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Dementia support in Bristol: Experiences of people with dementia and their carers

Neighbourhood health and wellbeing insights – November 2026



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Purpose

This project aimed to examine the role of dementia navigators in Bristol, who function within the Bristol Dementia Wellbeing Service (BDWS), with a particular focus on improving outcomes for service users, carers, and staff. A member of the Healthwatch Bristol Local Advisory Group highlighted the need for a project on dementia support, and this was agreed as a project priority by the group. Healthwatch Bristol has also received feedback related to dementia support in Bristol. This project was conducted between April – June 2026.

Background

In Bristol it is estimated that there are 5000 people living with dementia. It is likely that this figure is higher as there are significant numbers of people that have not been diagnosed with dementia. Local health data and the Alzheimer's Society reveal that around 3,500 to 4,300 of these individuals are aged 65 and older, which equates to approximately 4.8% of Bristol's over-65 population.

Approximately 75% of Bristol's estimated dementia cases have a formal diagnosis, which is higher than the national average (65.6%). There is a national aim to identify two-thirds (66%) of people with dementia and provide appropriate support. Most dementia cases are diagnosed within primary care, usually by GPs. Recent JSNA data (September 2025, Bristol City Council) also gives an insight into dementia prevalence in relation to gender and ethnicity.

Gender

In 2020 it was estimated there were over 1,900 men 65+ years with dementia in Bristol and over 2,300 women 65+ years. More women than men develop dementia as women live longer on average.

Ethnicity

Research by the Alzheimer's Society suggests that the number of people from ethnic minority communities living with dementia is expected to increase more rapidly than in the population as a whole, partly reflecting the ageing of communities established through post-war migration. Vascular dementia (caused by problems with the supply of blood to the brain) is thought to be more common among Asian and Black Caribbean people because they are more prone to important risk factors for vascular dementia such as cardiovascular disease, hypertension and diabetes.

Bristol Dementia Wellbeing Service (BDWS)

The BDWS provides support to people affected by dementia who are registered with a Bristol GP. "The team at Bristol dementia wellbeing service create personalised wellbeing plans with the person with dementia at its heart, providing support, guidance and help when, and where people want it, and in a way that suits them". (https://www.bristoldementiawellbeing.org/ accessed May 2026).

Patients are diagnosed with dementia often via a GP and then referred to the BDWS. The key aims of this service are:

- Continuous support from diagnosis until the end of life
- An assigned named dementia practitioner/dementia navigator
- 6-monthly proactive contact
- Access to an advice line; signposting to support and activity groups (via the Alzheimer's Society), and practical support for example, benefits and care planning

The BDWS also offers in-reach support to GPs and community engagement work.

In April 2026 Healthwatch Bristol Engagement staff spoke with staff at BNSSG ICB about the BDWS prior to receiving feedback from carers as part of this project. Recent work conducted by the BNSSG ICB (Dementia Care in BNSSG, Discovery Report, August 2025) on the BDWS revealed that despite the existence of this service, there is a lack of ongoing, accessible support for people diagnosed with dementia. ICB staff informed Healthwatch Bristol that carers and people with dementia stated that they feel they do not know what happens next following a dementia diagnosis and report a lack of clarity about support pathways. It was reported that people felt that diagnosis is not always clearly communicated and thus there is fear and uncertainty post-diagnosis.

Local Healthwatch research on dementia

Local Healthwatch research (Delving into Dementia, April 2025) from other parts of the country reveals significant issues around accessing diagnosis, post-diagnosis information and seeking support for people with dementia and their carers. Healthwatch Thurrock wanted to find out people's experience of dementia support to inform the review of the South Essex and Thurrock Dementia Strategy. They heard from 151 people; this is a summary of project findings:

- difficulty in securing a dementia diagnosis locally.
- Many families reported long waiting times and inconsistent information, making it harder to access early intervention and plan for the future.
- Some individuals felt unsupported following their diagnosis, with a lack of clear pathways to local services, leaving them uncertain about where to turn for help.

- The complexity of navigating health and social care, some people felt that available support was fragmented or poorly communicated.
- Carers play a vital role in supporting loved ones with dementia, yet many reported feeling isolated and undervalued.
- respite care and tailored carer support remains limited.
- Many carers expressed the need for opportunities for training, peer support, and access to mental health services to help them cope with the demands of caregiving.

