



Living Well with Dementia

Report July 2026

Living Well with Dementia in Bolton

About Healthwatch Bolton

Healthwatch Bolton is your local health and social care champion. We exist to listen to your feedback about your experiences of using your health and care services. If you access GPs and hospitals, pharmacies, care homes or other NHS support services in your area, we want to hear about your experiences. As an independent statutory body, we have the power to make sure NHS leaders and other decision-makers listen to local feedback to help shape and improve standards of care. We can also help you to find reliable and trustworthy information and advice.

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The final question in the online survey invited respondents to share any concluding reflections that may not have been captured elsewhere in the report. As a prompt, respondents were asked whether there was anything further they wished to share about their experiences of living with dementia or caring and supporting someone to live well with dementia. Responses included personal reflections on receiving a dementia diagnosis, the impact on current and former care partners, and insights from health and care professionals, with recurring calls for support that is easier to find, navigate and sustain.

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Introduction – What is Living Well with Dementia?

Living well with dementia means that people living with the condition can maintain the best possible quality of life. It focuses on supporting people living with dementia (PLwD) to remain as independent, active, and engaged as possible while respecting their dignity, choices, and personal identity.

Living well with dementia means having access to local, timely and appropriate health and social care services.

Living well with dementia means care partners receive the support they need so they can provide effective care, for as long as they believe they are able to, without becoming overwhelmed.

To enable people to live well with dementia means that staff and the services they work for and with are adequately equipped to meet the needs of their local communities.

We believe that with compassion and the right support in place, people living with and affected by dementia can stay as healthy as possible, be involved in meaningful activities, maintain relationships with family and friends, live in a safe and supportive community and enjoy life for as long as possible.

This report follows people's journey of dementia, from the early stages of memory loss to diagnosis and the later stages of dementia.

Methodology

To understand the experiences of PLwD, unpaid carers (current and former), and professionals across health, social care and the Voluntary, Community and Social Enterprise (VCSE) sector in Bolton, we adopted a mixed-methods approach combining **quantitative** and **qualitative** data collection.

Survey

We developed four comprehensive online questionnaires to explore the views and experiences of PLwD, unpaid carers, and professionals. Before launching the survey, we shared the draft questionnaire with the Local Authority, Greater Manchester Mental Health Trust (GMMH), Bolton Dementia Support and other VCSE stakeholders for comment. Their feedback ensured the questions were relevant, inclusive, and aligned with local dementia priorities.

The online surveys were launched from mid-May 2025 until 30 September 2025. A total of **166 responses** were received.

The online survey was shared on social media channels, newsletters and partner newsletters, bulletins and the website. In addition to this, extensive community engagement also took place with various groups and at events in the community, to ensure people who did not access information online could still take part in the survey.

Case studies

We conducted five in-depth case studies, using some survey questions but also allowing discussions to flow naturally to encourage deeper conversations.

The case study participants are from diverse backgrounds and represent different stages on the dementia pathway.

- One person living with **young onset dementia** shared their experiences of self-advocacy and the importance of patient participation.
- One **male Afro-Caribbean** current carer shared their experiences of the impact of caring for his mother and family dynamics.

- Three former carers shared their experiences of caring for their loved ones at home and in hospital, accessing local support, end-of-life care and bereavement support.

Focus Groups

We facilitated **three focus groups** with Bolton Dementia Support, Bolton Hospice Memory Café and Sisterhood (women's support group).

Dementia Community Talks

We arranged six dementia awareness sessions titled *"Let's Talk About Dementia"* with: Bolton Black History Group, Befriending Refugees and Asylum Seekers (BRASS), Bolton Deaf Society, Changing Life Directions, Women Together and Bolton Senior (South Asian) Men's Group. Because Healthwatch Bolton is not a clinical organisation, all sessions were supported by the Trusts' Admiral Nurse, Bolton Hospice's Palliative Care Clinical Educator, GMMH's Memory Assessment Team Manager and Dementia Advisor and the Alzheimer's Society's Team Sahara. Feedback from these events contributed to our understanding of the public's awareness of dementia and their information needs. All sessions were well received and highlighted an appetite for these sessions to continue.

Information, Advice and Guidance (IAG) Enquiries

Twenty-five dementia-related enquiries received via our IAG service or community engagement activities are included as an appendix as additional data and are categorised into themes.

Data handling and ethical considerations

All comments included in this report are reproduced verbatim. To protect the privacy of contributors and deceased individuals, all identifiable personal information, including the names of respondents and staff mentioned in the feedback, has been removed or anonymised. Unfortunately, we have not had the space to quote everyone's deeply insightful answers to all our surveys. Community Insight boxes include brief summaries about what people have shared in the overall responses we have received.

Please be assured that they have all been read diligently and have helped us to write this report. We sincerely hope it reflects the wide range of experiences and feelings shared with us.

Chapter One - Diagnosing Well

The very **first step** in the journey of dementia is typically the emergence of early symptoms. We asked PLwD what symptoms they had, and care partners what they noticed in the person they care/cared for memory, that gave them cause for concern and influenced them to seek an initial Memory Assessment Test (MAT). Symptoms included:

- Forgetfulness and memory problems.
- Behavioral changes, such as mood swings, irritability, and confusion.
- Recommendations from healthcare professionals, such as GPs or nurses to have a MAT.
- Concerns raised by family members or workplaces noticing unusual behavior.
- Specific symptoms like reduced confidence with driving, depression, or imagining things.



“I knew I was forgetting things really quickly. I'd ask the same question over and over again. This made me really teary or angry.” (PLwD)

“I was concerned the person was forgetting the names of local landmarks and road names that he'd known for years.” (current carer)

“Changes in memory skills and habits a few years ago. I am about to arrange another test for her today or tomorrow as getting worse imagining items being brought in the house, mood swings, frail, walking slowly.” (Current carer)

Sometimes, concerns were raised by health professionals involved in a person's care.

“I was in Hospital when I was diagnosed. Our family hadn't heard of Korsakoff before then.” (PLwD)¹

¹ ([Wernicke-Korsakoff syndrome | Alzheimer's Society](#)) and [438 What is alcohol-related brain damage \(ARBD\)?](#)

There were instances when the person experiencing issues with their memory were in denial of their symptoms. This can prevent people from being formally diagnosed and accessing services.



*“I told the GP in 2000, there was something wrong with mum, mum would not acknowledge she had an issue and therefore, no treatment took place.”
(Current carer)*

In Bolton, people should raise initial concerns about memory loss with their GP who will conduct an initial test. If dementia is suspected, the GP should refer them to the Memory Assessment Service (MAS), provided by Greater Manchester Mental Health NHS Foundation Trust (GMMH), where they will be assessed and diagnosed or referred for further investigations.²

² Bolton Dementia JSNA Summary (updated January 2026) [Powerpoint Template](#)

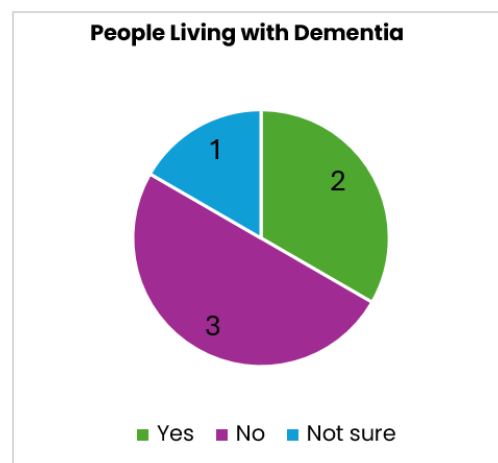
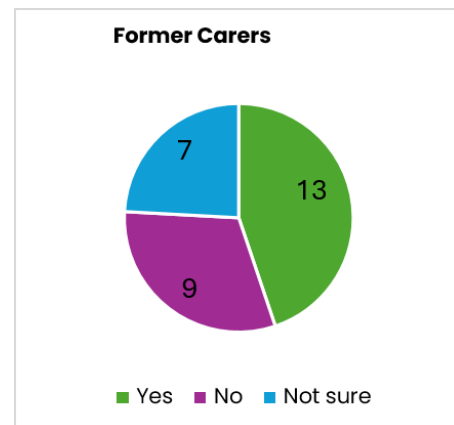
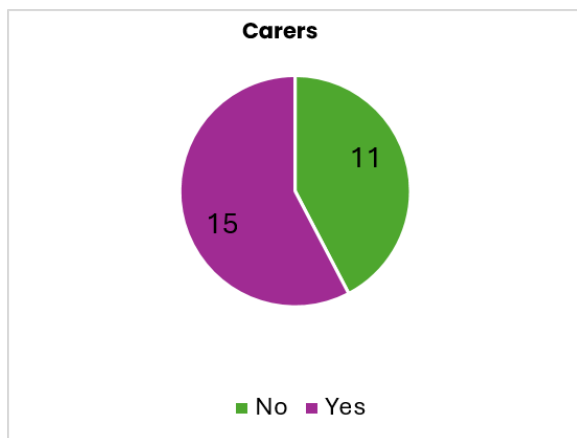
Community Insight – Awareness, Understanding and Early Symptoms

- Need for clear explanations of dementia and stages
- Confusion between normal ageing vs dementia
- Questions about heredity, risk factors, menopause, lifestyle
- Misinformation (e.g. statins causing dementia)
- Dementia is highly prevalent within families
- Symptoms often confused with menopause (brain fog, memory issues)
- Early signs recognised in hindsight, not at the time

People don't just notice symptoms, they struggle to interpret them

Memory Assessment Test (MAT)

We asked respondents if they, or the person they care for, knew what to do or where to go for a Memory Assessment Test:



Overall, several respondents knew that **their GP** was the appropriate first point of contact:



“We first contacted the doctor.” (PLwD)

“The doctor sent the referral to the service.” (Former carer)

“Yes. Only because I am a retired health professional.” (Current carer)

Others did not know where to go and/or relied on guidance from other health and care professionals, family members or previous experiences with dementia care.



“... Nurse at Drs practice explained everything.” (Current carer)

“We knew where to go due to relative’s previous experience of caring for a loved one with dementia.” (Current care)

“[The] hospital did all this as his stroke recovery involved so didn’t need go looking for it.” (Former carer)

Community Insight – Access and Advocacy Challenges

- Difficulty getting GP appointments
- Lack of follow-up after raising concerns
- Uncertainty about how to push for referrals
- Experiences of needing to advocate strongly

Others highlighted challenges in navigating the system or accessing an onward referral to the Memory Clinic.



“Initially when contacted GP was referred to a mental health nurse who diagnosed depression. So contacted GP again and insisted on GP face to face appointment.” (Current carer)

“The person I cared for had five memory assessments at the doctor's before eventually failing the memory test by one. We both knew that he should have been having treatment for at least three years before he eventually failed the memory assessment. If he had had help three years previously, he may not have got to the stage, he was at before he passed away. The memory assessment isn't a good assessment for Alzheimer's (it's not fit for purpose). Failed.” (Former carer)

Community Insight - Inconsistent diagnostic pathway

- Long delays between referral, scans, diagnosis
- Poor communication between services
- Lack of clarity on type/stage of dementia
- Carers chasing information
- Verbal diagnoses without written confirmation

We asked PLwD, current and former carers, who had spoken with their GP first, what response they received:

Responses varied significantly, with some finding their GP helpful and others reporting minimal or no support. These highlight inconsistent experiences with GP support for dementia-related concerns. One respondent mentioned being diagnosed in the hospital, others could not recall the GP's response.

“Very good, no hesitation in checking things out.” (Current carer)

“Spoke to Dr after nurse - both very positive and helpful.” (Current carer)

“The GP was excellent. He listened and looked at what I had found/described and made the referral.” (Former carer)

“When he had a quick test, he told us that his score some dementia so he would contact the mental health team at Breightmet.”

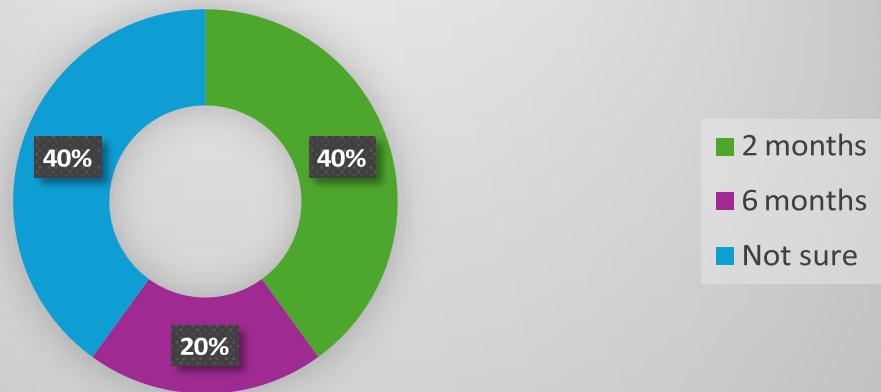
“[GP] Thought he was too young to have dementia.” (Current carer)

“Not helpful.” (PLwD)

“Not a very positive response, we resulted to emailing the GP with specific concerns, issues as well as obvious memory decline and behaviour changes.” (Current carer)

“Spoke to the GP about my concerns, but the response was limited. Because there was no formal diagnosis, they didn’t really take it further or give much feedback. It felt like they noted what I said, but no proper support or follow up came from it.” (Former carer)

Waiting Times for a Memory Assessment Test



A very small number said they had their MAT “immediately”, within “10 days” or “three weeks.”

On average, people waited between **two and six months** for a formal Memory Assessment Test (MAT).



“Three months after persistent advocating for our loved one. The memory assessment visit was a cancellation and not dealt with satisfactorily, we were interviewed together which was incredibly challenging as our loved one was very unaware of any issues.” (Current carer)

Several respondents could not recall how long they had waited. **Several patients had waited a year or longer:**

“The GP referred my husband to the memory clinic in March 2026; they told us they have a six to 12 months waiting list.”

“A long time.” (PLwD)

“12 months later we requested to repeat the mini mental test and re-referral to memory clinic.” (Current carers)

“Year later he had 2nd memory test and was slightly worse than the 1st. That's when he was referred to. It was a month later he was sent for brain scan. It was another 6 months before he was diagnosed with Alzheimer's took over two years to receive diagnoses.” (Current carers)



Others said their GP did not refer the patient for a MAT **despite repeatedly raising concerns** about a loved one's memory.

"They were never given a Memory Assessment Test. I raised concerns with the GP, but it didn't lead to a referral or diagnosis at the time." (Former carer)

"Four years total, but only a few months after the referral was made." (Former carer)

"It was done in hospital - but they never told us or dad, and we didn't know for at least a year." (Former carer)

We asked respondents what information and support they would have found helpful, while waiting for a MATS and/or diagnosis.

Responses to this question highlight the need for **better support and information** during the waiting period. Two PLwD expressed they would have found "**Brain exercises**" and "**Information about symptoms**" helpful. Overall, current and former care partners expressed a need for:

- Emotional support for both the person awaiting diagnosis and their care partner(s).
- Clear explanations of the diagnosis process and expected timelines.
- Information (including in Easy Read format) about dementia symptoms, progression, and prognosis.
- Guidance on available support services, such as dementia and carer support groups.
- Practical advice on managing symptoms and behavioral changes.

Community Insight – Information Needs While Waiting

- Questions about where to go for help (e.g. "Is there a dementia hub?")
- Desire for practical advice (e.g. take someone to appointments)
- Strong appetite for education sessions

Clear unmet need for information and support pre-diagnosis

"...If possible, a separate appointment to give confirmation of diagnosis so you can be prepared for it."

“Information about dementia. How to deal with it.”

“Emotional support for both of us to come to terms with the diagnosis. More information to understand the diagnosis and the processes.”

A professional observed increasing younger onset dementia linked to lifestyle, specifically “alcohol related.”

Professionals believe people waiting for a Memory Assessment Test need to know the following information:

“What to expect from the test and what happens following either a positive or negative outcome.”

“Realistic info about waiting times.”

“Appointment letters should go to Next of Kin as patient often forgets or doesn't open them.”

“What to expect: A heads-up on what the test involves, like the types of questions and tasks.”

“How to prepare: Tips on what they can do beforehand, like bringing glasses or hearing aids.”

“What to bring: A list of things to take along, such as ID, medication lists, and a family member or friend.”

“Who to contact: Details of who to get in touch with if they have questions or need to reschedule.”

“What outcome there may be including dementia diagnosis, referral to other services or no dementia. That not all people need an MRI scan, and it does not always show dementia, and this is why a thorough multifactorial assessment is complete. We do not diagnose other memory impairments; the memory service is to assess dementias.”

“What happens next: An explanation of what to expect after the test, including how and when they'll get the results.”

Experience of Diagnosis

We asked PLwD, current and former carers about their experience of getting a diagnosis of dementia.

Many participants described receiving a diagnosis as a “*cliff edge*,” with limited follow-up and overwhelming information, leaving them feeling unsupported at a critical stage.

Overall, the responses highlight a mix of experiences, ranging from emotionally challenging, denial, claims of misdiagnosis, a “*smooth*” process and a feeling of “*relief*.”



