teaching NHS Foundation Trust

1. Reduce waiting times for dementia assessments and diagnosis.
2. Develop a 'waiting well' package of information for people waiting for an assessment and for their carers.
3. Provide routine dementia reviews following diagnosis.
4. Routinely discuss research and clinical trial opportunities where appropriate.

Calderdale & Huddersfield NHS Foundation Trust & Mid Yorkshire Teaching NHS Trust

5. Strengthen dementia awareness training for frontline staff.
6. Improve discharge planning and communication with families.
7. Ensure reasonable adjustments are consistently provided for people living with dementia.

Local Authorities

8. Improve access to social workers and social care assessments.
9. Review access to respite and short-break services across Kirklees and Calderdale, with particular attention to concerns raised by Calderdale carers regarding availability, waiting times and out-of-area placements.
10. Improve information about future care planning and support options.
11. Introduce routine wellbeing checks for unpaid carers to identify support needs and signpost to appropriate services, including respite and emotional support.

West Yorkshire Health and Care Partnership and Local System Partners

12. Develop a clear and consistent dementia pathway across Kirklees and Calderdale.
13. Ensure every person diagnosed with dementia and their carers have access to a named contact or dementia navigator who can provide ongoing advice, coordinate services and act as a single point of contact throughout the dementia journey.

14. Produce clear, consistent guidance for people living with dementia and carers explaining the local dementia pathway, including what support services are available, when they can be accessed, how to access them, and the role of services such as Dementia Hubs, Admiral Nurses, Memory Clinics and carers' organisations.
15. Continue commissioning and supporting community-based dementia groups and peer support networks, including those for carers.

Community and Voluntary Sector Organisations

16. Improve promotion of local support so people know what help is available.
17. Work collaboratively to ensure information remains accurate, accessible and up to date.