Recommendations

The following recommendations have been developed based on the needs identified during this piece of work.

- Bristol Dementia Wellbeing Service (BDWS) should review how information about the Dementia Navigator role is communicated to carers of people with dementia to increase awareness of what support is available.

Information

- BDWS should review the quality of personalised wellbeing plans to ensure individuals' needs are addressed and that information on support is specific to people's situation
- Bristol City Council Adult Social Care should review information on adult social care and provide clear digital and non-digital information for unpaid carers on accessing social care services, including how to access social workers and care packages.

Respite care

- Bristol City Council Adult Social Care should review the availability of short-term respite care provision. The findings of this should be shared with dementia support services to increase awareness of availability and the limitations on what is on offer.

Cultural competence

- Review cultural competence training for staff across health services and VCSE support providers. Ensure cultural competence is integrated into assessment processes to assess people from diverse communities for dementia effectively and to provide appropriate advice, guidance and support.

Access to mental health support

- **BNSSG ICB and primary care staff** should increase access to mental health assessments for unpaid carers through GP surgeries.
- **GPs and primary care staff should signpost unpaid carers** caring for people with dementia **to emotional and mental health support including NHS Talking Therapies**.
- The **BDWS Navigator and VCSE providers need to review how social isolation is addressed amongst unpaid carers** supporting family members with dementia, potentially through six-monthly Dementia Navigator assessments.

Dementia progression

- The BDWS should review how advice on dementia progression and changing care needs is provided, including support where needs change rapidly between reviews.

Prevention

- GP surgeries, community clinics and neighbourhood health services should review how information on dementia prevention information and education is provided, particularly for minority ethnic communities, including lifestyle advice.

Engagement methodology

The Healthwatch Bristol engagement team met with stakeholders to discuss the project; this included Bristol, North Somerset and South Gloucestershire ICB (BNSSG ICB) staff, and Voluntary, Community and Social Enterprise (VCSE) dementia support staff.

The Healthwatch Bristol team identified dementia support and activity groups across Bristol. These included groups facilitated by the Alzheimer's Society, Bristol Dementia Awareness Alliance and other VCSE providers including support groups across Bristol.

This included Singing for the Brain, art groups, coffee mornings and culturally specific support groups. The engagement team contacted 20 support and activity groups across Bristol, to engage with organisations providing dementia support and set up focus groups with carers and those living with dementia.

Engagement Officers attended 8 dementia support and activity groups across Bristol including those in Fishponds, Brentry, Lawrence Weston, Shirehampton, Knowle, Knowle West, Stockwood and Withywood. Focus groups and 1:1 interviews were conducted with 28 carers and people living with dementia (see table of participants). Groups were held at support group venues across the city.

Methodology

One focus group was facilitated by Healthwatch Bristol with carers of people with dementia. This was held in South Bristol with 7 members of a dementia support group, who were all carers of people with dementia and one who had, had a recent dementia diagnosis and been a carer of a family member. This economically disadvantaged area of South Bristol has the highest percentage of people with dementia in the city and Healthwatch Bristol was informed that little dementia support is offered in this area.

Three telephone interviews were conducted by support workers held in a community cultural wellbeing support group in central Bristol with two carers of family members with dementia and one with a person with dementia.

1:1 conversations were also facilitated with 18 carers of people with dementia at local support and activity groups across the city (see demographic table for postcode areas). Focus group discussions were recorded, transcribed and emerging themes analysed. 1:1 conversations were written up from detailed notes and themes analysed. Recommendations were developed from emerging themes drawn from what carers fed back to Healthwatch Bristol, and how they felt that things could be improved.

Table 1. Demographic data - project participants

Age - years	Gender	Ethnicity	Postcode
40-49 4 people	Female 21 people	White British 24 people	BS3 1 person
50-59 1 person	Male 7 people	Black African 1 person	BS4 7 people
60-69 18 people		Chinese 3 people	BS9 1 person
70-79 4 people			BS10 3 people
80-89 1 person			BS11 4 people
90+			BS13 1 person
			BS14 8 people
			BS16 3 people

Findings

Stakeholder views

The BSWS, delivered in partnership by Devon Partnership NHS Trust and the Alzheimer's Society, is held up as a gold standard in the BNSSG area. This is due to its model of support from diagnosis to end of life, including continuity of care through its navigator role, and working collaboratively with GP practices, care homes and the wider health and social care system. VCSE support providers identified that dementia support is uneven across different geographic areas of Bristol.