“It was very upsetting.” (PLwD) “I was devastated.” (PLwD) “Very smooth” (PLwD)

“The memory team at Bolton were great but mum didn't accept that her memory was bad.” (Current carer)

“I found it a bit of a battle to be believed about the changes I was seeing in my husband. In front of medical practitioners, I felt they did not see the full picture that I was seeing and living on a daily basis... (Current carer)

Community Insight – Emotional and Social Impact

- Fear and anxiety around memory loss (including menopause-related concerns)
- Personal caring experiences shared openly
- Sessions reduced fear and increased confidence

Advanced Care Planning (ACP)

We asked PLwD, current and former carers, if they or the person they care/cared for has ever been offered support to develop an Advance Care Plan. An Advance Care Plan is created with the patient. It helps carers and health and social care professionals understand what is important to PLwD and their future healthcare preferences such as the type of care they would want or not want if they can no longer make decisions for themselves.³

³ [Quality statement 3: Advance care planning | Dementia | Quality standards | NICE](#)

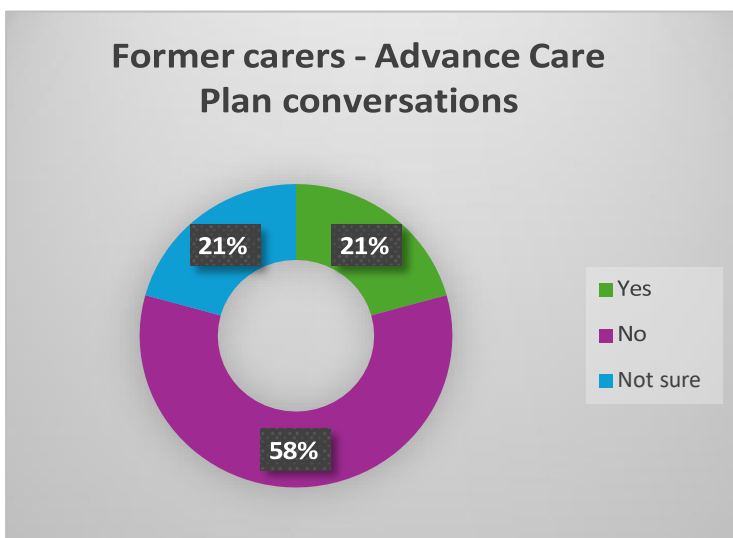
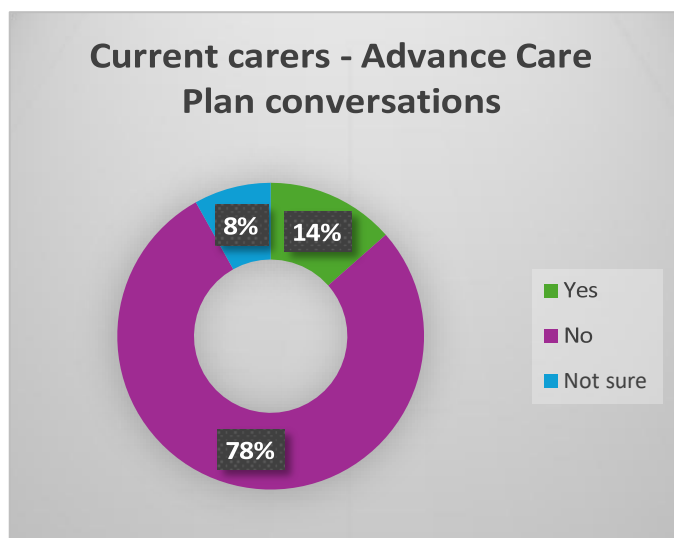
Caleb and his siblings care for their mother, Barbara who was diagnosed with dementia in 2022. Emigrating from Jamaica to Bolton in the 1960s, Caleb fondly refers to his mother as the cornerstone of the family. Caleb focuses on creating moments of happiness with his mother rather than correcting or confronting memory loss. Caleb believes dementia still lacks public understanding and visibility, despite its prevalence and impact. **Advance Care Planning was not discussed** with Barbara or the family at any point. Caleb highlights how difficult managing dementia care is for families, especially when family relationships are complex/fractured.

“The (paid) carers are brilliant. Really and truly, they don’t do much. They do mum’s medication, make sure the house is warm in the winter, make a brew, heat microwave meals. Mum has daily visits at 10am, 1pm and 5pm.

I think any support is good support. Because I’m not there all the time, if I was in my younger brother’s role, it would be nice if a paid carer came in and went through things with the main carer. I am not having a go at my brother, but I think there are lots of things my brother should be doing that he is not. He handles mum’s finances and everything. It would be better experience if someone from adult social services came to spend time with the carer and did routine, unannounced spot checks; just rock up to see what is going on. Otherwise, social services are just going off the carers word. I know my brother loves my mum, but this doesn’t mean he can care for her...”

“The film ‘Father’ with Athony Hopkins, captures what it is like caring for someone living with dementia. Caring for someone living with dementia is such a massive thing, I think that most people really don’t know about it. Considering how many people are diagnosed with it you would think that people would have a better understanding of dementia. It’s massive. You’ll hear about cancer and whatever, but dementia doesn’t seem to have the same profile. I am thinking how many people are diagnosed with dementia, but there doesn’t seem to be a focus on it. It’s such an evil disease. There is the Alzheimer’s Society advert that says people [living with dementia] die so many times - it is so true. You say goodbye so many times. It is really hard. When I look at my mum, she was like a super woman. I remember times she would make our tea in the Dutch pot, and we would sneak into the kitchen for food. We just couldn’t pull the wool over her eyes. She was so sharp and funny. My mum is an amazing woman.”

Most respondents stated that ACP was not offered or discussed.



A few respondents noted that they understand the benefit of discussing the topic with family members, are working towards an ACP, or had Lasting Power of Attorney (LPA) in place.

“Not in need of this at present but may be a good long-term plan.” (PLwD)

“Not at the point of diagnosis. A year before mum passed away, she was showing signs of deterioration, and the GP practice were the first to have Advance Care Planning conversations with me. However, not long after mum was diagnosis, she made a will and appointed me and my brother as Lasting Power of Attorneys. So, in essence she had done this herself at the beginning so we were all very clear on what her wishes were, and we could communicate these to health and care professionals.” (Former carer)

“We have power of attorney which we sorted ourselves as a family.” (Current carer)

A few respondents mentioned ACP was initiated by the GP or social services.

“GP at surgery helped put a plan together.” (Former carer)

“Not sure if that’s what it was called. We had a multi-disciplinary meeting at my parents’ house in the final year, but this was because my dad was diagnosed with cancer too. Had this not been the case, he would not have received anywhere near the level of support he did e.g. carers.”

“Social services.” (Former carer)

Some respondents were unsure how to go about creating an Advance Care Plan. Others mentioned that the person they care for would not understand or cooperate with such a plan.

“Wouldn’t know how to go about this?” (current carer)

“He wouldn’t understand anything like that.” (Current carer)

One respondent stated that their mother did not want to discuss ACP:

“I had documents to complete but mum never wanted to discuss so we had to make decisions based on what we believed would be her wishes.”

Community Insight – Understanding of Advance Care Planning

- Need to clarify difference between palliative and end-of-life care
- Low awareness of ACP before explanation
- Once explained → better engagement and openness
- ACP conversations seen as important but overwhelming
- Better received in trusted, supportive environments
- Need for pacing and emotional support
- ACP was seen as **important but emotionally overwhelming**
- Carers often felt **unprepared or unsupported** during these conversations
- Timing and delivery were critical - ACP discussions were better received in settings with time for discussion (e.g. hospice, peer groups)
- Opportunities to revisit conversations over time
- Emotional support alongside practical planning

ACP is under-utilised and poorly embedded

Information, Help and Support

We asked PLwD, current and former carer partners what information, help and support they needed at the point of the dementia diagnosis.

Two PLwD expressed a **need for reassurance**, with one fearing their life would be cut short. One PLwD said they did not feel they needed any support at that time.



“Reassurance that it wasn't as bad as I thought.” (PLwD)

“Getting the Medication correct.” (PLwD)

“We were informed of the diagnosis and that someone would contact us.” (PLwD)

Community Insight – Accessibility Barriers

- Information too complex / small font
- Need for simpler, accessible formats
- Issues remembering appointments/medication
- Importance of tailored communication

Collectively, current and former carers agreed on the types of help and support they needed when the person they care/cared for received their diagnosis:

Positive Experiences: A few respondents mentioned receiving helpful support from the Memory Assessment Team, Bolton Dementia Support (including their memory cafes), Bolton Carers Support, the Admiral Nurse (based at NHS Bolton Foundation Trust) and social workers, but these were exceptions rather than the norm.



“Once diagnosed, we were referred to 6-week education sessions. This was very informative and finding out the services available. This is where we learned about Bolton Dementia Support group.” (Current carer)

“NHS memory team Bolton, later on we went to Bolton Dementia Support memory cafes which were good.” (Current carer)

“A social worker visited and medication was started by the GP.” (Current carer)

“I received support from Bolton Carers very quickly, especially with completing the Attendance Allowance form and arranging a council tax rebate, which was a huge relief as I felt overwhelmed. Since the diagnosis, Dr X and the memory clinic team have continued to support us, and it really helps that my husband sees the same staff each time. I've also had support through my GP, including a carers review, input from

a mental health practitioner and a referral for CBT, as well as social prescribing. Overall, the support from Bolton Carers, the memory clinic and my GP has felt well-coordinated, although I've had to access private counselling as some services are no longer available..."

Lack of Follow-Up: some respondents noted that after the diagnosis, there was often no follow-up or ongoing support, leaving them feeling isolated and overwhelmed.

"Not much support after memory nurse discharged us." (Current carer)

"I did not get a proper diagnosis - low mood/depression, when in fact she had frontotemporal dementia. I figured that out from doing my own research." (Current carer)

Many **carers emphasised the need for emotional support for themselves and the diagnosed person**, i.e., how to cope with the diagnosis and its impact on their lives and relationships.

"We needed explanations, what we could do to help, exercises to do, and medication to see if it would help. Explanations to the diagnosed person. Group therapy - maybe for cared for and carers/friends/family." (Former carer)

Information and Guidance: Respondents wanted clear and accessible information about dementia, its progression, and practical advice on how to care for their loved ones.

"Since my Dad was diagnosed... you get support for 6 weeks and then nothing. Not a single thing since we have just managed everything as a family and my mum who is now 79 is his full-time carer." (Current carer)

"My mum was never diagnosed, which meant we missed out on support that should have been available. At that stage, I needed clear information on dementia, practical advice for day-to-day care, and guidance on services I could turn to. It would also have helped to have support that recognised our cultural background and community context, rather than generic information that didn't always fit." (Former carer)

Practical Support: Some respondents highlighted the need for assistance in managing behavioral changes, agitation, and anger in the person living with dementia.

"It had been happening before diagnosis, but someone to highlight the trust problems associated with short term memory loss." (Current carer)

Access to Services: Several respondents expressed frustration about the lack of immediate support and guidance after diagnosis, with some feeling overwhelmed, left to manage on their own and do their own research. Carers sought details on available services such as respite care, financial support, and how to navigate the healthcare system.



“Local services available and no referral to Admiral Nurse.” (Current carer)

“Someone from the memory service came to my Mum's home and shared the outcome of the tests. They gave a printout of information from the Alzheimer's Society and advised to have the annual review with the GP regarding tablets. I was asked at the same home appointment if my Mum could live with me. This was not appropriate in light of the information that had just been shared. There was no other help provided. We felt very alone and left to navigate on our own.” (Former carer)

Overall, the responses indicate a significant gap in support in both pre-and post-diagnosis. There is a clear call for better resources, guidance, and practical emotional support for both people living with and affected by dementia.

Community Insight - Post-Diagnosis Support

- People felt “left on their own” after diagnosis
- Information overload with no guidance
- Lack of consistent follow-up
- Peer support groups (e.g. dementia cafés) are highly valued
- Provide belonging, routine, informal support
- Fill gaps left by statutory services
- Offer respite for carers
- Diagnosis and living with dementia is an ongoing emotional journey
- Themes of loss, adaptation, identity change
- Humour, relationships and support networks help coping

We also asked professionals what information and support PLwD and their care partners need at the point of diagnosis.

There appears to be a very fine line between the call for the MATS to provide a wealth of information and to ensure PLwD and their care partners are not overwhelmed by it:

“Positive information about how they can live well with dementia. Carers information and information about direct payments. Simple information about their type of dementia and any support available including cafes.”

“Let the person lead the way on how much or how little information they need. information of support etc. to be given over a long period - not bombarded all at once.”

“Information about the diagnosis if they want it. How to live well with dementia. Support services information after they have received a diagnosis. Social opportunities as patients’ needs have often changed.”

“Access to charities and support groups such as Age UK, Bolton Dementia support, Bolton Carers Support, Admiral Nurse virtual and Nationwide clinics, Knowledge and awareness of the Admiral nurse service at the Royal Bolton Hospital Making GP's and GP federation aware for yearly reviews and Dementia support. Access to the British Legion for community admiral support if they were in the military.”

Community Insight - Inequalities and Cultural Barriers in Access

- Underuse of hospices/services in communities of colour, due to cultural expectations of family care
- Concerns about accessing services
- Language and culturally appropriate support needs
- Strong engagement when sessions were culturally tailored

Conclusions – Diagnosing Well

Focus group feedback reinforced the survey findings: diagnostic pathway is fragmented, poor communication and delays, lack of post-diagnosis support and strong reliance on voluntary/community sector.

- ✚ There are **significant inconsistencies across the diagnostic pathway**, particularly in GP response, referral processes, and waiting times.
- ✚ **Earlier recognition and timely diagnosis** are hindered by delays, misdiagnosis, and lack of proactive follow-up.
- ✚ People living with dementia and carers experience a **gap in information, emotional support, and practical guidance**, both before and after diagnosis.
- ✚ **Communication and coordination across services need strengthening**, especially to ensure smoother transitions from initial concern to diagnosis and beyond.
- ✚ **Advance Care Planning is under-utilised** and not routinely embedded into practice.

Overall, there is a strong need for a more **joined-up, person-centred approach**, with consistent support, clearer pathways, and improved access to information and services.

Feedback from **community sessions** echoed survey findings, with participants reporting difficulties accessing GP appointments, limited follow-up after raising concerns, and uncertainty about how to advocate for a memory assessment.

Chapter Two - Supporting Well and Living Well

This chapter draws on survey responses, case studies, and qualitative insights from focus groups and community engagement sessions.

It examines how people with dementia in Bolton are **supported to live well**, including **access to public information** about dementia and services, where individuals **obtain information, engagement with community groups, and how accessible and useful that information is**, as well as **barriers to access, health support and preventative care** (including annual health checks and carer registration), perceptions of Bolton as a dementia-friendly place, and contrasting lived experiences through case studies of positive and negative support.

NHS England's *Well Pathway to Dementia*, states that people living with and affected by dementia should be able to:

- “Access to safe high-quality health and social care for people with dementia and carers.” (We also include the VCSE sector too as providers of invaluable sources of information, care and support).
- “Live normally in safe and accepting communities”
[england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf](https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf)

Positive experience of accessing care and support:

Case Study – Harold and Aileen

Harold cared for his mother, Aileen, who lived with Alzheimer's disease for around eight years before she passed away in January 2020, aged 89. Aileen was a former piano teacher and primary school teacher who enjoyed gardening and caravan holidays with her family.

In the early stages, Harold and his father received limited but valued support from a professional who visited weekly and helped guide them to available services. As Aileen's condition deteriorated, the family began self-funding care through Home Instead, while Harold reduced his working hours and eventually gave up work entirely to care for both parents. With no extended family support, the emotional and practical pressures were significant, particularly as his (late) father, aged 84, was also becoming frail and in need of support himself.

Despite these challenges, Harold described good access to practical equipment via the Local Authority, including adaptations that helped them manage at home. However, navigating financial and care systems was difficult. An initial application for Continuing Healthcare (CHC) funding was declined, with Aileen deemed “*not bad enough*.”

A turning point came in 2017 when Aileen was admitted to hospital and placed on end-of-life care. Harold described distress at being asked to make urgent decisions without having the Lasting Power of Attorney in place and fought to bring his mother home. Believing she had been prematurely assessed as end of life, he supported her recovery at home, after which CHC funding was awarded. While this removed financial pressure and provided structured support, it also meant losing trusted carers and adjusting to new staff.

CHC support enabled Harold to have some respite and regain small parts of his social life, which he described as invaluable. However, there were ongoing tensions around care decisions, particularly where he felt dignity and personalised care - such as toileting - were not always mutually agreed upon.

In 2018, Harold’s father passed away (leaving him as sole carer). Despite the intensity of this period, Harold was supported to remain with his father at the end of his life through additional care provision at home to care for his mother.

As Aileen’s condition progressed, she lost the ability to communicate verbally, but moments of connection remained. Harold described how she still responded to children’s television programmes and showed empathy, recalling a moment where she tried to “*feed birds she saw on the screen*.” These moments were deeply meaningful.

Reflecting on the support received, Harold highlighted the importance of practical help, respite, and professional input, including training he received on pressure sores and skin integrity. While he described the system as complex and sometimes rigid, he acknowledged that many professionals involved were committed and very responsive.

Access to **timely and accurate information** is essential for people living with and affected by dementia because it helps them to better understand the condition, manage symptoms, make informed decisions, access appropriate care and support when needed, maintain independence and overall quality of life for as long as possible.

With this in mind, **we asked PLwD, current and former carers which services they get their information and support from and the quality of this information.**

We have also included the voices/experiences of the health and social care **professionals** who provide information and support for PLwD and their care partners because we wanted to ascertain **how well resourced and supported** they are to care for others.

Findings from **community engagement sessions** reinforced survey data, highlighting uncertainty about where to access support and a reliance on informal networks.

Participants frequently asked whether a central “**dementia hub**” exists in Bolton. Some respondents reported encountering misinformation about causes of dementia, reinforcing the need for clear, accessible, evidence-based information.

Two PLwD told us that they obtain information from the **internet**. One respondent received support from their **care home**. Two PLwD stated they **received no support or had to find help on their own**.

We asked current carers which services they and the person they care for get information and support from. Out of 40 responses, the following services were mentioned:

Memory Clinic: many respondents highlighted the support received from the Bolton Memory Clinic at Brightmet Health Centre.

“Once diagnosed, we were referred to 6-week education sessions. This was very informative and finding out the services available. This is where we learned about Bolton Dementia Support group.”

Bolton Dementia Support (including their Memory Cafes and Carers Equip sessions) were appreciated for providing emotional support and practical advice.

“We were referred to 6 weeks education session. That equipped us with information about services we can tap into. Then was referred to Bolton Dementia Support group. This has been the lifesaving.”

Bolton Carers Support: Several respondents mentioned Bolton Carers Support as a helpful resource for information and assistance, including help with completing forms like Attendance Allowance and council tax rebates.

Relatives with previous experience of dementia care:

“Relatives initially, with experience of caring for a loved one with dementia. Eventually received a home assessment visit from an occupational therapist I believe is attached to the memory clinic.”

Other Services: Some respondents mentioned receiving support from the Admiral Nurse, social services, Age UK Bolton, and the Alzheimer's Society.

A few respondents noted limited or no support after initial diagnosis, with some feeling left to manage on their own after a short period of assistance.

“Not much support after memory nurse discharged us.”

“None, unless I sought them out myself.”

Ruby and Earl’s less than positive experience

“... We’ve had private carers for three years now.... Earl fell last year and it was all taken out of my hands. I had to suspend the private carers while he was in hospital. He spent six weeks in hospital and then they moved him to Laburnum Lodge.

They did a discharge plan and then a care plan, but they did not discuss or shape the care plan with me. Not only did they not share the care plan, but they put social care in place. I told them that I didn’t want to have social care; I wanted to reinstate the private carers (at home) because I know Earl will have consistency and his care needs met, they didn’t give me the option. Earl went into meltdown; he couldn’t cope with the new arrangements. We were both absolutely shattered. The carers were coming four times a day... and the carers were rough with him, Earl said he didn’t want them. It was a battle from January 2025 until early April 2025 - that I was able to get the private care company back.”

CHC Funding

“The social worker turned to me and said, ‘how do you know about CHC?’ I said I’ve done my research. She said, ‘Earl will not be eligible for it’. I asked, ‘How do you know? The social worker replied, ‘because there’s a criteria to fill.’ I said, ‘Well I won’t know if he’s eligible until I apply for it.’ I had this conversation with the social worker on 6th May 2025. I asked for more CHC information. I did not receive it. The social worker came again on 10th July, and I asked her again. [To date - 29th July 2025, Ruby still hadn’t received CHC information from the social worker].

Former carers highlighted a range of information sources and experiences, some individuals received support from Bolton Dementia Support, Admiral Nurses (past and present), and Bolton Carers Support. Some respondents noted positive experiences with specific services, such as

memory cafes and social workers:

“Mental health team, I found their support very useful as I had no idea of how to support mum.”

“Dad attended meetings with me that were organised by this service and went to memory cafes, dancing, Bar Lane. These were great social events. Dad also went to The Thicketford Centre one day a week.”

“Healthwatch Bolton, Bolton Carers Support, Dementia Support.”

However, many respondents reported a lack of **adequate support**, with some relying on their own research or family networks to navigate care. Several mentioned receiving little to no guidance or follow-up after a dementia diagnosis and described their experiences as inadequate or distressing, and others expressed frustration with the lack of awareness and training among healthcare professionals.

“Excellent advice from an Admiral Nurse but she worked part time and was very stretched. GPs were good. District Nurses were HORRIFIC.”

“Didn’t really get anything initially. We found out about Admiral Nurses ourselves. The GP hadn’t heard of them.”

“We didn’t really get support through official dementia services, because my mum was never diagnosed. Most of the help and information came from family, community networks, and our own cultural background rather than health or social care. There was very little tailored support available at the time.”

“At the time of mum’s diagnosis, the Alzheimer’s Society was active in Bolton, and they had a team of Dementia Advisors (DA). Mum’s DA came to see her at home a week or so after diagnosis. We were given a blue folder with lots of information and told the DA would remain in regular contact with us. However, the Alzheimer’s Society lost their funding for DA service in Bolton and six weeks after we received a letter from them saying mum no longer had a DA. We did not access services for a very long time...”

Professionals were asked what information, and support would help **them** better support people living with dementia and their carer partners. There was a strong call for:

- **Clear, up-to-date information about local services and support groups.**
- **Dedicated outreach** workers to assist people in their homes and provide regular check-ins.
- **Designated specialist roles** such as Admiral Nurses, to provide ongoing support and Advance Care Planning.

- **Groups designed to cater to different levels of cognitive ability** to avoid negative impacts on individuals with mild symptoms.
- **Improved signposting** for financial and practical support, including welfare benefits and council tax reductions.
- **Training** and more **resources** on communication techniques, managing challenging behaviors, and understanding dementia stages.



“Outreach workers to support people in their own homes, up to date information about social groups and how to access them.”

“Support groups that people can access that are appropriate for their level of cognition, i.e., those with mild symptoms may struggle with those whose symptoms are more advanced. Could have a negative impact on how they view their journey.”

Professionals called for better collaboration between local charities, healthcare providers, and mental health services to ensure comprehensive care, and increased availability of respite care, telecare equipment, and practical tools for carers.

“Access to mental health services and better GP link up for community care such as Advanced Care Planning for the PLWD and their families. More support for the local charities such as Bolton Carers Support and Bolton Dementia Support. Linking up with Dementia UK so carers have access to the Admiral Nurse clinics and helpline. Having an Admiral Nurse working with GPs to support patients and carers in their own home.”

“To properly support people living with dementia and their carers, I'd need a good understanding of the specific type and stage of dementia they're dealing with. Information on local resources, like support groups and day care centres, would be really useful. Knowing about effective communication techniques and strategies for managing challenging behaviors would help me provide better assistance. Access to training on dementia care and the opportunity to connect with other carers and professionals for advice and support would also be invaluable.”

“More practical support and services for people with dementia and their carers.”

“Full up to date history contained in referral.”

“How to communicate with that person, encouragement to seek support for carers. Practical support. Guidance to access benefits they are entitled to.”

“Simple snapshot leaflets.”

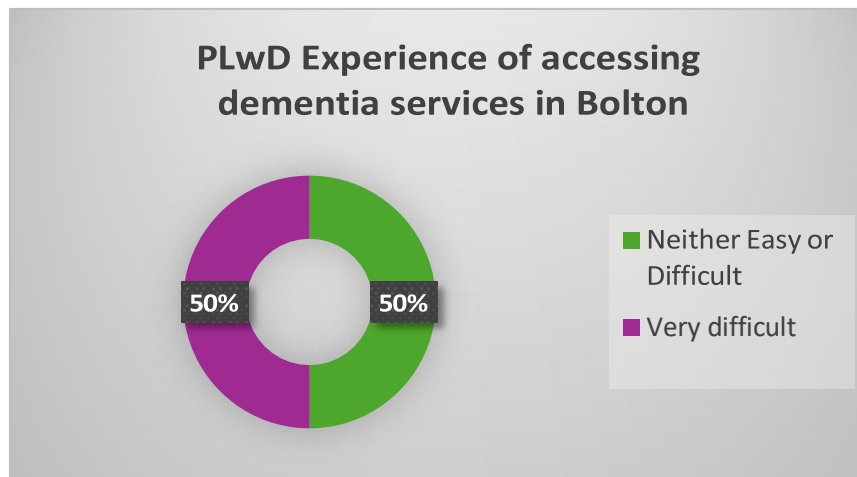
“A designated person for at least the first six months after diagnosis.”

“Us knowing where to flag on for support until their assessment happens. Nothing better than being with people with lived experience.”



Access to Services

We asked all respondents whether dementia services in Bolton are easy to find and if they meet their needs, including any barriers.



One PLwD found support at the Memory Café on Tuesdays at Bar Lane. Another PLwD said they had not actively sought services yet.

Some **current carers** mentioned that support became easier to access after a diagnosis, with help from the Memory Clinic, their GP, and Bolton Dementia Support and Bolton Carers Support.

“Initially a battle. Once diagnosed, made easy by GP support memory clinic and Bolton carers.”

Many **current carers** found it difficult to access help and support initially, citing both a lack of knowledge about available resources, and too much information and feeling overwhelmed.

“Lots of information out there - too much - but getting the right type of support is the crux.”

Others highlighted challenges such as navigating complex systems, lack of signposting, and limited emotional and practical support for working carers, which left them feeling isolated and stressed.

“Not great, and not great now. They just leave you to get on with it, there is no-one checking upon how it's all going, you don't really know where you can go if you need help. We are fortunate we have family members who can help us out, but if you don't have this then it must be very hard. Carers need to be taken care of too.”

“It has been extremely difficult to access help and support and to be perfectly honest we feel totally let down by the current system, we have had to fight every step of the way to even get our voices heard.”

“There is absolutely no support as a carer, oh yes you can ring someone but then nothing is actual help, all support groups are in work time, so you are left isolated trying to work full time and look after dad leave no room for a life.”

“We don't have any help and support. My mum won't ask for help because she doesn't want anyone to interfere with her routine of how she manages Dad, but the only break she ever gets is when my sister or I look after Dad. We don't really know what help and support is available.”

We asked former carer partners how easy it was for them to access dementia support services in Bolton.

The majority (59%) found accessing services "not very easy," "difficult," or "very difficult." Only 7% found services "very easy" to access, and 33% found them "fairly easy." Many **former carers** expressed frustration with the lack of awareness, visibility, and accessibility of services. Some noted that they were unaware of available services or struggled to find them, while others highlighted issues with the quality of care and support provided.

“Didn't really access them - Mum and I had a good relationship and shared interests so planned activities myself to keep her engaged.” (Former carer)

“I work full time and a lot of support services are during the day, and the carer has to be present. There were no/very few activities for communities of colour in Bolton. For example, my mum enjoyed gospel singing.” (Former carer)

“Wasn't aware of any at the time and, when you're going through it, you don't have the time or energy to look.” (Former carer)

“Found Admiral Nurse ourselves. The lead for the District Nurses in our area was appalling. Staff had no idea what they were doing. Some really terrible decisions were made by the District Nursing team responsible for my dad.”

Case study: Blair and Marjorie's' Dementia Journey

Marjorie and Blair spent 44 years together. Blair loved music and had played in a 1960's road show band, which often performed for dementia patients. Marjorie first noticed changes around two years before diagnosis, including confusion, unsafe decision-making and later incontinence.

"One day he started to drill in the wall to try and put a socket in but there was no wire for him to put the socket in."

Although Blair initially passed a GP memory test, Marjorie felt something was still wrong. After a second test, Blair was referred to the memory clinic, where staff indicated they were *almost* certain he had vascular dementia but did not provide a formal diagnosis. The family were told he would be reassessed in six months.

What happened

The lack of a confirmed diagnosis delayed access to practical support, including bladder and bowel services and wider dementia support. During later hospital admissions, Marjorie repeatedly explained that Blair likely had dementia and that he masked his symptoms well. She raised concerns about his care, including staff not following information about his diabetes risk, poor hydration, delirium, bruising and restraint. Blair was eventually diagnosed with vascular dementia in hospital in February 2024. This was communicated to Marjorie by email, she says *"it never felt like a clear or official diagnosis."*

What helped

Some care made a real difference. Two healthcare assistants (who are also activity coordinators) got to know Blair; playing the keyboard and John Denver songs to engage him. The Admission Avoidance Team were also described as excellent: they always introduced themselves and asked what support was needed.

End-of-life experience

After discharge from hospital, Blair declined rapidly. Marjorie sought continuing healthcare funding but was initially told by a hospital social worker that Blair did not meet the criteria. Marjorie managed to secure Power of Attorney and coordinated care at home. At the end of Blair's life, delays and medication-record issues meant he did not receive medication promptly to ease his breathing. Marjorie and her daughters found Blair's final hours extremely distressing. Marjorie made a formal complaint and continues to carry the impact of what happened during her husband's final hours. *"I don't want to feel guilty, because it wasn't my fault."*

Professionals were asked if dementia support services in Bolton are easy to find, use, and meet people's needs. Their experience and key observations include:

Services are hard to find - especially for people who are digitally excluded:

“All services are difficult to find for people who are digitally excluded.”

Even those with internet access report difficulty reaching a real person:

“I think they are relatively easy to find if you are on the internet, but I find it difficult to be able to speak to someone, a first point of contact. People report that the Dementia Support services are not responsive to calls and emails.”

Some professionals felt that communication from services is inconsistent or poor:

“No, sadly they are very few. The main one we refer to BDS (Bolton Dementia Support) are very poor at communicating. Patients report lack of or very little engagement. We often find that information packs have not been sent out. There’s a lack of variety in what support is offered.”

“They are easy to find community memory cafes are good and well attended however other support such as outreach/carer support for those who are housebound is not easily obtained. There used to be a sitter service that was valuable, no community Admiral Nurses. Memory team do respond well when things change, however consistent/ongoing support is limited.”

Others felt that support is limited or does not meet people’s needs:

“There is a local charity offering general support but not in-depth enough.”

“No, the family and carers need to look for the services. Information could be provided post discharge from the memory clinic about the services in the community.”

“From my experience, dementia support services in Bolton are not easily accessible, navigable, or comprehensively meeting the needs of the community, as evidenced by the challenges I’ve faced in locating dementia cafes, buddy clubs, and other resources.”

“Sometimes we are waiting a long time for a visit from the CMHT.”

“They are when you know where they are.”

“Yes. Usually, good response from BDS. Unsure if role of dementia care navigator is still active; communication not great with this. Need more support in the community to see people and their families at home.”

“Only Bolton Dementia Support. Do not meet people’s needs no.”

“We know of the services as we developed links over the years, so possibly as a

patient it may be difficult to find.”

“My neighbour and her daughter was given this once my neighbour had a care act assessment. Then given information and she is under mental health now also. Because it has just touch me directly, I would usually look up and give people information if I have been called into support and help with an attendance allowance form or if they were already on a benefit to inform say DLA 65 plus.”

*From some professional’s perspectives dementia support in Bolton is viewed as **hard to find, poorly communicated, inconsistent, and heavily reliant on individuals navigating the system, with significant gaps in outreach, follow-up, and specialist provision***

All respondents were asked where else they turn to for information and support:

One PLwD shared that they went to The Hub in Bolton for counselling but found it unhelpful:

“Nowhere. I went to The Hub in Bolton for Counselling, but this didn't help, it just made me more anxious and stressed.”

Most respondents turned to friends and family networks:

“Turned to family, friends, and people in our community for support, but people can only give so much and after a while it felt isolating. There wasn’t much clear guidance from health services, so I relied on word of mouth and voluntary groups. Our cultural networks helped where they could, but most of the time it felt like we were piecing things together alone without proper direction.”

Other respondents used the internet and/or joined dementia-related groups via social media:

“Internet - on line dementia courses from Wicking Institute (University of Tasmania), joined dementia forum on Facebook for support, Contented Dementia book pivotal in teaching us how to enter Mum's world. GP for physical symptoms such as anxiety and sleep issues.”

“Internet to see what support services available in the area.”

Community insights strongly echoed the importance of community groups. Participants described Dementia Cafés and similar spaces as providing friendship, belonging, and emotional reassurance, often filling gaps left by statutory services.

Community and peer-led groups were consistently described as “*lifelines*,” offering emotional support, structure, and opportunities for respite not available through formal services.

We asked what community groups people go to:

Three **PLwD** told us they go to Bolton Dementia Support, Music in Mind, and non-dementia-specific groups such as University of the Third Age (U3A) and Walking for Health in Harwood):

“Not ‘dementia’ groups but involved with Bolton U3A and the walking for health Harwood group.”

“Yes, Bolton Dementia Support group and we usually go every week.”

“Yes, Dementia Support [and] Harwood Music in Mind Bolton stadium.”

Current carers said they attend the following groups. **Bolton Dementia Support including their Memory Cafes and Cares Equip), weekly craft group at Thicketford House, Bolton Octagon Theatre and Music in Mind (held at Bolton Wanders Stadium),** and referred to them as lifelines and invaluable sources of information and emotional support.

“There are several support groups we go to Monday to Friday, all of whom provide a lifeline for me and my husband.”

“Have attended line dancing, sound bath session, flower classes.”

Out of 37 responses, a significant number of respondents indicated that they do not attend any carers support groups.

Barriers to accessing groups and social activities participation:

Several respondents mentioned that the timing of support groups does not align with their caregiving responsibilities, making it difficult for them to attend while some respondents noted that they prefer not to attend support groups.

“No, because the times don't fit in with caring for my husband.”

We asked PLwD, current and former carers if they had any difficulties accessing health care and other information such as welfare benefits advice and community groups for themselves and the people they care or cared for.

Focus group participants described significant challenges accessing primary care, particularly in securing GP appointments and obtaining follow-up after raising memory concerns. Many were unsure how to advocate for further investigation, reflecting wider issues around navigation and system complexity.

“Not at present.” (PLwD)

“Yes, GP delayed referral to CMHT.”

“Community Groups. Definitely. I went to a group at The Well in Farnworth, but I didn't find this helpful. The Group members were all carrying their own baggage, so it turned into a chat group rather than a Support Group.” (PLwD)

“Financial support is a minefield; nobody is able to tell you what you are entitled to. You have to complete the application and wait for a reply to say whether you are entitled or not. Surely in these circumstances someone should be able to help to navigate the benefits system and get quicker results. We have no income and have spent all our savings, can't work because I'm caring for my husband 24/7.”

“Yes, after Bolton memory team support group ended it was just me my mum and dad dealing with her dementia. Although mum did go for an assessment every year at GPs.” (Current Carer)

“Without the dementia support group I would have accessed nothing. Martin Lewis (the Money Saving Expert) informed me about the council tax reduction. Attendance allowance must have been 18 months after diagnosis.”

“Takes weeks goes round in circles never seen the mental health team since 2021.” (Current carer)

“My main concern is the care company I use every morning for 1 hour to get my wife washed & dressed. The office who set the rotas does not appreciate how important timing is. Their priority is profit not care. The front-line carers are generally good, but they have a thankless task. Dementia is so different to the infirm who also need such a company and who the carer has to accommodate.”

“Yes, because I don't know where to turn to.” (Current carer)

“My husband had some extremely challenging times in our local A&E after being fitted with a catheter waiting 12 hours only to come home and being confused in the night and taking it out only to have to visit A&E again to wait another 12 hours because a community nurse wasn't able to visit. This happened a few times.” (Current carer)

“We struggled to find an NHS dentist.” (Current carer)

“There are difficulties because you're not sure what to ask for/who to speak to.”

It's a bit of a minefield in the early days. Waiting for a place in daycare took months.” (Current carer)

“If I couldn't use technology, it would be impossible. Getting through to different health departments over the phone can take an age, 39-40 minutes on the phone are not unusual. Knowing which of the many mental health departments you need is a minefield. Some things the doctor will refer you to directly, others like bladder and bowel you need to contact yourself. The dreaded 40 minutes on the phone. It is rare for anyone to actually make an appointment to see us. When bladder and bowel agree to send samples back to 40 minutes on the phone to say too large, or too small. No one discusses the degree of urinary incontinence. Little accidents, full on bladder or bowel emptying. Over the phone is difficult especially as you are stressed due to the wait while trying to care for your loved one who is like a 2-year-old and into everything.”

Health and care professionals shared insights and the difficulties **they encountered while supporting PLwD and their care partners**. Only one professional said they did not experience any issues. Some professionals stated the following:

“It’s embarrassing the hoops people have to jump through.”

“Respite, especially for those that need more specialised care.”

“Agencies need to be aware that to access support is difficult, you can’t always leave the person living with dementia to attend a benefits app etc.”

“Large percentage are unaware of welfare benefits especially council tax reduction. Community groups are available; transport can be an obstacle.”

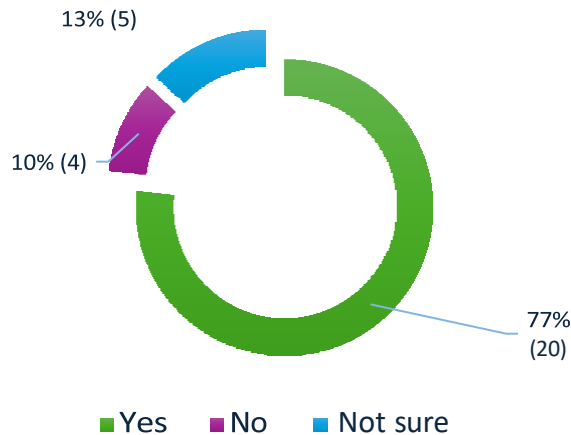
We asked PLwD, current and former carers if they are satisfied with the support they received to look after their health. We specifically asked current and former carers if they are/were registered as a carer with their GP practice and what benefit this was, i.e. medication reviews, annual health checks

We asked current carers if they are registered as a carer with their GP practice, and how well supported they are to look after their own health.

Responses to this question show that most caregivers **77% (20)** are registered as carers at their GP practice. **10% (4)** are not, while **13% (5)** are unsure.

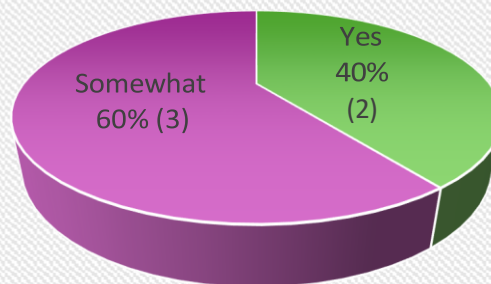
Focus group discussions highlighted that many carers feel “invisible” within the system, with their needs often secondary to those of the person they support. Experiences of burnout, emotional strain, and limited meaningful engagement during carers’ assessments were common themes.