In parts of South Bristol, dementia support provision is very limited. A VCSE support provider highlighted that transport, financial constraints and fragmented care are significant barriers that carers face in accessing dementia support groups for family members, in more economically disadvantaged areas of the city.

Healthwatch Bristol was informed by a VCSE support provider that some outreach work is taking place promoting dementia support groups in more disadvantaged and underserved areas for example, in Lawrence Weston and in areas in South Bristol. Other key issues highlighted by VCSE support providers were that many dementia services require payment, and that there is a lack of a "wrap around" model of care.

Contact with the Bristol Dementia Wellbeing Service

Focus group 1 (South Bristol) participants stated that most of them had had contact with the BDWS following their family member's dementia diagnosis, usually via their GP. Their family member had contact with a Dementia Navigator generally within weeks of their diagnosis and had received either face-to-face home visits or telephone calls on a 6-monthly basis from a Dementia Navigator.

Five out of the seven focus group 1 participants had this experience. However, of those we spoke to during 1:1 conversations and feedback received from support organisations (20 carers across Bristol), 11 carers had not had any contact with a Dementia Navigator following their family member's dementia diagnosis, and several were not aware of the BDWS service.

Ten carers we spoke with had contact with a Dementia Navigator, including two who said that they had limited contact with this service. One participant that had been very recently diagnosed (two months ago) with dementia had not been offered any support such as the BDWS.

Carers overall felt that they had to be proactive in finding support themselves whether this was in relation to locally accessible support groups, or in terms of advice about looking after someone with dementia. This project has revealed that the carer feedback Healthwatch Bristol received showed aspects of the service that are still considered inconsistent.

The following quotes illustrate participants' experience of the BSWS, and dementia navigators.

Some carers had a positive experience of the dementia navigator service acquiring information about local activity and support groups:

> "We did not receive much support straight after his diagnosis, apart from a home visit from Bristol Dementia Wellbeing Service. They suggested that we apply for Carer's Allowance and supported us with the application, and it has been quite helpful".

"I persuaded her (wife) to go to the doctor and did medical tests. Somebody came round to assess her and then came back after an MDT meeting with a diagnosis. Then had contact with dementia navigator every 6 months by phone but there was nothing we desperately needed support with, so it goes on for the next 6 months. We've been given layers of information on what's available for

support. We've joined various groups, Singing for the Brain, she was a bit unsure of at first. Age UK – we've got in touch with them about applying for carers' allowance and the blue badge for us. We were told about this by the dementia navigator".

One carer of a family member with dementia said that the most helpful thing that the current dementia navigator had done for her was to complete a specialist dental service form to book an appointment for her family member with dementia. This carer stated that the previous navigator was thought to be easy to talk to however, it was felt that they did not have enough knowledge of dementia.

On being asked about experience of the Dementia Navigator, a carer from the Chinese community stated that they were unaware of what this was:

> "Regarding the Dementia Navigator service, I have no idea what it is. Perhaps a member of staff from BDWS mentioned it before, but I do not remember. Therefore, I don't think my husband and I have received any support from the Navigator service".

Other carers knew of the BDWS however were not aware of the Dementia Navigator role and how they could help.

Another carer commented on geographical accessibility of dementia support groups:

"I've been pretty fortunate, my wife was diagnosed 8 months ago, so relatively new. They (Dementia Navigator) gave me a pile of literature, by the time you read it all, you find very little that's any good to you if you live in X (South Bristol area). If somebody was to draw a circle around (the local area) and put in it where all the local groups are. I can't find this out by going to all the other groups in all the other areas. I've found out through friends with these issues (partners with dementia)".

Others also felt that for those caring for family members with more advanced dementia, the dementia navigator service had been of limited help:

"I don't feel that the service has been that helpful, I often do referrals for my family member for Occupational Therapy and equipment for his home myself. If a problem comes up with him, I don't think, oh I'll contact the dementia navigator team, I deal with it myself. I have to chase them (dementia navigator team) up sometimes and I don't feel like they're very confident in supporting someone like my (family member), who now has very reduced capacity". (Woman carer, caring for family member at home)

Who provides support?