Current carers registered as a carer



Some current carers shared mixed experiences of their annual carers health checks. One carer expressed, ***“I think this is important”*** Others stated that while their physical health was checked, health professionals did not ask them about their mental health and how they are coping with caring commitments. One carer stated, ***“... I’m listed as next of kin, I don’t get paid for caring due to having a full-time job.”***

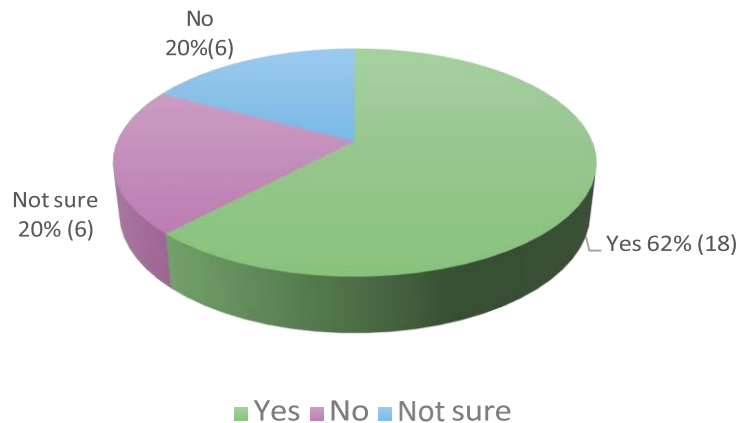
PLwD - are you satisfied with the support you received to look after your health?



“Useless appointment told to lose weight round my middle (I’m 5.7 and was 10.5 stone) eat more veg cook more meals, by a nurse who clearly doesn’t know how time poor being a carer makes you.”

“There is a lack of full carers assessment at GP. I had a carers assessment where I had blood tests, BP and BMI recorded. I was not asked anything related to caring. When I questioned the health professionals, I was told that if I have any problems then to make another appointment and they will signpost me to appropriate services.”

Former carers registered as a carer at their GP practice



Yes, I registered as Earl's primary carer, had a carers assessment and it was quite laughable. It was with one of the nurses. She did weight, height, blood pressure, took bloods, asked how I was feeling. I started crying. I said my mental health is in my boots. She said, 'Oh right, have you spoken with our mental health nurse and do you find it helpful?' I said, Yes, I have had two appointments, and I have one tomorrow. I find it helpful but it's not really resolving the issues, and no one is providing adequate support because I still feel like I am on my own with this.' The nurse said, 'Right I get you.' I came out of there and thought, 'what was that all about?' No signposting to other organisations. I got signposting for the mental health nurse. I have all this support for Earl, but it's me, I am the one who is sinking. You are consumed. I feel like I have nothing to talk about because it's all about Earl. I don't mean that to sound selfish. It's not about how do I feel, I haven't got dressed today... I don't go out, I don't see anyone, I buy my groceries online. On edge all the time."
(Former carer – July 2025)

One current carer stated that they couldn't remember whether they were asked if they are a carer and therefore do not know whether they are registered with their GP practice as such.

"I may be, but honestly, I can't remember it being said."

Most **former carers** said they were registered with their GP practice:

Asked if they received support to look after their own health, such as accessing annual health checks at their GP practice, only (approximately) half of former carers received annual health checks, vaccinations, or other support from their GP practices.

“Yes, I had annual health checks at my GP practice. This also included making sure I was up to date with my vaccinations, i.e., flu jab.”

“Yes, I work for NHS, so knew what entitlement I could have.”

Others stated they received no support or were unaware of any available services for carers:

“I received one medical checkup on Monday 23 December 2019.”

A few respondents shared negative experiences, such as lack of empathy from healthcare professionals, inadequate support, or being left to manage their health alone.



“We were offered for my dad to go into respite. But I knew how bad the place he was offered was and wasn’t prepared to let him go there. It would have been worse for him being there for us as well as him. So, it would have been no help for us at all. I went on a ‘carers’ day. This was a joke. I was told the idea of it was to help us care for our relatives. Everyone there was more than capable of looking after their relative. We didn’t need ‘tips’, we needed help and support from people who knew what they were doing. And that wasn’t given. I know everyone who has been invited there felt patronised and very very angry with the whole day. It was a complete waste of time. From what I can remember the only thing that the GPs offered was a bit of sympathy for what we were doing as a family. The District Nurse manager was a disgrace to her profession. It made me feel embarrassed that I was part of the same profession. The first time she came to the house to introduce herself and tell us what her team could do for us, she told us that she couldn’t believe what we were doing for my dad. And that there was no way she’d do that for her mum. As she finished work at half 3 and wouldn’t do anything else after that. That kind of attitude didn’t leave us with any faith at all in getting help/support of any use. Her attitude remained the same until my dad died. Fortunately, she was the worst person in her team.”

Overall, the responses highlight **inconsistent access** to health support for former carers, with many feeling overlooked or unsupported in managing their health and own well-being.

Collectively, while most respondents were registered as carers, many were either not registered or unsure about their status. This indicates a need for better awareness and communication from GP practices about **the benefits and importance of registering as a carer**.

Dementia -Friendly Services

A **dementia-friendly community** is one that is intentionally considered and designed to support the independence, dignity, and well-being of PLwD and their carers. It incorporates clear signage, familiar layouts, appropriate lighting, reduced noise, and safe, accessible spaces to minimise confusion and anxiety. Equally important is the understanding, attitudes and behaviours of the people within communities: staff, paid carers and the wider community. Dementia-friendly approaches promote inclusion and awareness within society, helping to reduce stigma and ensure that people living with dementia remain valued and respected members of the community. ⁴

Participants reported high levels of engagement in the Let's Talk About Dementia awareness sessions, with initial apprehension shifting to a sense of **empowerment and increased confidence** in seeking support.

We asked PLwD, current and former carers if they feel public services, space, transport, and facilities in Bolton are dementia-friendly?

Out of 36 **current carers** responses, a significant number of respondents expressed that public services, transport, and facilities in their area are **not** dementia friendly. Equally, many respondents were unsure or did not have enough experience with public services to provide a definitive answer.

Positive Feedback: Only one carer felt that their area was dementia-friendly, but this was not a common sentiment.

Challenges Identified:

- Several respondents mentioned that public transport is not suitable for individuals with dementia, especially those with physical or cognitive limitations.
- Lack of training for public service staff was highlighted as barriers to accessibility.

“Community groups sometimes are unsure how to support someone living with a dementia.”

“Our relative is completely unable to use public transport, sadly we don't live in a dementia friendly community.”

⁴ [Dementia friendly communities](#)
[| Alzheimer's Disease International \(ADI\)](#)

“Accessible transport is always a huge barrier for people. I actually think there is a good range of dementia support services in Bolton but people without transport and who have mobility problems often struggle to access them.”
(Professional)

The majority of **carers** **former** 81% (22) said that public services, transport, and facilities in Bolton are not dementia friendly. 15% (4) felt services were "Somewhat" dementia-friendly, and 4% (1) were "Not sure," and no respondents' felt services were fully dementia-friendly.

Challenges highlighted include transport issues and services and public facilities:

“No, I don’t feel public services, transport, and facilities were dementia friendly. At the time there was little awareness or understanding, and nothing in place to help my mum live independently or safely. It often felt like we were managing alone, without the community being set up to support people with dementia.”

“When mum was able to get about Ring and Ride service was very sketchy. Currently, Bolton Town Centre is not very appealing and although mum is no longer with us, I do not feel Bolton Town Centre is dementia-friendly.”

“I feel a lot needs to be done to make services dementia friendly there is a lack of awareness and understanding.”

“Not easy to access buses.”

“Unless they have a really large family/friends network. There is so much work to be done with dementia care. The quality of carers is getting even worse since my dad died. I worry about how I will get looked after in the future if I end up with dementia.”

“We were rural and public transport was extremely sparse and unreliable.”

“Mobility issues and unpredictable buses made public transport too difficult, and I don't drive so had to rely on local taxi -drivers were very good.”

Personal Experiences:

- One respondent shared a positive experience where a council worker helped their father with dementia navigate the town center and return home safely.
- Another respondent highlighted the lack of understanding among hospital staff about the challenges faced by people with dementia.

“As each person with dementia is unique and each person they encounter out in the world this is very difficult to answer.”

“I don’t think people who have never been close to someone suffering with dementia have any idea how hard it is. Even staff in hospitals do not understand how it affects people, it is a total life change. The patient is

completely stripped of their personality and life skills. No one chooses to be like that.”

Engagement sessions with communities of colour highlighted cultural expectations around caring for loved ones at home, which can contribute to lower uptake of hospice and formal care services. However, targeted awareness sessions were shown to positively shift perceptions and increase openness to support.

Conclusions – Supporting Well and Living Well

- ✚ **Access to support is inconsistent:** Some people receive helpful guidance, but many report little or no support and must navigate services alone.
- ✚ **Services are difficult to find and navigate:** Many carers struggle with complex systems, poor signposting, and limited follow-up after diagnosis.
- ✚ **Carers are under significant strain:** Emotional, financial, and practical pressures are high, with insufficient support for carers’ own health and wellbeing.
- ✚ **Community organisations are essential but limited:** Groups like Bolton Dementia Support and Memory Cafés are valued “lifelines,” but it was felt that provision is not enough to meet demand.
- ✚ **Bolton is not widely seen as dementia-friendly:** Barriers in transport, public services, and awareness mean many people feel the area does not fully support those living with dementia.

Overall: The system relies heavily on **individuals and families** to find and coordinate support, leading to **unequal experiences and unmet** needs.

Community engagement and focus group findings reinforce the conclusion that support pathways are fragmented, with people often left to navigate systems independently. They also highlight the critical role of trusted community organisations in filling gaps and providing culturally appropriate, accessible support.

Chapter Three –Palliative and End of Life Care and Bereavement Support: Experiences of former carers and professionals

The survey asked PLwD, current and former carer if they **experienced distress or crisis related to the symptoms of dementia and what support was available.**

Six PLwD responded. One PLwD has not experienced distress or crisis related to dementia symptoms. Five PLwD shared their experience and some expressed how they managed that period:

“Some stress due to not remembering things.”

“Yes. No Local Support”

“I get very teary, especially in the early days.”

“I have been depressed and the doctor arranged counselling.”

Out of 24 respondents, four former carers had not experienced a crisis with the person they cared for.

Some mentioned helpful services like district nurses, Bolton Dementia Support, Bolton Carers Support, Bolton Hospice, the police and Alzheimer’s Society.

“Any physical issues e.g. falls dealt with brilliantly by telecare or ambulance service, even once police. Once rang Alzheimer’s care line after 26 phone calls overnight from Mum.”

“I experienced crisis as a sole unpaid carer, contacted social services and instigated the process to move my mum into care.”

“I have a yearly carers appointment at the GP, and I’m asked about my wellbeing.”
(Current carer)

“The Admiral Nurse was incredible, as was my husband’s social worker and the lady from Alzheimer’s Society.” *(Former carer)*

“Yes. Able to talk to someone from Dementia Support and Bolton Carers Support.”
(Current carer)

Some respondents stated that support was often inadequate or unavailable, with some respondents relying on family, community, or private services. Many reported experiencing significant distress, especially during end-of-life care or crises such as falls, incontinence, or behavioral changes.



“Yes, I did experience distress related to my mum’s symptoms. It was overwhelming at times, especially without a diagnosis or clear support plan. There was very little formal help available, no crisis team or specialist guidance, so I had to manage things myself with occasional help from family and community, which often felt like not enough.”

“Yes, when mum forget walk and her legs gave way as she was walking upstairs. Luckily, I was standing behind her. This was a game changer regarding how safe it was for mum to be at home on her own for any period of time. Following this episode I contacted adult social care for urgent respite. They responded quickly. Unfortunately, the care home that could accommodate mum for two weeks had an outbreak of Covid and could not accept her. We had to private fund mum’s respite care which was out of the borough.”

“I don’t think the doctors were very good at prescribing appropriate medications. This led to some very difficult times. We were left to deal with new onset of incontinence with no help/support whatsoever. Had to sort out our own referral to the incontinence team. Had to sort out the involvement of the therapy team at the Hospice to get equipment due to the incompetence of the District Nursing team. Ended up requiring a fortnight of 4 visits daily from the Hospice at Home team after the District Nursing team deeming him not to be a priority. After a head injury following a fall, they refused to visit to assess dressing that had been applied in A&E. He didn’t get out of bed for 2 weeks after having been fully mobile. Hadn’t looked at pressure areas, offered hospital bed. When we said we wanted him to be downstairs living, I asked how we would get him downstairs. The manager said she would send 2 members of staff to get him downstairs. They hadn’t even tried to stand him up at this point. Questioned this decision asking what would happen if he fell or fell onto one of the nurses and said I was worried about everybody’s safety (He was 6’4). I was told not to worry as they had done this many times before. This was when I contacted the Hospice as fortunately, he got bladder cancer. I say fortunately this gave us access to the Hospice where everyone was great.”

Others expressed frustration with the lack of timely and effective support from healthcare professionals.

“I had difficulty obtaining a blue badge for my Mum until she could no longer walk and I couldn’t physically manage to get her in my car.”

“Yes - I rang the GP but again they were most unhelpful. By the time the GP finally did agree to come and see my grandad at home, I had already rang for an ambulance and my grandad was taken to hospital and admitted.” (Former carer)

Several respondents emphasised the need for better crisis support, training for healthcare providers, and improved access to resources for both carers and patients.

“I ended up burning out from trying to deal with caring and working at the same time, as well as crises relating to her symptoms like her being the victim of bank fraud and causing a car accident. I ended up at a private counsellor because I didn't know what support was available or how these things worked.”

“Yes, I've struggled caring for mum and seeing her decline as I'm her sole carer. I've recently had 4 weeks on sick through stress and anxiety and last week had another major breakdown.” (Current Carer)

We also asked professionals if they had supported PLwD and their carers during a crisis, what support was available, and how easy it was to access to ensure the PLwD and their carers received timely and appropriate support. Out of 17 responses, the key themes were:

Positive feedback about support from the Memory Clinic and social services:

“Yes. I referred back to the memory service who were very supportive and went out of their way to speak to the persons carer to offer support and guidance.”

“Yes. Social services team helped find respite care quickly. I supported the carer.”

“From my experience, yes, I have supported a person living with dementia and their care during a period of distress. While we had good support from the mental health team, there was a delay in awaiting a referral, which I believe is time-sensitive in these situations.”

Mixed experience and offering suggestions for improvements

“Yes, it's part of my role as the Admiral Nurse. The support was ok but there is a lack of knowledge and approach about Dementia and how to manage their needs. i.e., reassessment GP management needs to be linked up to Older adult mental health services and memory clinics.”

Negative

“Very little support available. Mental health services do not care about dementia.”

“Yes, many times. Support can be very sporadic with a lot of changes such as staff, teams, new projects, old projects no longer available, not flexible enough.”

“Yes, and I feel there was very little support at that time. Besides a GP appointment and Bolton Carers Support, I struggled to find the correct support. Social Work

appointment can take a while.”

Limited Support – some professionals reported minimal or insufficient support and a lack of joined-up working and knowledge about dementia:

“Yes, minimal support. I seem to be the support for this. Social Services rarely can offer anything & respite is difficult to find. Unsure of the role of dementia care navigator within Bolton Dementia Support. They seem to focus on events in the community rather than ongoing tailored support.”

Challenges in Accessing Support:

“Yes, listening, referrals to appropriate services. Discussing the patient in the MDT, advice on how people can try and support someone experiencing BPSD [Behavioral and Psychological Symptoms of Dementia]. Carer support referrals, OT [Occupational Therapist], SW [Social Worker] Package of care can be difficult to arrange at times and feel like you need to 'prove' the difficulties the patient is having before the referral is accepted and request capacity assessments as even with evidence we get told things like the 'person said they didn't want support'. Even when there is risk, no insight or capacity.”

Professionals told us they also turn to the following colleagues and organisations for information and support:

- Admiral Nurse
- Social prescribing colleagues
- Online resources such as Dementia UK, Alzheimer's Society, and Bolton Dementia Support
- Local organisations like Bolton Carers Support, Age UK, and British Royal Legion
- Council Neighborhood Teams, social workers, and community therapy teams

“[Staff member] VR, my QA [Quality Assurance] officer, is very proactive in supporting our care home. When I look for additional information and support, I turn to professional organisations like the Alzheimer's Society or Dementia UK. They offer a wealth of resources, helplines, and support networks. I also rely on support from local councils, NHS services, my GP, and my regional manager for guidance and care pathways. Engaging with online forums and support groups connects me with other carers and professionals, offering practical advice and emotional support.”

“The internet, Dementia Carers Count have been useful, Bolton Carers Support are amazing. Social Care are great but overstretched. GP appointments. Befrienders are great and I would use the knowledge that we have in our Team.”

“Dementia UK (Admiral Nurses forums and groups). Line manager for appraisals.”

“Online to Dementia UK and Alzheimer’s Society. Occasionally liaise with (the current) Admiral Nurse at the hospital, Memory team as needed also.”

We asked former carers if they had to make difficult decisions (e.g. moving the person they cared for to a care setting) and what their experience was. Out of 27 respondents:

A few respondents mentioned positive experiences with specific care homes or live-in carers, but these were exceptions:

“We chose not to as we were more worried about the level of care that he would get there. It was very insulting that the District Nurses inferred that he was at risk at home with us. The Hospice at Home team were amazing.”

“Yes. After a brief spell in respite while I got her house renovated, she decided she would prefer to be in care full-time. It was a difficult, emotional decision but actually a huge relief as her illness was progressing beyond where 1 person could keep her safe - she wandered in the night, and I had to sleep sometime. She is now safe and well-cared for by a professional round-the-clock team and seems much happier and more relaxed.”

“We had great care from Home Instead carers, firstly twice then three times a day. As symptoms increased family urged me to consider residential care and I agreed to look at a couple of homes, but I knew Mum wouldn’t cope with a move. We did employ a live in carer during the week for final year - myself mainly staying at weekends. Luckily my father had had a good pension.”

A few respondents stated that moving the person they care for into a care setting was not an option:

“No, I never considered moving my mum into a care home. My focus was always on doing my best to look after her at home for as long as I possibly could. Residential care wasn’t an option I wanted for her.”

“No, refused to put mum in residential care.”

Many found the decision to move their loved one into residential care to be emotionally challenging and heartbreaking, often feeling guilt and distress.

“Yes, it was absolutely soul-destroying. Mum always said she never ever wanted to go into a care home. I felt like I was letting her down when she needed me the most. It was one of the hardest decisions I have ever had to make in my life. More support needs to be available for individuals who are faced with this decision.”

“Mum moving from her family home to a care home was very traumatic and heartbreaking for us as a family, if home adaptations would have been approved, we could have cared for her longer at home.”

“Yes, it was difficult for us all.”

Some respondents chose to care for their loved ones at home, citing concerns about the quality of care in residential facilities and lack of stimulation:

“My mum once took my dad to a Home for a morning of respite, but she said the place was so inappropriate (dementia patients sitting alone in a room, completely unstimulated) that she returned to pick him up 20 minutes later, vowing that he would never go back there.”

We asked former carers if they needed information, advice and guidance on the long-term care of the person you cared for, such as respite care, home care/care home fee, carers assessment, financial assessment and how beneficial the information was.

Out of 24 respondents:

Some respondents relied on the Admiral Nurse, social workers, GP, the internet, Bolton Dementia Support, Dementia UK, the Alzheimer’s Society or welfare rights services for assistance, which was helpful in certain cases.

“Admiral Nurse - she was invaluable. Every dementia patient / carer should have access to an Admiral Nurse.”

“No one apart from the Admiral Nurse was able to give us any constructive advice. Unfortunately, we rarely saw her. I think there were a lot more families who needed her more than we did. Fortunately, I knew most things and knew who to contact at work for the odd thing that needed clarifying.”

“I needed advice on everything - respite care, home care, how to get a place in a care home, how to get support, how to try to keep her safe, how to get her food safely while I was at work, and got all of the above from the social worker, her GP or internet searches. It was very helpful because I had no idea how any of it worked. To start with, I didn't even know you could go to a GP about someone "acting strange.”

“I got information based on my experience as a nurse, online organisations, Dementia UK, Alzheimer’s [Society], Bolton Dementia Support and social workers.”

Many expressed a need for information on long-term care options but found it difficult to access and/or were unaware of available resources. Others had to independently research and navigate the system, often finding the process confusing and time-

consuming, and in one instance had to deal with unhelpful and inadequate support from a member of staff:

“We were not offered a carer’s assessment at any point.”

“Yes, I needed this information. It was tricky to find out what jurisdiction mum was under because we moved her out of Bolton due to no available respite in Bolton. There was a significant wait for Bolton Local Authority’s Finance Team to respond to any queries. The previous form on the website (in 2023) was very confusing too. It was hard knowing what to do; whether mum was eligible for some support or not.”

“Was never given a choice in care homes available was placed in an area that was hard to access on public services.”

“I would have loved this information and guidance, none provided, a bunch of leaflets handed to a sole carer who has just been told that their mum has dementia is not giving info, advice and guidance.”

“The financial assessment officers who attended my Mum’s home were rude and abrupt. It was unpleasant.”

We asked people if the person they cared for received palliative or end-of-life care, and if so, which organisation provided this, and if it was beneficial.

‘Palliative care aims to improve the quality of life of individuals who have a life-limiting illness. The [National Institute for Health and Care Excellence \(NICE\) guidelines](#) set out that palliative care aims to provide relief from pain and other distressing symptoms, integrate the psychological, social and spiritual aspects of the person’s care, and continue to offer a support system to help people to live as actively as possible until their death. End of life care overlaps with this approach but focuses specifically on the final year of life, including the last days and weeks when death is imminent.’⁵

According to Dementia UK, ‘End-of-life care for individuals with dementia in the UK focuses on ensuring comfort, dignity and support for both the person with dementia and their family. End-of-life care for people with dementia is essential as it addresses the unique challenges posed by the condition. Dementia is a progressive, life-limiting illness, and good end-of-life care is crucial to ensure that individuals and their families receive the support they need during this difficult time.’⁶

⁵ *’([How to fix palliative and end of life care for dementia - Dementia UK](#))*

⁶ *[Dementia end of life care - late stage dementia - Dementia UK](#)*

Community sessions highlighted a **lack of clarity and understanding** around palliative and end-of-life care, particularly:

- Confusion about the **difference between palliative care and end-of-life care**
- Limited awareness of **what hospices offer and when they can be accessed**
- Misconceptions that hospice care is only for the very final days of life

Sessions that explicitly explained palliative and end-of-life care were described as **valuable and empowering**, suggesting that earlier and clearer communication is needed.

Former carers were asked if the person they cared for received palliative or end-of-life support, where they received it, and whether it was beneficial. Out of 28 respondents:

The majority of respondents stated that the person they cared for did not receive palliative or end-of-life support, often due to a lack of diagnosis or inadequate communication from healthcare providers.

“No, my mum didn’t receive any palliative or end of life support. Because there was never a diagnosis, those services were never offered. Everything was managed within the family, which made it very difficult and left us without the professional guidance and comfort we should have had.”

“Due to not having had any support from social workers, we missed out on knowing that mum could have been eligible for Continuing Healthcare Funding to remain in her own home. Mum lived the last year of her life in a care home. She had great access to palliative and end of life care there. We, her family, made that happen.”

Positive experiences included compassionate care from the Woodlands (GMMH) Bolton Hospice and care homes, a GP, the Admission Avoidance Team and Manchester Royal Infirmary:

“Yes, he was at Woodlands, what a superb facility this is, they looked after dad really well it’s just a shame all care places can’t have the same level of care.”

“We had some support from Bolton Hospice in terms of equipment - bed, commode etc, but this was because of my dad’s cancer, not his dementia. Prescribed morphine by GP at the very end.”

“From GP surgery, yes was very helpful”

“Yes, was put in place by district nurses from admission avoidance very caring team helped with easing care role.”

“Yes, the Manchester Royal Hospital. The staff were very helpful and tried to help keep her dignity as much as possible.”

Negative experiences highlighted poor hospital care, lack of communication, and insufficient support during end-of-life stages.

- Some communities of colour may be **less likely to access hospice or formal end-of-life services**
- It is often perceived that ethnically diverse communities prefer to care for loved ones at home
- Limited awareness and familiarity with hospice services contributes to **lower uptake**

These findings reinforce the need for:

- **Culturally sensitive engagement**
- Earlier conversations about **care choices and options**
- Building trust with communities who may not traditionally access these services

“Nothing was offered. I spoke to the GP practice on a number of occasions concerning my Mum’s change in eating, social engagement or swallowing and I was offered no help or support regarding end-of-life support.”

“Palliative care in the Royal Bolton Hospital. To be honest I was going to complain. I asked PALS for Dad’s records but didn’t end up complaining or going through the problems we had. I don’t think they knew or took into account that Dad had Alzheimer’s when he was taken into hospital. He then had another bang on the head. I just don’t think they were aware of his Alzheimer’s.”

“Yes. In the end my grandad passed away in hospital. He was put on end-of-life care however it was family who looked after him mostly. We were the ones cleaning his mouth etc. Care in hospital was very poor.”

Several respondents expressed frustration with the lack of timely or adequate palliative care and the burden placed on families to manage end-of-life care without professional guidance.

“Hospice at Home team - this wasn’t when my dad was palliative though. See above re Marie Curie - he was palliative then. The palliative care nurse came twice. Once to introduce herself. Here she just told my sister a list of things that they didn’t offer. The second time one came round, my dad was clearly dying. This person didn’t do anything/offer any other services or advice. I came in from work just as she said she would come back to visit in a fortnight. Don’t sit down

with family and discuss that his death looked imminent. If I'd not been a nurse, I felt I would have been led to believe that he would still have been alive in a fortnight. As it was, he died that evening."

Access to Support at End of Life

Across discussions, participants described **wider system challenges** that impact end-of-life care:

- Ongoing **difficulty accessing GP and hospital appointments**
- Concerns about **lack of timely responses when health deteriorates**
- Uncertainty about **who to contact or how to escalate concerns**

These barriers risk delaying access to appropriate palliative care and end of life support at crucial stages.

Bereavement Support

Bereavement care supports family and friends when their loved one dies.

Bereavement support can also support carers who have experienced prolonged grief (before someone dies) – known as anticipatory grief. Providing this support can help carer partners to process their emotions to cope with the loss of their loved one.

We asked former carers if they were offered bereavement support and if yes, which services provided it. Twenty-eight former carers responded to this question.

Most former carers stated they were not offered bereavement support, leaving them to cope with their loss on their own.

A few respondents mentioned receiving support from care homes, hospital bereavement teams, or chaplains, which they found helpful.

"Yes, I was offered some support from the hospital counsellor, but that was only at the time of my mum's passing. Beyond that, there was no ongoing bereavement support or follow-up, so most of the coping was left to me and my family."

"Yes, from the Care Home Chaplain. It's been nearly two years since mum passed away and we can still approach the care home (in Manchester) for support."

“Yes, from the Ambulance service, Bolton Carers Support and Bolton Council of Mosques.”

“Yes, I know it is there if I need it. I am aware of the Bereavement cafe and plan to attend.”

Some respondents accessed bereavement support through self-referral to organisations like Sue Ryder or were supported through their workplace:

“Accessed bereavement counselling from Sue Ryder via a self-referral, none offered otherwise.”

“No, but one of my part time jobs gave me talking therapies which I still have as it was realised I have two other people to care for too and I suffered two other traumatic life events since dad’s death - had flexible working re: dad’s care.”

Several respondents expressed frustration with the lack of follow-up or ongoing support, with some noting that the support offered was limited or insufficient:

“I was told I could ring Bolton Dementia Support for 6 weeks only. It took 3 weeks before my Mum’s funeral and I was having to deal with everything. This timescale was not helpful. I wasn’t offered any support from my GP practice even though I was registered as my Mum’s carer and they knew she had died as she was a patient with them. I was left to deal with everything myself and adjust to a life after 10 years of being a sandwich carer.”

“Minimum support from bereavement team at hospital.”

“From hospital with Bereavement Nurse not able to complete fully due to ongoing issues with Royal Bolton Hospital.”

Maria and Shaun's Story

I have been married to Shaun for 33 years. He has always been an active, kind-hearted man who would do anything for anybody. He worked all his life, first for the Council and later fitting UPVC windows after training as a painter and decorator. He loved being outdoors and would regularly walk five miles every morning. We shared many happy years together, and if he were well enough, I would love to take him back to Mauritius one last time.

Everything seemed to change after Shaun's kidney transplant. Although the transplant itself was successful, it appeared to trigger a significant decline in his health. The consultants explained that the transplant and subsequent dialysis treatments may have acted as a catalyst for his dementia. Watching this progression has been heartbreaking. The man I knew has changed, and there is very little I can do to stop it. One of the few pleasures he still enjoys is sitting outside in our garden, which has become a place of comfort for him.

The first signs that something was wrong appeared around 2022. Initially, I thought it was simple forgetfulness, but I began noticing unusual behaviours. Shaun would put milk in the cupboard instead of the fridge, confuse household items, and make mistakes while driving. We visited the GP and were referred to the memory clinic, but we waited approximately nine months for an appointment. During that time, Shaun's condition deteriorated significantly. Eventually, following assessments and scans, he was diagnosed with mixed dementia, including both Alzheimer's disease and vascular dementia.

The period between referral and diagnosis was incredibly difficult because we received virtually no support. Apart from two information booklets, I was left to cope on my own. Looking back, I realise how little I understood about dementia and what lay ahead. I needed someone to explain what to expect, how the condition might progress, and what support would be available. Instead, I felt as though I was working blindly, trying to piece information together for myself.

Over the past year, Shaun's condition has worsened considerably. He was once calm and gentle, but he can now become angry, frustrated, and aggressive. He sometimes uses language I have never heard him use before. These changes can be frightening and distressing. Much of what I have learned about dementia has come not from professionals, but from my sister, whose husband also had vascular dementia. She has provided guidance, resources, and practical advice that I wish had been available through formal services.

Caring for Shaun has become an all-consuming responsibility. I often feel invisible. Friends and family have drifted away, and there are days when the only people I speak to are the carers who come into our home. It can be an incredibly lonely experience. People focus on the person living with dementia, which is understandable, but carers also need support. I feel as though I have lost my identity. I am no longer seen as Shaun's wife; I am simply his carer.

The emotional and physical toll has been immense. I have had to give up many aspects of my life, including hobbies, volunteering, and social activities. Every day revolves around Shaun's needs. I am constantly alert, especially at night, listening for movement in case he falls, becomes confused, or

experiences hallucinations. There is no real opportunity to switch off or rest.

My own health has suffered significantly. When I have occasionally managed to take a short break, my body seems to collapse from exhaustion. I have experienced serious physical illness, including broken ribs and a blood clot on my lung, yet even during hospital admissions my primary concern was who would look after Shaun. There is no reliable contingency plan if I become unwell. When I needed emergency treatment, arranging care for Shaun was stressful, expensive, and largely unsupported.

At times, the pressure has become overwhelming. There have been occasions when I have experienced suicidal thoughts. Although I eventually received support from the mental health practitioner at my GP practice, the underlying issues remain unchanged. The practical pressures of caring continue, and often it feels as though services acknowledge the problem without providing meaningful solutions.

Financial worries are another constant source of anxiety. We have spent significant amounts of money on care because I believe Shaun's needs are best met through a consistent team of private carers. They understand him, treat him with dignity, and support me as well as him. However, our savings are running out rapidly. I am terrified about what will happen when the money is gone. Shaun wants to remain at home, and I want to honour that wish, but I do not know how we will continue to fund the care he requires.

My experiences with Adult Social Care have been particularly challenging. I have spent months disputing financial assessments, chasing information, and trying to get professionals to listen. I often found myself dealing with different people every time I made contact, having to repeat the same information over and over again. Decisions were made without consulting me, including care arrangements following hospital discharge. Care plans were not shared, my concerns were dismissed, and I felt that my expertise as Shaun's primary carer was overlooked.

I have also struggled to obtain information about Continuing Healthcare funding. Despite repeatedly requesting guidance, I was left waiting for months without receiving the information I needed. This uncertainty has added significantly to my stress and anxiety about the future.

One of the greatest challenges of caring for someone with dementia is the need to plan constantly for what comes next. Yet I have never been given clear information about Shaun's stage of dementia, what progression to expect, or how his care needs are likely to change. I need professionals to help me understand where we are now and what the future might look like so that I can prepare accordingly.

I have received limited practical support from family members, despite asking for help. What I need is not financial assistance but respite and shared responsibility. Even a short period of support would allow me to recharge and continue caring for Shaun at home. Without that support, the burden remains entirely on my shoulders.

There have been positive experiences. The private carers who support Shaun are exceptional. They provide consistency, compassion, and understanding. Some professionals have also shown genuine empathy and kindness, and those moments have made a tremendous difference. Simply being listened to and understood can feel like a lifeline.

What I would like to see improve is better communication, consistency, and support for carers. Families need clear information about dementia, guidance about what to expect, and opportunities to connect with others in similar situations. Carers should not have to navigate the system alone or fight continually

for support. We need professionals to listen, involve us in decisions, and recognise the realities of caring.

Above all, I want people to understand that caring for someone with dementia affects every aspect of your life. It is a 24-hour responsibility that can consume your identity, health, finances, and wellbeing. Carers need to be valued, supported, and treated as partners in care, not as an afterthought. Being told to look after yourself is not enough; carers need practical help to make that possible.

Despite everything, Shaun remains the person I love. Watching him live with dementia is heartbreaking, and I often find myself asking, "Why us?" But we continue to face each day together, doing the best we can with the support available to us.

Bereavement support and coping during Covid pandemic.

"I felt guilty because it is a huge relief for both of us [when my mum died]. I feel really guilty about that. I wasn't happy about it. I was really sad it ended. Suddenly, your life completely changes. You can't put it into words."

[Healthwatch Bolton and the interviewee talked about anticipatory grief¹.]

I never had bereavement support. There's two points to this. When mum died in 2020, we had to make the funeral arrangements and family to deal with. Suddenly your left with this huge open space with no one to support you. I think carers need the support, even when the caring role ends. I went to back to Horwich RMNI – they took me on holiday. I found a group in Brownlow Fold. Then we went into lockdown and that was a double whammy. Suddenly, your free and feeling guilty for it and then you're locked up again. I couldn't see anyone because lockdown prevented me doing so.

¹ [Anticipatory grief | Grief before loss | Marie Curie](#)

After mum's funeral, all the wonderful equipment goes back to Adelaide House. Everything feels so empty. I had one phone call from Bridgewater Home Care Agency. No one else asked how I was." (Former carer – Case Study)

Consistent with survey findings, focus groups and community sessions highlighted:

- **Very limited or no formal bereavement support** offered after death
- A sudden **loss of contact with services** once the caring role ended
- Isolation after long-term caring commitments

Caregiving Participants described:

- A “*cliff edge*” experience when support stopped
- Ongoing emotional impact after caring roles ended
- The need for **continued recognition of carers beyond bereavement**

Some individuals accessed support independently (e.g. community groups), but this was **not routinely offered or signposted**.

Conclusions – Palliative and End of Life Care and Bereavement Support

Community and focus group participants said that **community and voluntary sector support** was consistently highlighted as more **accessible and emotionally supportive** than formal services. Important in both:

- Late-stage care (supporting coping and respite)
- Bereavement (ongoing social connection)

✚ **Support is inconsistent and often insufficient**, with many carers reporting limited access to timely, coordinated, or specialist help, particularly during crises

✚ **Positive support exists but is unevenly distributed**, with services such as Admiral Nurses, hospices, and some social care teams providing valued support when accessible.

✚ **Distress and crises are common** among people living with later stages of dementia. Carers often site the following challenging symptoms such as increased memory loss, behavioural changes, falls, and incontinence.

- ✚ **Carers frequently experience high emotional strain and burnout**, especially sole carers without adequate guidance or respite.
- ✚ **Navigation of care systems is complex and challenging**, with many carers unaware of available services or needing to independently seek information about care options, funding, and support.
- ✚ **Decisions about moving into residential care are highly emotional**, often associated with guilt, distress, and a perceived lack of viable alternatives or support to remain at home.
- ✚ **Palliative and end-of-life care is often not provided or introduced too late**, frequently due to lack of diagnosis, poor communication, or system gaps.
- ✚ **Quality of end-of-life care is variable**, with some examples of compassionate, high-quality care alongside reports of poor hospital care and inadequate support.
- ✚ **Bereavement support is largely lacking**, with most carers receiving little or no follow-up, leaving them to cope independently after the caring role ends.
- ✚ **There is a clear need for better coordination, earlier intervention, and improved communication** across health and social care services to support both PLWD and carers effectively throughout the care journey.

Across all engagement activities, there is a consistent pattern:

- End-of-life and bereavement care is often introduced too late or not at all
- Families are left to navigate the final stages largely unsupported
- Support frequently ends abruptly following death, with little follow-up
- Where compassionate, continuous support is provided (e.g. hospices, peer spaces), it is highly valued and impactful

Chapter Four – Looking to the Future: Patient and Public Involvement: Working with PLwD and their Carer Partners

Patient and public involvement (PPI) is essential to ensuring that health and social care services are relevant, effective, and responsive to the needs of those they serve. By actively engaging patients, their representatives and wider communities in decision-making, PPI promotes transparency, improves the quality and safety of care, and helps align services with real-world experiences. It also fosters inclusivity, trust, and accountability, ultimately leading to better outcomes and more person-centred care.

Challenging Stigma and Promoting Patient Participation

James, who lives with his wife Pearl, was diagnosed in 2016 with Cortical Vascular Dementia advocates that, given the opportunity, many PLwD can articulate their views very well and actively (and positively) contribute at strategic levels. He demonstrates the importance of engaging with PLwD directly rather than excluding them based on assumptions.