Participants said that their main sources of practical and emotional support were mostly family and friends, if family members lived locally. Peer support by carers of people with dementia (met at support and activity groups) also gave carer participants emotional support overall as they had lived experience of caring for a close relative with dementia at home. Other participants said that they had received practical support such as benefits advice, or applying for a blue badge for disabled parking via guest speakers who were invited to speak at their local support group, and from local Age Concern staff. Others had received advice about home adaptations and physiotherapy support from Sirona nurses via their GP. One carer commented on this:

> "X comes to the group, she was brilliant, she works for the council. I wouldn't have known about all that (benefits advice, blue badge) if I hadn't come here".

Another carer said that they mostly got advice and support from the Dementia UK and the Alzheimer's UK helpline and felt that these were more helpful and accessible than a Bristol Dementia Navigator.

Experience of types of support

Carers told us that dementia support and activity groups were very important to provide peer support, including emotional and practical support from other people with lived experience of caring for someone with dementia and all its challenges. This is illustrated by the following comments.

> "My family, friends and X (cultural support group, East Bristol) provide most of the practical and emotional support. For example, my children and support staff help me arrange the GP appointments. I seek emotional support from my friends".

"The people I do get support from are groups like this (South Bristol group) where people discuss various things and you go `Oh yeah, that's right'. I do go to a group somewhere near X, and one down in Y, and what a lot of people there were going through was worse than me. It helps you as it tells you either what to look out for or you know, how to go about things. I find out a lot of things from people in the same situation".

Other carers commented again on the geographical accessibility of dementia support groups across Bristol:

"If it wasn't for these (support) groups, we would literally have nothing because the information, the big pile of information we got given (by the dementia

navigator), and unless you've got a car and if you can drive (to get to the support groups), they're no use at all".

"Things go on in Clifton (support and activity groups), in churches, complete waste of time… we can't get there". (carer, living in South Bristol)

Carers in the focus group revealed the social isolation carers of family members with dementia can often experience and highlighted the importance of local support groups:

"I just kept coming here to the coffee morning and it was very helpful. When you're on your own its company isn't it? With me, I've got no family, so this is your social life as well. My family are busy working a lot".

Awareness of wider services

Most carers we received feedback from were aware of other dementia support groups and some attended other groups in the local area, and across Bristol more widely (only where they could drive or had access to and were able to use public transport). Carers told Healthwatch Bristol they also sourced information from a variety of sources including social prescribers, their dementia navigator and from people running dementia support groups.

Barriers to accessing support

Barriers to accessing support for people with dementia and their carers included:

- a lack of support and activity groups in local areas
- a lack of public transport
- travel distance to support groups
- cost implications of travel to groups rather than statutory services
- language barriers and the need for interpreters, translated materials and information in community languages
- mobility issues of carers
- mobility issues of people with dementia
- not being able to drive
- the cost and availability of accessible respite care
- people with advancing dementia not wanting to go out
- long wait times for social care services for example, home repair services and home adaptations

This is illustrated by the following comments:

"It depends where you live, you can't get to these other groups in other areas as buses don't run regularly here, when I can't drive… driving is hard for me now as have hand arthritis, my wife used to drive but can't now (has dementia)".

"It's not the lack of information that they (dementia navigators) give you but lack of locally available groups. Need for reliable respite support with trusted people".

"They (dementia navigator) give you a list of support services but it's not always easy to manage because I had a husband who would want to stay in bed and it was difficult to get him up and out".

Cultural barriers to accessing support

Carers from different cultural communities commented on cultural issues and language issues which were seen to be a barrier to accessing support by their community.

"I believe cultural issues can be a major barrier for people in the Chinese community when accessing support. For example, I am also suffering from depression, but I would not feel comfortable talking about this with a stranger. This is one of the reasons why I rarely seek emotional support. Furthermore, it was only through this interview that I realised I could request more support from BDWS. However, I still have no idea what kind of support I can ask for, and I don't think I have received enough information from BDWS. I believe that people who cannot speak English may find it even harder to access the support".

Another carer commented on the process of getting a dementia assessment through BDWS and the need for cultural sensitivity around this.

"We believe that BDWS has very little understanding of our culture and cultural norms. BDWS even offered to carry out the dementia assessment during Chinese New Year and suggested a home visit. We felt very uncomfortable about this. I believe that many Chinese would not want to discuss health issues during the New Year, as we believe that doing so could bring bad luck. Furthermore, having a stranger visiting our home can feel very intrusive to us".