“I think the main thing would be not to be frightened of it, a lot of people think because you have the diagnosis that you can be potentially violent and in some people that may be the case. Don’t be frightened of it, try to get people involved there are a vast number of organisations that can help”.

“They wanted me to go to Men in Sheds, it is not for me. I want to keep my mind ticking over. I am on the Board of Dementia United. My support has been self-sought through the Alzheimer’s Society. I was on the Manchester Airport Forum and helped to develop the sunflower lanyards”.

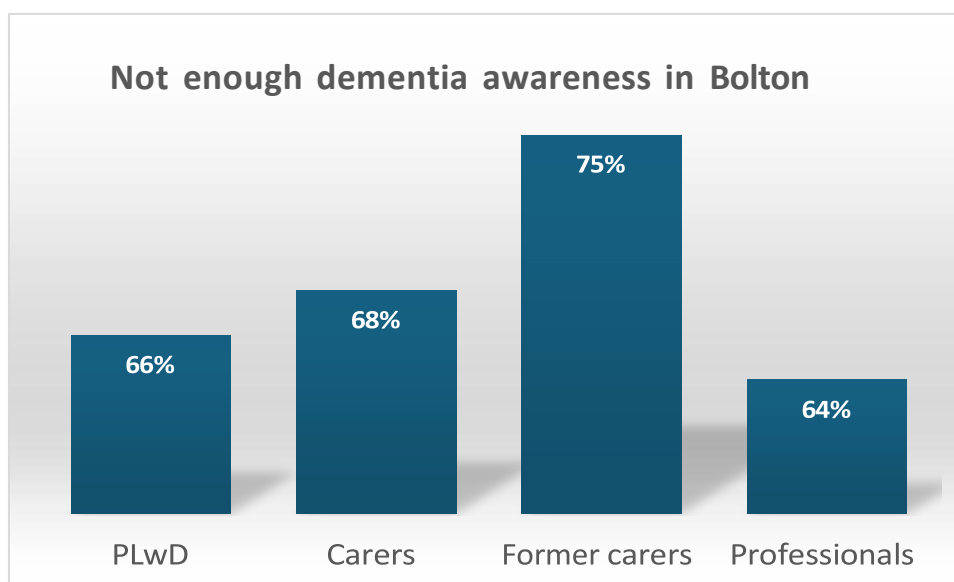
“Being involved with the University, Dementia United, taking part in parliamentary meetings it’s definitely a form of therapy and helps with self-esteem as your confidence takes a battering. We meet some amazing people; even been on stage singing with Dana.”

Pearl stated, “In June (2025) we have been nominated for citizens of the year, in Salford, for the work we did. We received little badges and a photograph. We have done all kinds of stuff.... Work for Humphery Booth Resource Centre. There were so many good causes there - all community based. Every so often James gets invited to things like that and this shows how people appreciate his input. He’s currently doing work for Leeds University.

James call to action to action, *“Talk to people with dementia, you would be surprised at how articulate some PLwD are. There is a vast number of organisations where PLwD sit on Boards. I have a vote on many influential things. I am not unique in that. The difficulty is trying to persuade or involve people. I use the phrase ‘contempt prior to investigation’ which basically is assuming something isn’t going to be suitable for you without listening or making enquiries. For example, the number of people I have seen with dementia going to one meeting and then you never see them again. What these people are doing is depriving themselves of opportunities of keeping the brain going, having somewhere to go, having a purpose in life and socialising – it’s important.*

I have a suggestion to the Alzheimer’s Society with regards to first aid training in dementia if they come across dementia what would their characteristics be? Would they have something to identify themselves to the person? They may find it difficult. The fact is you are very likely to meet someone with dementia.” (PLwD Case Study – September 2025)

We wanted to know whether, in Bolton, there is **enough public information about dementia and dementia care services in Bolton. (to include how to stay healthy before and after a diagnosis)**



One PLWD stated, *“Absolutely nothing helpful at all.”*

Former carers told us:

“More engagement is needed with local communities to raise awareness.”

“Conversations are getting there slowly does need a lot more work.”

“This could be improved.”

“Bolton Council should provide training for council workers who are out and about. For example, one day a council worker in his van, driving through the town centre, spotted my dad looking lost in the town centre. He recognised my dad (ex-teacher), realised something wasn’t right, phoned a friend who somehow knew where my dad lived, and drove him home! We were so grateful. It would be incredible if all council employees had the same level [of] awareness.”

“Need more consolation in the communities.”

“More awareness is needed on how to handle patients with dementia.”

“I am Chair of Bolton Adult Autism Support. It would be useful to have someone come along to talk with our parent/carers about how the Police can help if/when dementia becomes an issue.”

“It is improving but nowhere near enough awareness that those with dementia can be included with consideration.”

Professionals told us:

“I think it is increasing as there is quite a lot of media coverage currently.”

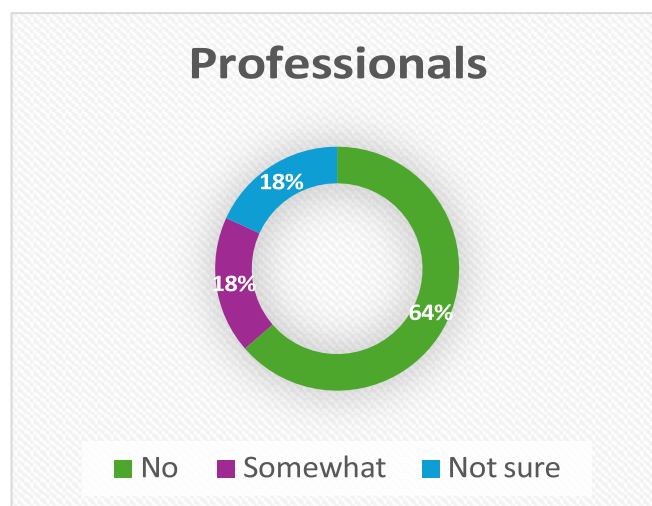
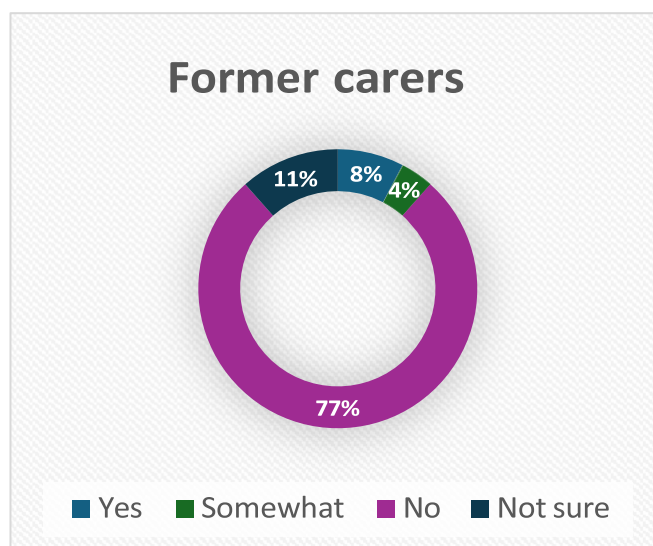
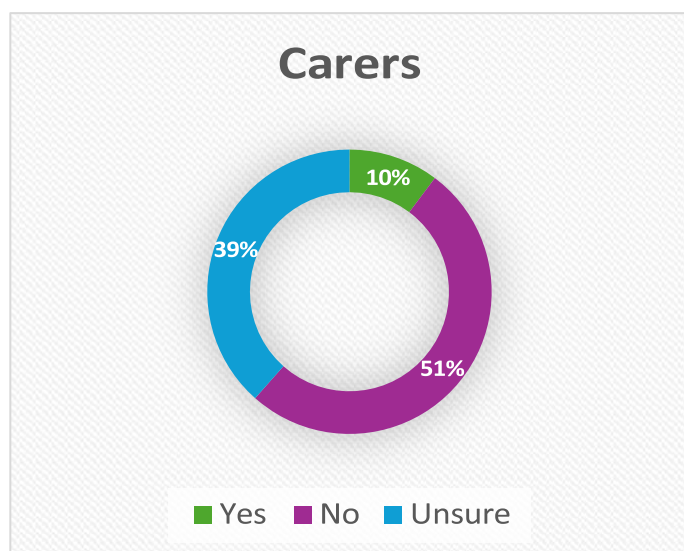
“Not many people have access to the services as they may have to travel across the town.”

“People only care when it affects them.”

“Bolton Dementia Support isn’t active on social media and hasn’t been for a long time”.

“We see TV advertisements - what is needed is local information, I know with looking for Bolton Dementia Services. But you have to be digital literate.”

We asked PLwD, current and former care partners, and professionals if they feel there is a clear and coordinated approach to dementia (e.g., having named leads for dementia care who can work across health and social care services)



Some carers told us:

“I’m not really aware of this.

“Speakers come to the dementia support group from some of the groups that offer services telling us carers about processes and they are completely misinformed. A room full of carers have on several occasions disabled them of their notions. E.g. a GP federation representative told us we would all have a social worker. WRONG.”

“Absolutely not, it's all fragmented! I have to navigate and coordinate everything myself.”

“Only as the illness progresses do you begin to find care services. It's not one path. From beginning, need to be given some kind of checklist - what is likely to happen and who you need to call when it does.”

“If you fit under CMHT [Community Mental Health Team]. No if you don't.”

“Nothing is joined up.”

“Dementia is so fragmented.”

“Some professionals that come present to the group know less about the systems than those of us living with it. A spokesman for the GPs assumed everyone would have a named social worker. Most had never had one.”

Some former carers told us:

“Yes, once we used the memory team service it was straightforward and they were helpful.”

“No, yes more coordination is ESSENTIAL.”

“No, I don't feel there is a clear or coordinated approach to dementia care in Bolton. From my experience, there weren't any obvious named leads or joined up working across health and social care. It felt fragmented, with no single point of contact or guidance to help families navigate the system.”

“No, because there is no publicity about it.”

“I don't know how much things have changed since 2013.”

“No, not at all, there was no evidence of this in my caring experience.”

Some professionals told us:

“Not sure there probably is but I am not sure who they are.”

“I'm saying no because I am unaware of any.”

“This is what is needed. I can't understand having an Admiral Nurse in the hospital but not the community where there is a massive need. Some kind of outreach coordinator support role is very much needed. This is currently a big part of my caseload, but my experience is limited. I think I am right in saying this goes for most of Boltons social prescribing teams.”

“From my experience working in social care, I do see a clear and coordinated approach to dementia care in Bolton. We have named leads for dementia care who

actively work across both health and social care services, which helps to streamline the process. However, I also recognise that this might not be apparent to someone outside of the system. A family who hasn't navigated these services before could easily find it difficult to understand and access the care they need. While we have structures in place, there's definitely a need to improve how we communicate and make these resources more accessible to the public."

"I think there is a huge need for this."

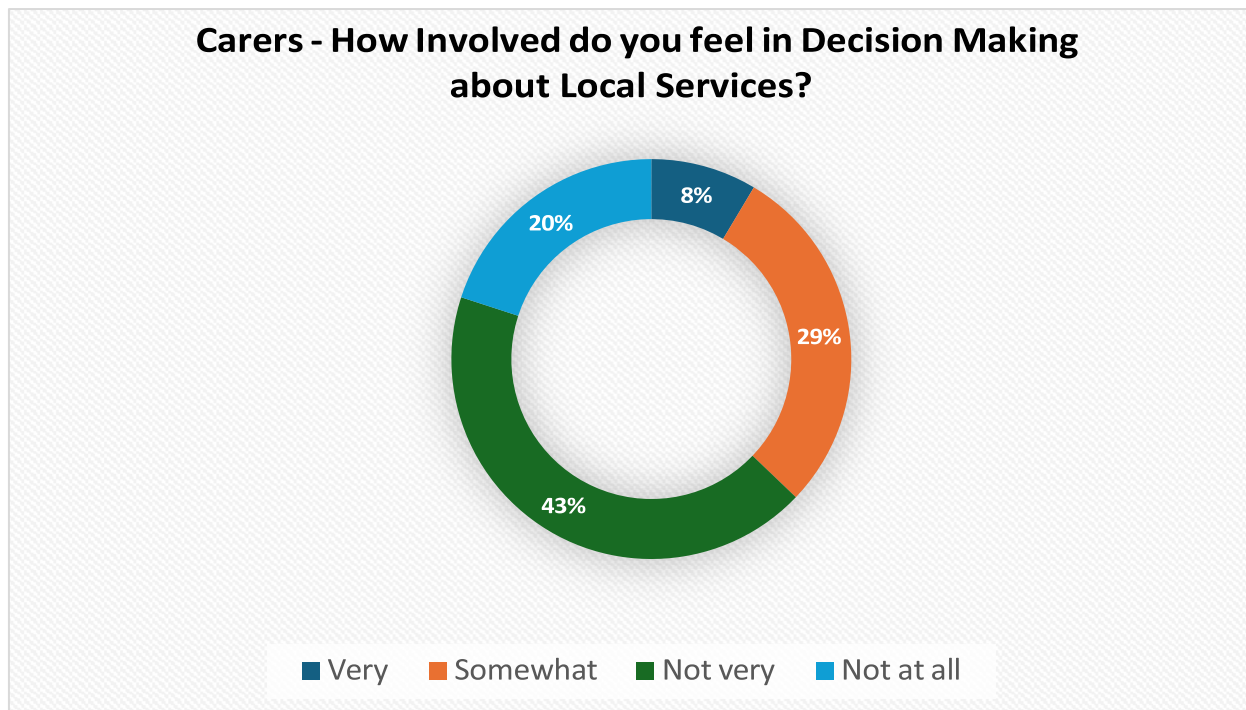
"This is very disjointed and often a lack of understanding in social services."

Community Insight

These sessions provided valuable insight into the experiences, concerns and priorities of local people affected by dementia. Participants from a range of communities, including Black, South Asian, Middle Eastern and D/deaf groups, shared lived experience, asked thoughtful questions and highlighted practical barriers to accessing support. Feedback emphasised the importance of culturally appropriate engagement, accessible information, interpretation and outreach through trusted community settings.

These conversations also identified key priorities for the future, including continued dementia awareness sessions, stronger links with local support services, clearer information about assessment and post-diagnostic support, and improved accessibility of resources. There was clear appetite for ongoing involvement, with communities expressing interest in further education, case study development and closer partnership working to ensure services are better understood and more responsive to local needs.

We asked current and former care partners and professionals how involved in people living with and affected by dementia are in decision-making about local services:



Carers told us:

“Don’t know as I wouldn’t have any spare time.”

“I don’t think there are many opportunities to be involved?”

“It’s controlled by the local council via care plan after care plan. Ticking boxes again.”

Former carers told us:

“There is more awareness now than when mum had dementia, I wish I knew then what I know now.”

“Whilst people can contribute it was clear from my involvement that professionals didn’t wish to listen and act on feedback.”

“Cannot think of any consultation.”

“People living with dementia and their carers don’t feel very involved in decision making about local services. From my experience, there was little chance to share views or influence what support looked like. It often feels like services are designed from the top down, rather than shaped by the voices of those directly affected.”

“I volunteer at a Memory Cafe to try to help people now. The best knowledge is having experienced watch your partner disappear daily before your eyes.”

“Not at all. People need to know about the groups/initiatives in the first place. I would like to see the LA and other stakeholders engagement more with local groups and communities - to make them more aware of what is going on and how people can get involved.”

Professionals told us:

“Unsure. People I work with say they are bored of the same activities on offer.”

“How involved people living with dementia and their carers are in decision-making about local dementia services varies, and, frankly, I don’t think there are enough dementia services locally for families; they’re usually at breaking point by the time they escalate it to adult care. Ideally, their involvement should be central, ensuring services are tailored to meet their needs and preferences. In practice, the level of engagement can depend on factors like the local authority’s approach, the resources available for outreach and consultation, and the capacity of individuals with dementia and their carers to participate. Some areas have established advisory groups or forums where service users can provide feedback and influence planning, while others may rely on more limited consultation methods. It’s generally acknowledged that greater involvement leads to more effective and person-centred services, but achieving this consistently remains a challenge.”

“Not very as there are a lot of people not registered with dementia support services therefore not on the radar. As part of my role, I encourage registration with Bolton Dementia Support & Bolton Carer Support.”

“I don’t think they are involved enough but changes are being made.”

“Somewhat. Everyone on the dementia register should be contacted when services need feedback etc.”

“I don’t believe they are. I try to register all with Bolton Dementia Support & Bolton Carer Support so that the figures are reflective.”

“Not involved at all.”

Current and former carers were asked if they would like to be involved in local carer initiatives, such as local carers' strategies or the Dementia Carers Expert Reference Group (DCERG).⁷

Overall, most respondents expressed an interest in being involved in such initiatives, emphasising the importance of carers' voices in shaping local services and strategies.

“Yes, I would like to be involved in local carer initiatives such as the carers strategy or Dementia Carers Expert Reference Group. Having been through the experience with my mum, I think it’s important that carers’ voices help shape services, so others don’t face the same gaps in support.”

“Yes, although I don’t think it should be voluntary. These kind of things should be paid. We as previous carers have already done more than our share for nothing.”

Some respondents expressed a willingness to participate in the future. A few respondents were skeptical about whether their involvement would make a difference, citing concerns about the effectiveness of such initiatives.

I will when I retire.... but I’m sick and tired of the yabber jabber at these well-meaning groups, what is needed is people, money, jobs, action, training programmes, sick of layers of managers that suck funding pots dry so the people actually delivering the work are stretched and inefficient. Sick of talking about how to do things more efficiently which only ever equates to ineffective services for those suffering with a life-changing diagnosis like dementia - just stop pretending that anyone with any money or power gives a squiggle for those suffering. We’ve lost respect for our elderly and treat them as burdens before dementia, so it gets worse with this diagnosis. Dad felt like he was a crippling burden to me and therefore just wanted to die, carer services were appalling and would not accommodate dad’s wants and needs until we got an all African organisation. I’ve forgotten the name, but their compassion, care, humour and attentiveness was outstanding. Language and accent was a huge problem, but they put the best English speakers with dad - dad had mobility issues and stroke and heart failure so needed care before dementia diagnosis so, as I say, dad is a holistic story...”

Some respondents mentioned being unable to participate due caregiving responsibilities or involvement in other charities.

“I am involved with 3 charities at present, therefore cannot take on any additional duties.”

“No, I am visiting three of my friends at moment suffering with dementia; is there something in water?”

⁷ [Dementia Carers Expert Reference Group - Dementia United.](#)

Overall, the responses show a **strong interest in contributing to local carer initiatives** but also highlight barriers such as time constraints and scepticism about the impact of participation.

We asked professionals if they have any ideas to encourage PLwD and their carer partners to become more involved in decision-making about local dementia services, their suggestions included creating more opportunities for feedback, such as surveys, focus groups/outreach sessions in various locations, advisory groups to gather more input from people, and increasing registration with local support services.

“To have meaningful outcomes that are measurable.”

“To boost involvement of people with dementia and their carers in local service decisions:

- 1. Advisory Groups: Create local groups for regular input to service providers and councils.*
- 2. Training & Support: Offer skills training to participate effectively.*
- 3. Accessible Methods: Use easy surveys, focus groups, and accessible venues.*
- 4. Feedback Systems: Implement simple feedback options with clear responses.*
- 5. Awareness Campaigns: Promote involvement importance, sharing success stories.*
- 6. Partnerships: Coordinate efforts between councils, providers, and charities.*
- 7. Financial Support: Cover participation costs like travel and respite.*
- 8. Recognition: Acknowledge contributions with certificates or public thanks.*
- 9. Co-production: Involve people with dementia and carers in all service stages.*
- 10. Regular Forums: Host events for discussion and relationship-building.”*

“Increase registration & local awareness. Could people be registered after the diagnosis with memory clinic help. More drop in/cafe events in more areas.”

“Employing dedicated roles, such as Admiral Nurses or outreach coordinators, to provide ongoing support and facilitate involvement in decision-making.

“Employ an Admiral Nurse to link in with GP and community services to help make these more accessible to families and PLWD. Admiral nurses in the community could be involved with Advanced decision making and care planning to help support PLWD.”

“It would be good to have a local helpline that is manned and responsive that people can ring for advice.

“Providing clear information about available services, personal budgets, and advanced care planning to empower individuals and carers”.

“More “drop in” events. Regular contact/check ins from outreach teams in the community. Respite care should be more readily available. Should be given info about personal budgets at diagnosis.”

“Using social media, home visits, and direct contact to reach out to people living with dementia and their carers.”

“Ask them, look on the dementia register for people who will give opinions. Go to their homes and ask. Use social Media.”

Community Insight

Dementia is widely experienced at a personal level, with carers and people affected actively contributing lived experience and supporting one another through peer networks that reduce isolation and provide a sense of belonging.

Community and voluntary sector services are consistently valued as the most effective sources of support, highlighting the importance of strengthening and integrating these in future models of care.

Carers play a crucial and central but often under-recognised role, frequently navigating fragmented systems and experiencing emotional strain, reinforcing the need for better recognition and structured support.

There is a clear need for more joined-up, timely pathways with better communication and clearer guidance on diagnosis, progression, and “what happens next.”

Conclusions – Chapter Four: Patient and Public Involvement

- ✚ Patient and public involvement in dementia care in Bolton is **valued but not consistently embedded in practice**. Opportunities to contribute appear limited, and many people living with dementia and carers feel **insufficiently involved in decision-making**.
- ✚ There is a clear perception of a **fragmented and poorly coordinated system**, making it difficult for individuals to understand how to engage or influence services. Despite this, there is a **strong appetite for greater involvement**, particularly through lived experience, though barriers such as time, awareness, and accessibility reduce participation.
- ✚ Overall, a **more structured, inclusive, and transparent approach to involvement** is needed. Embedding co-production and improving communication will help ensure services are **more person-centred, responsive, and reflective of local need**.

Chapter Five – Public Awareness of Dementia, Keeping Healthy, What is Working Well, Areas for Improvement and What People Say They Want in the Future

We asked people what improvements, if any, they would like to see regarding dementia information, care and support in Bolton:

Across all respondents: PLWD, current carers, former carers, and health and social care professionals, there was a strong and consistent message that dementia support in Bolton needs to be more accessible, better coordinated, and more proactive. The most frequently raised themes were improved information and communication, ongoing support after diagnosis, greater support for carers, increased respite and day care provision, and better awareness of dementia within the wider community.

Better Information and Easier Access to Support

Many respondents felt they had to actively search for information and support, rather than being guided through available services. There were repeated calls for clearer information at diagnosis, improved signposting, and information being available in community settings such as GP surgeries, libraries and health centres.

One person living with dementia said:

“Not to have to feel like you are fighting for information or even for help.”

A former carer highlighted the need for:

“Clearer, easier to find information and a more joined up approach across health and social care, so families aren’t left guessing.”

Ongoing Support After Diagnosis

A recurring concern was that support often drops off after diagnosis. Respondents wanted regular follow-up, continued professional contact and a clear pathway through the progression of dementia.

One current carer commented:

“There needs to be continued support after diagnosis. When I spoke to medical professionals about this the response was they only deal with new cases.”

Another suggested:

“A named qualified person allocated to each dementia sufferer which could be contacted for advice and support.”

More Support for Carers

Carers consistently reported needing more practical, emotional and crisis support. Many wanted dedicated appointments, support groups, better information about disease progression, and greater involvement in decision-making.

One carer explained:

“We need to know what to expect, rather than having bits of information thrust on you.”

Another stated:

“Information and what to expect and much more care and support for carers, especially if you are in a crisis situation.”

Increased Day Care and Respite Provision

The need for more affordable, flexible and accessible day care and respite services was one of the strongest themes. Respondents described difficulties accessing existing provision and highlighted the growing demand for these services.

Typical comments included:

“Easy access to day care, I know some people who are struggling to get this.”

and

“More daycare please. Also, short term respite... Need more for growing problem.”

Improved Coordination Between Services

Respondents frequently described services as fragmented and called for better communication between GPs, hospitals, social care, memory services and voluntary organisations.

A former carer simply stated:

“Co-ordinated approach between the agencies.”

Similarly, a professional observed:

“There needs to be better coordination between health and social care services and hospitals.”

Greater Dementia Awareness and Dementia-Friendly Communities

Many respondents felt there was limited public understanding of dementia and wanted more training and awareness across communities, public services, shops, cafés and transport providers. There was also a desire for more dementia-friendly spaces that enable people to retain independence and social connections.

One carer noted:

“I think perception of dementia is not accurate.”

Another respondent called for:

“More dementia friendly spaces where people with the disease can have a greater sense of normality and autonomy.”

Inclusive and Culturally Appropriate Support

Several respondents highlighted the need for services to better reflect Bolton's diverse communities, including culturally appropriate activities, targeted awareness-raising and support for underrepresented groups.

One former carer suggested:

“Support should be offered earlier, not only after a diagnosis, and it needs to reflect Bolton’s cultural diversity, so all communities feel included.”

Key Message

Overall, respondents were looking for a dementia support system that is easier to navigate, more joined up, and provides continuous support from diagnosis onwards. Priorities include improving information and communication, increasing support for carers, expanding respite and day care services, promoting dementia-friendly communities, and ensuring services are coordinated, inclusive and responsive to individual needs.



Chapter Six – Final Thoughts

Information and Advice

Feedback from PLWD, carers and professionals highlighted a strong desire for better information, more ongoing support, and improved coordination between services. Many respondents felt that information was difficult to access, inconsistent, or only provided at times of crisis. People wanted clear, accessible information available through trusted community settings, with one person suggesting *"Information in public libraries/GP surgeries"* and another calling for *"Easy read"* information. A common frustration was *"not to have to feel like you are fighting for information or even for help."*

Support Following Diagnosis

A significant theme was the need for continuous support following diagnosis. Many carers felt that support reduced once a diagnosis had been made and wanted clearer guidance about what to expect as dementia progresses. Respondents called for *"continued support after diagnosis"*, *"early diagnosis and follow up"*, and *"more information around the different stages of dementia."* One carer explained that families need *"to know this is what you can expect, this is what will happen, rather than having bits of information thrust on you."*

Support for Carers

Carers consistently highlighted the emotional and practical challenges of supporting someone with dementia and called for greater support for carers in their own right. Suggestions included dedicated carers' groups, regular check-ins, helplines, and named professionals who could provide ongoing advice. One respondent said there should be *"a named qualified person allocated to each dementia sufferer which could be contacted for advice and support,"* while another stated, *"More support after diagnosis which is ongoing. A helpline."*

Respite, Day Care and Community Support

There were frequent requests for improved access to respite care, day care and community support services. Respondents described difficulties accessing suitable provision and concerns that services are not keeping pace with demand. Comments included *"Easy access to day care"*, *"Better day and respite care that is affordable"*, and *"More daycare please. Also, short term respite."* Professionals similarly highlighted the need for *"more resources in the community"* and *"greater continuing support."*

Coordination Between Services

Respondents also emphasised the need for better coordination and communication across services. Families often felt they were left to navigate complex systems independently and wanted more joined-up working between health, social care and voluntary sector organisations. One former carer called for *"a more joined up approach across health and social care, so families aren't left guessing,"* while another simply requested *"co-ordinated approach between the agencies."* Professionals echoed this view, commenting on the need for *"more linked up thinking of services from the Trust, GP's and mental health services"* and *"better coordination between health and social care services and hospitals."*

Dementia-Friendly Communities and Awareness

Many respondents highlighted the importance of creating a more dementia-friendly community and improving public awareness of dementia. Carers described situations where a lack of understanding from the public added to the challenges they faced. Suggestions included dementia awareness training, dementia-friendly venues and clearer identification of dementia-friendly businesses and services. One respondent wanted "*more dementia friendly spaces where people with the disease can have a greater sense of normality and autonomy*," while another called for "more dementia friendly signs in coffee shops, buses, libraries etc."

Inclusive and Personalised Support

There was also recognition that services need to be more inclusive, personalised and culturally appropriate. Respondents requested support that reflects Bolton's diversity, including "*more culturally diverse activities for communities of colour*", support for younger people living with dementia, and services built around individual preferences rather than assumptions about what people with dementia may enjoy. As one respondent noted, services should "find out what they like and work on that."

Overall Reflections

Across all groups, respondents repeatedly stressed the importance of practical support, clear information pathways, specialist expertise and recognising carers as partners in care. One professional summarised this well by stating that "*patients and carers report feeling isolated. Not sure who to talk to about medication, symptoms, behaviour change etc.*" Another concluded that "*Bolton has a lot of good services, but they need linking up.*"

Chapter Seven– Impact of this Project

Overview

This project has provided valuable insight into the lived experiences of PLwD, unpaid carers, former carers, and professionals in Bolton. Through a mixed-methods approach, including surveys, focus groups, case studies, community engagement, and Information, Advice and Guidance (IAG) enquiries, the project has captured a wide range of perspectives across different communities and stages of the dementia journey.

With 166 survey responses and direct engagement with individuals and community groups, the project has strengthened understanding of both the positive experiences and the challenges associated with dementia care and support in Bolton.

Importantly, this work has amplified the voices of those who are not always heard, including individuals from diverse communities, people at different stages of dementia, carers with varied experiences and professionals. Furthermore, it has also created opportunities for dialogue and collaboration between communities, professionals, and local services.

Impact on Individuals and Communities

A key impact of this project has been the increased awareness and understanding of dementia among members of the public, particularly through the delivery of community-based information awareness sessions.

The **“Let’s Talk About Dementia”** sessions were delivered to a range of local groups, including culturally diverse and underserved communities. These sessions were supported by clinical professionals and partner organisations, ensuring that information shared was accurate, relevant, and tailored.

Feedback from these sessions demonstrated that they were well received and highlighted a clear appetite for ongoing engagement of this nature.

As a result, the sessions contributed to:

- **Improved awareness of dementia and its symptoms**
- **Greater confidence in recognising when to seek help**
- **Increased understanding of available services and support**
- **Opportunities for open discussion, helping to reduce stigma associated with dementia**

For many participants, particularly those from communities where dementia is less openly discussed, these sessions provided a safe and supportive space to ask questions and share personal experiences.

Impact on Awareness and Information Needs

This project has highlighted significant gaps in public awareness and access to information about dementia. While some respondents knew to approach their GP for support, others reported uncertainty about where to go or relied on informal networks and previous experience.

The findings also demonstrate a clear demand for:

- Accessible, easy-to-understand information
- Clear guidance on the diagnosis pathway
- Information about what to expect following diagnosis
- Practical advice on managing symptoms and behaviour

Participants emphasised the importance of receiving timely and appropriate information, particularly during the waiting period for assessment and diagnosis, where many reported feeling anxious, unsupported, and unsure what to expect.

By gathering and evidencing these experiences, the project has identified key areas where information provision can be improved to better support individuals and families at every stage of the dementia journey.

Impact on Services and System Insight

The project has generated robust, local evidence that highlights inconsistencies and gaps within dementia care and support pathways in Bolton.

Key issues identified include:

- Delays in accessing Memory Assessment Services, with some people waiting several months or longer for assessment and diagnosis
- Inconsistent experiences when seeking help from GPs
- Limited support during the pre-diagnosis waiting period
- A lack of follow-up and ongoing support after diagnosis

By bringing together the perspectives of PLwD, carers, and professionals, this project provides a comprehensive picture of where the system is working well and where improvements are needed.

This evidence will support stakeholders, commissioners, and service providers in identifying priorities for improvement, including:

- Strengthening early intervention and referral pathways
- Improving communication and consistency across services
- Enhancing pre and post diagnosis support
- Ensuring people do not feel “left to navigate the system alone” by improving access to information, advice and guidance
- Ensuring bereavement support information is available
- Ensuring continuous engagement with PLwD, carers and professionals

Impact on Partnership Working

This project has fostered strong partnership working across health, social care, and the VCSE sector.

Collaboration with organisations such as Bolton Public Health, Greater Manchester Mental Health NHS Foundation Trust, NHS Bolton Foundation Trust’s Admiral Nurse, Bolton Dementia Support, Alzheimer’s Society, Bolton Hospice and other stakeholders helped shape the research approach and ensured that engagement activities were inclusive and relevant.

The involvement of professionals in community sessions also strengthened links between services and communities, enabling:

- Improved communication between organisations and the public
- Increased awareness of available support among community groups
- Greater opportunities for joined-up working

These partnerships will continue to play a vital role in responding to the findings of this report and improving dementia care in Bolton.

Impact on Engagement and Voice

The fundamental aim of this project was to ensure that the voices of PLwD and their carers were heard and reflected.

The findings show that many individuals feel that services are fragmented and that they are not always involved in decision-making about their care or local services.

Through surveys, focus groups, case studies, and community engagement activity, this project has:

- Provided a platform for individuals to share their experiences
- Captured both positive and negative experiences of care

- Highlighted the emotional, practical and financial impact of dementia on families
- Demonstrated the importance of lived experience in shaping services

The project has also identified a strong willingness among carers and individuals to be more involved in shaping local services, provided that opportunities are accessible and meaningful.

Ongoing Impact and Legacy

The impact of this project extends beyond the publication of this report.

The feedback gathered, particularly from community engagement sessions, demonstrates a clear demand for continued awareness-raising and support. The success of the “*Let’s Talk About Dementia*” sessions highlights the value of taking information directly into communities and engaging people in familiar and trusted settings.

As a result, there is potential to:

- Expand community-based dementia awareness sessions
- Develop targeted outreach for underrepresented groups
- Improve access to culturally appropriate information and support
- Improve access to age-appropriate information and support
- Strengthen ongoing engagement with carers and people living with dementia
- Develop a dedicated Dementia Hub in Bolton

Conclusion

Overall, this project has had a meaningful impact by increasing awareness of dementia, highlighting gaps in information and support, and bringing together the voices of those affected by the condition.

It has provided a strong evidence base to inform future planning and service development, while also strengthening relationships between communities, services, and stakeholders.

Most importantly, this project has ensured that the lived experiences of people in Bolton remain central to improving dementia care and support now and in the future.

Chapter Eight – Recommendations and Conclusions

Recommendations

- 1** Commission and strengthen community-based dementia information and support within a place-based integrated care model, building on VCSE provision
- 2** Develop a single point of access for dementia information and advice (e.g. integrated helpline or dementia hub)
- 3** Expand capacity and equity of access to respite care and crisis support across localities
- 4** Commission inclusive, culturally competent, age-appropriate activities and services, including targeted support for underserved groups and young onset dementia
- 5** Improve access to Memory Assessment Services and Admiral Nurses through workforce and capacity planning
- 6** Standardise and strengthen diagnostic pathway with improved GP responsiveness, reduced waits, clearer processes, and coordinated communication between patients and services themselves
- 7** Provide structured, timely information and post-diagnostic support, including signposting to bereavement services and community support
- 8** Carers Annual Health Checks to proactively explore carers' emotional wellbeing, stress, anxiety, low mood, and social isolation, alongside their physical health needs. Carers to be offered practical signposting to appropriate support such as including mental health services, carers' assessments, respite opportunities, and local carers' organisations.
- 9** Embed co-production and ongoing patient and public involvement in commissioning and service design
- 10** Record and share key information consistently across GP, memory clinic, hospital and community teams
- 11** Ensure hospital staff understand dementia, delirium, hydration, nutrition and personalised communication needs
- 12** Strengthen end-of-life planning so medication, records and responsibilities are clear and timely
- 13** To repeat this research in a few years to ascertain progress on living well with dementia in Bolton.

Conclusions

Surveys

This report sets out to understand what it means to live well with dementia in Bolton, by listening to PLWD, current and former care partners, and professionals across health, care and the voluntary sector. Across different settings and stages of the condition, people told us they want the same essentials: to be believed and supported early, to have clear information at the right time, to be treated with dignity, and to be able to stay connected to the people and places that matter to them.

In the earlier stages of the journey, our findings show that routes to assessment and diagnosis can feel unclear and inconsistent. People described variable experiences of GP support and long waits for memory assessment, which can leave families anxious and unsupported while symptoms progress. Participants were clear that the waiting period should not be “dead time”: they need realistic timeframes, accessible and clear explanations of what will happen next, and practical and emotional support for both the person awaiting assessment and those supporting them.

After diagnosis, many accounts point to a gap between receiving a diagnosis and receiving ongoing, coordinated support. Some people reported positive experiences with education sessions from the MATS, dementia support groups and carers services; however, these were not consistent, and many respondents described being left to find help alone. This reliance on self-navigation particularly disadvantages people who are from ethnically diverse communities, are living with a sensory impairment, are digitally excluded, newly diagnosed, socially isolated, or managing complex family circumstances. People told us they need simple, phased information, a responsive single point of contact, and clearer signposting to local support, benefits and financial advice, and inclusive and varied community activities.

A consistent thread through the feedback is the pressure on care partners. Carers described exhaustion, limited respite, and support that does not fit around work, inaccessible transport, or the realities of 24/7 caring. While some carers were registered as a carer at their GP and received health checks, others felt their wellbeing was not actively and meaningfully considered at these annual health checks. Sustaining caring roles requires proactive recognition of carers, timely assessments, access to breaks, and practical help that reduces rather than adds to stress.

In the later stages of dementia, respondents highlighted the importance of planning, crisis support, and compassionate end-of-life care. Most respondents told us that Advance Care Planning was not routinely offered or discussed, despite its potential to support dignity and reduce avoidable distress. Former carers also described variable experiences of crisis support, palliative care and bereavement support - often depending on which services they happened to encounter, and sometimes only where another condition (such as cancer) provided access to specialist help.

Families should not have to reach breaking point to receive coordinated support.

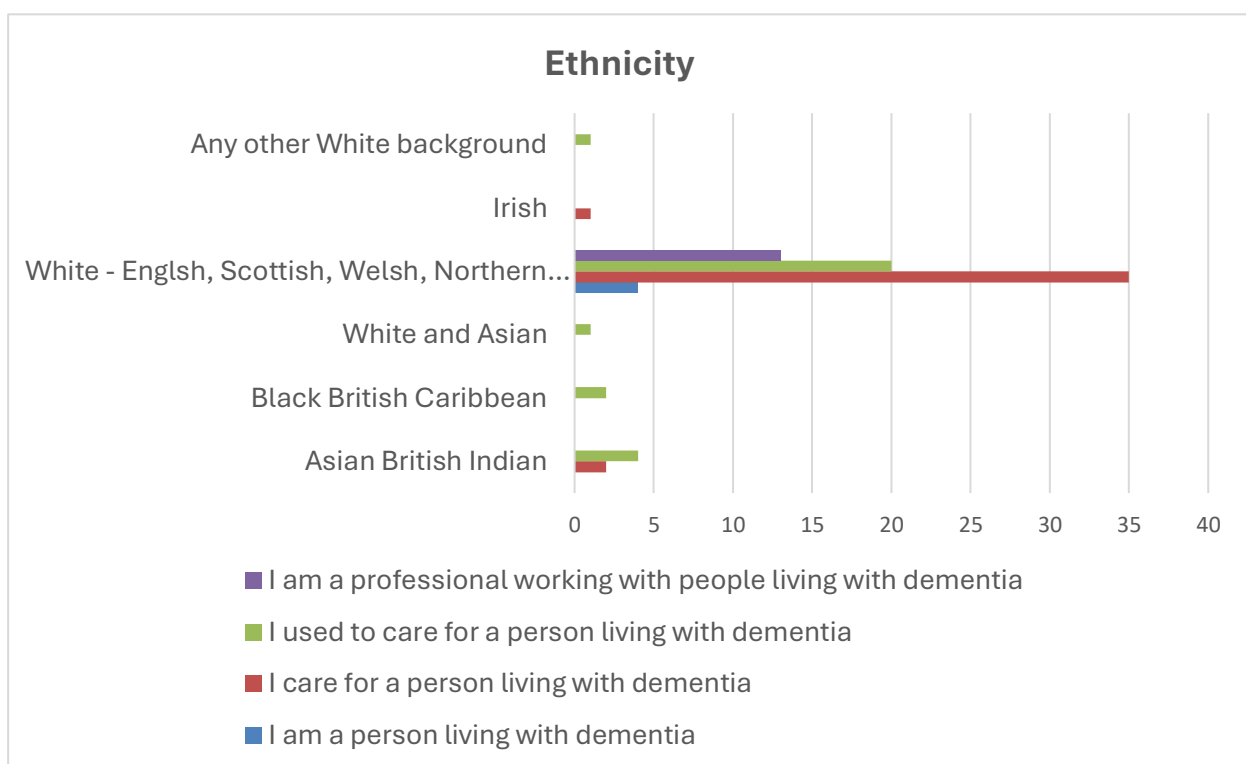
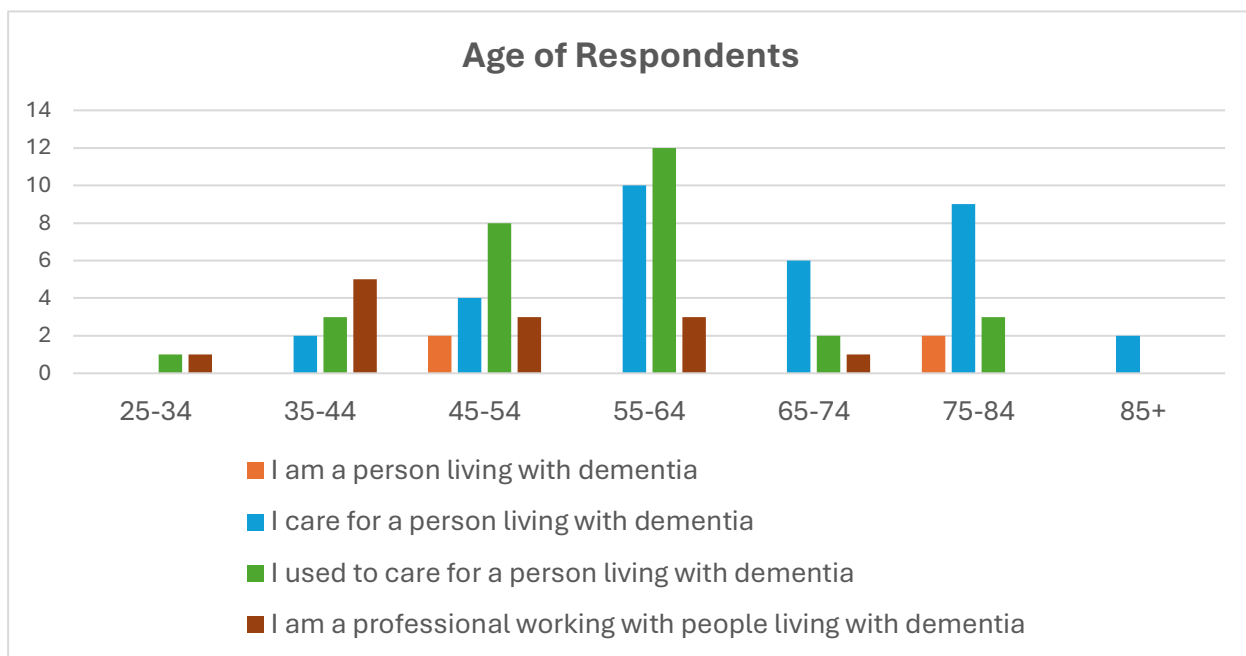
Beyond formal services, many people told us that Bolton does not yet feel consistently dementia friendly in day-to-day life - particularly in relation to public services, transport, and general awareness. Participants described the value of informed, compassionate staff (including examples where council workers and others made a positive difference), alongside concerns that dementia is still poorly understood and that people can feel excluded. Improving public awareness and dementia-friendly practice across workplaces and community settings is a key part of enabling people to live well.

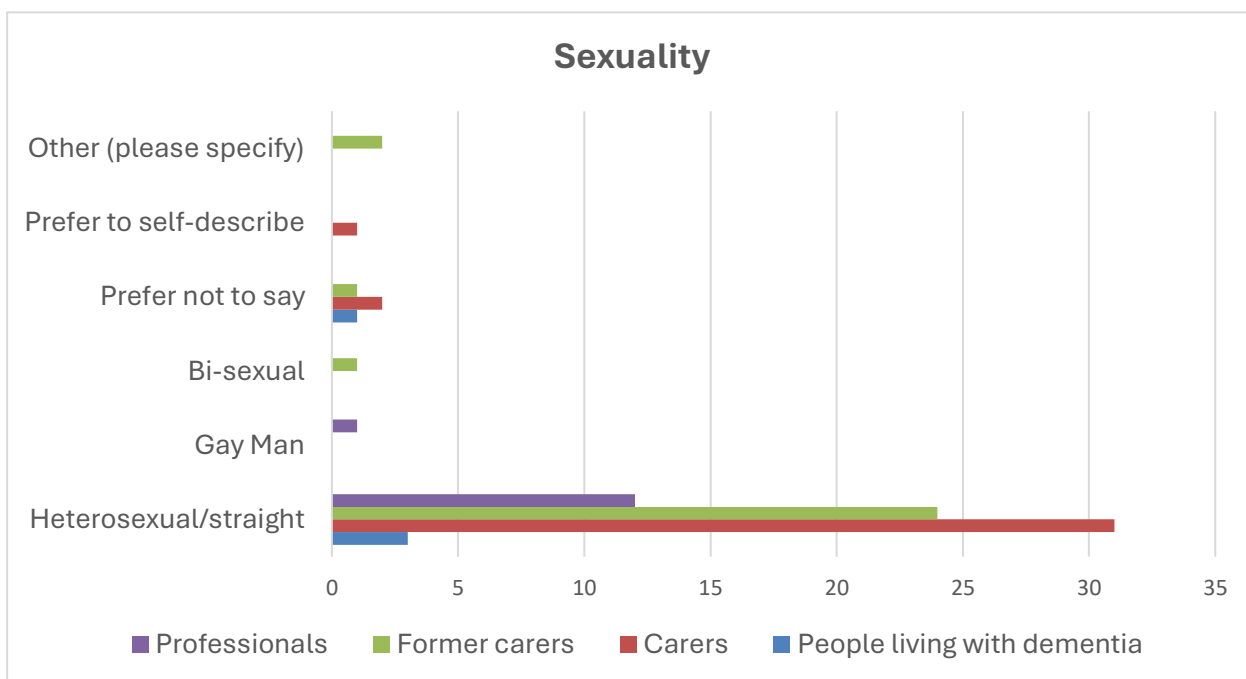
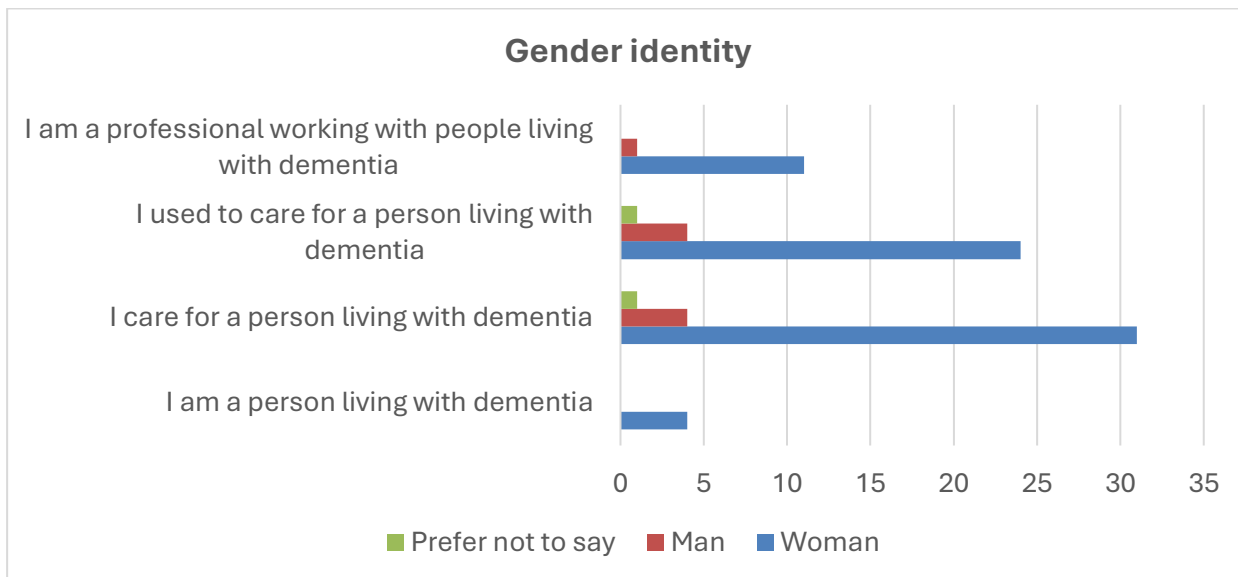
Finally, our findings suggest that people do not always experience dementia support as joined up. Some carers and professionals were unaware of named leads or a clear local pathway, and many felt coordination depends on individual knowledge and persistence. At the same time, there is strong appetite for meaningful involvement in shaping services—provided it is accessible and representative of local communities, respectful of people’s time and caring responsibilities, and fundamentally leads to visible change. Co-production with PLwD and carers, alongside clear feedback loops about what has changed as a result of their input, will be essential to building trust.

Taken together, the messages in this report point to practical priorities: shorten and better support the wait for assessment; ensure consistent, ongoing post-diagnosis follow-up; strengthen navigation and non-digital access to information; improve access to respite and carer wellbeing support; embed Advance Care Planning earlier; and develop a more dementia-friendly Bolton through workforce development and community awareness.

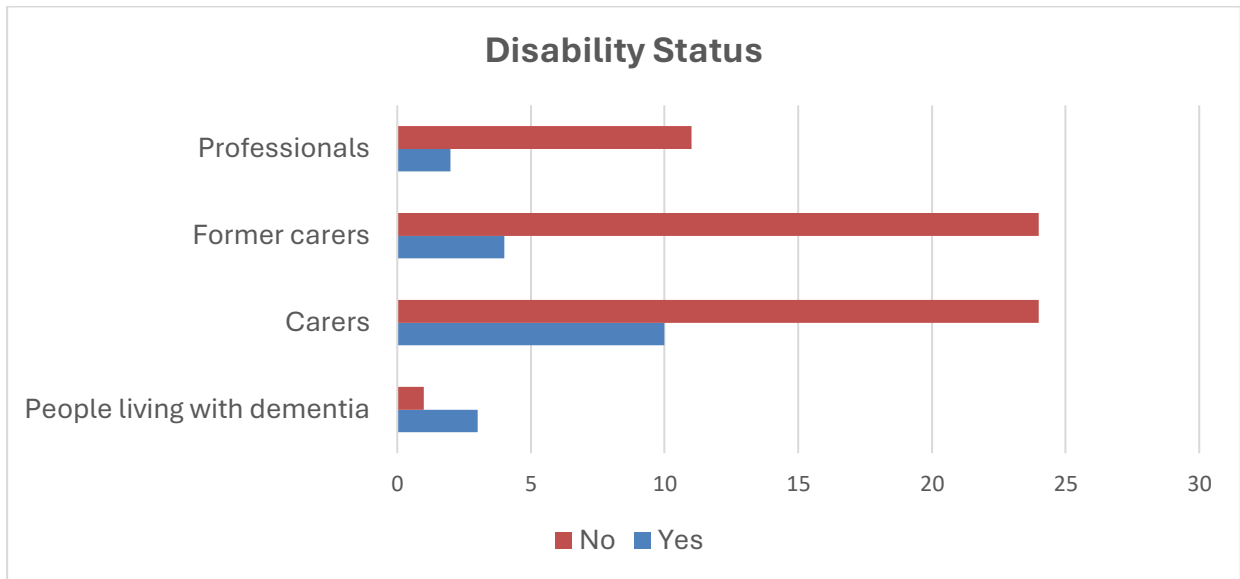
Healthwatch Bolton will continue to work with the Local Authority, NHS partners, and the voluntary sector to ensure that lived experience remains at the centre of planning, commissioning and improvement, and that people can see how their feedback is shaping dementia support in Bolton.

Demographics





‘Other’ refers to two respondents saying they don’t identify as anything



Veterans

One carer described themselves as a Veteran

Appendix – Information, Advice and Guidance – Themes

Based on a review of Healthwatch Bolton’s Information, Advice and Guidance (IAG) dementia-specific enquiries (25 enquiries from *Dec 2023–April 2026*, we have identified the following themes:

1. Care Transitions, Hospital Discharge & Care Home Placement

A number of enquiries relate to unsafe, unsuitable, or poorly communicated hospital discharges and care home placements. Families frequently reported:

- Being excluded from discharge decisions
- Care homes proposed that could not meet the person’s needs
- Pressure to accept placements quickly
- Repeated moves and resulting deterioration in health

This theme is especially prominent in cases involving CHC (Continuing Healthcare) eligibility disputes and safeguarding concerns.

2. Lasting Power of Attorney (LPA), Best Interest Decisions & Advocacy

Families often sought clarity on:

- Whether health and care professionals can override a Health & Welfare Lasting Power of Attorneys (LPAs)
- Best interest meetings and decision-making authority
- Family labelled as “interfering” when advocating for suitable care for the person they care for.

This highlights confusion and conflict between families and professionals regarding legal rights and responsibilities.

3. Care Funding, Fees & Financial Stress

Many enquiries reflect financial anxiety, including:

- Inability to afford care home top-up fees
- Requests for clarity on caps to social care fees
- Disputes over liability for care costs following discharge from hospital
- Frustration around CHC assessments and refusals

This theme underlines the financial concerns and vulnerability of families caring for someone living with dementia.

4. Access to Primary Care & Health Services

Difficulties accessing timely and appropriate healthcare were common, including:

- Dismissive or inappropriate GP attitude
- Long waits for GP appointments
- Digital-only access models disadvantage people with dementia
- Delay in memory assessments (6–12 months waiting time for an appointment – March 2026)

These issues risk delayed diagnosis, poor symptom management, and carer distress.

5. Quality, Compassion & Dignity of Care

Several enquiries describe experiences of:

- Lack of dignity and compassion in hospital settings
- Inadequate pain management and end-of-life care
- Poor communication and coordination between services

Families often chose not to complain formally but wanted learning shared to prevent recurrence.

6. Carer Strain, Support Needs & System Complexity

Carers consistently reported:

- Emotional, physical, and time pressures
- Difficulty navigating Adult Social Care processes
- Repetitive questioning and bureaucratic burden
- Feeling unheard or unsupported

7. Community Awareness, Inclusion & Cultural Stigma

There were calls for:

- Greater public awareness and early recognition of dementia
- Dementia awareness within South Asian communities
- Reducing stigma experienced by people with dementia

8. Practical Support, Equipment & Transport

Some enquiries focused on practical challenges, including:

- Delays in receiving equipment (e.g. bed rails, continence products)

A significant delay with NNAS non-emergency patient transport resulting in financial impact on family

While seemingly operational, these issues significantly affected wellbeing.

9. Information, Signposting & Engagement

Several entries relate to people seeking:

- Information about services (NHS dentistry, podiatry, continence team and dementia support)
- Signposting to carer and dementia networks
- Opportunities to engage in accessible dementia-related activities

This suggests gaps in proactive information sharing.

Overall Summary

Across the enquiries, the dominant themes are **poor care coordination, lack of meaningful involvement of families, financial and emotional strain on carers, and access barriers within health and social care systems**. Many issues are recurrent and systemic rather than isolated, making them highly relevant for intelligence reporting, service improvement discussions, and strategic planning.

Conclusion

Overall, the enquiries show that people affected by dementia and their families are most impacted by fragmented pathways—especially at points of discharge and placement—unclear decision-making and advocacy rights, and uncertainty about funding (including CHC). These pressures are compounded by difficulties accessing timely primary and memory services, variable dignity and communication in care, and practical delays with equipment and transport. Strengthening coordination, proactive information and signposting, and consistently involving families in decisions would address many of the recurring issues and reduce avoidable distress.

Thanks and Acknowledgements

Healthwatch Bolton would like to offer its most sincere thanks to all people living with dementia, and to their carers, both current and former, who generously took the time to share their personal experiences, views, and reflections with us, either via the on-line survey, focus group discussions or case study.

We are also grateful to the health and care professionals who contributed their insight and shared their experiences of delivering services for people living with and affected by dementia. Their time, openness and commitment are greatly appreciated.

Finally, we would like to extend thanks to the Trust's Admiral Nurse, Bolton Hospice's Palliative Care Clinical Care Educator, the Memory Assessment Team and the Alzheimer's Society for freely giving their clinical expertise and valuable support with our Let's Talk About Dementia awareness-raising sessions to communities in Bolton.

Without all of you, this report would not be possible. Together we can make a difference.