Others told Healthwatch Bristol about the impact of a dementia diagnosis and a lack of follow-up support:

> "My husband has been deeply affected by the assessment and diagnosis. It has caused us significant distress and emotional burden, particularly without appropriate follow-up support".

Experience of finding support

Overall carers that Healthwatch Bristol received feedback from felt that they had to be proactive in finding support and activity groups and services. They felt that

in relation to their experience of GP services and adult social care these had been mainly reactive services in relation to providing support for the person they cared for with dementia. One carer stated:

"You have to contact them, no one checks in with you and when it comes to social workers, you have to chase them to get reviews done or if you need help with anything".

Concerns for the future

The main concern identified by several carers participating in this project related to who would be able to look after their spouse with dementia if they themselves were unwell or had to go into hospital, or if they died in the future before the person they cared for.

The lack of affordable and accessible respite care was also highlighted as a significant concern.

Needs identified

Focus group feedback and 1:1 conversations with carers of people with dementia identified the following:

- **a lack of understanding and awareness of the Dementia Navigator role**, with participants unsure what support is available or how to access it.
- **limited follow-up support after diagnosis** and that available support does not always meet people's needs, particularly in the early stages following diagnosis.
- **a need for information on local support** and activity groups for people with dementia and their carers, information should be accessible in both digital and non-digital form via local GP surgeries, VCSE dementia support providers and adult social care at the point of diagnosis and six months later
- **a need for information (in digital and non-digital format) for unpaid carers on how to access adult social care services**, such as care packages, and a social worker. This information could be available via adult social care, GP surgeries and VCSE organisations.
- **a need for affordable practical support/respite care for people with dementia and their unpaid carers** – someone to look after the person with dementia whilst their spouse/informal carer needed to go out shopping, go to medical appointments and do household tasks
- a need for accessible and affordable **emotional and psychological /mental health support for unpaid carers** particularly as their family member's dementia progresses. Need to increase the availability of mental health assessments for unpaid carers – via GP surgeries and VCSE signposting

- **language barriers and the need for interpreters**, translated materials and information in community languages on managing dementia and local support available
- **carers' concerns about staff cultural awareness and sensitivity**, including understanding cultural beliefs and approaches to discussing health and dementia.
- a need to **address the social isolation of unpaid carers** looking after family members who have dementia. Carers felt that this should form part of the BSWS Dementia Navigator 6-monthly assessment.
- a need for **accessible support and advice on changes over time** and the impact of dementia progression for those looking after someone with dementia. Carers emphasised that changes in care needs can happen quickly often in less than 6 months and dementia progression, suggests the need for availability of a phone helpline.
- a need for **information and education about how to prevent dementia onset**, particularly for those in minority ethnic communities (lifestyle advice) This could be provided via GP surgeries, community health clinics and in community settings, including the newly developing neighbourhood health settings.

These needs are partly illustrated by the following participant comments:

"My problem is for someone to look after him (husband with dementia) if I have to go to hospital appointments. My daughter came for a few hours, (but I need more sometimes), that's the main issue".

How could services be improved?

Healthwatch Bristol asked carers and people with dementia how could services be improved and work better for people. These are some of the comments received:

"I would suggest holding the meetings (with the BDWS Dementia Navigator) more frequently, as meeting every six months feels quite a long gap especially when you're newly diagnosed. Services should also be available in different languages, with appropriate interpretation and translated materials provided".

"We believe that BDWS or even the GP practice, should be able to offer more and better support. We cannot say whether the main barriers are language or culture. However, they should be more culturally sensitive when talking about health issues, particularly when working with older people".

Organisations Healthwatch Bristol engaged with as part of this project

All of the following dementia support organisations' members were invited to participate in focus groups and conversations with Healthwatch Bristol. This included carers and people with dementia living in Bristol.

Forget Me Not, Stockwood
Friends Together, Hengrove Christ Church
Alive Activities groups
Happy Days Hub, Lawrence Weston
Fishponds Memory Café
South Bristol Carers support group, Withywood Centre
East and Central Bristol peer carers support group
Memories Café, Zion Bristol, Bishopsworth Rd
Withywood Singing for the Brain, Withywood Centre Withywood Light up Art Group, Withywood Memory Café
Knowle West Singing for the Brain, Bristol Community Links South
Brislington Activity Group, St Lukes Church Hall
Art Together Thursdays, Redcatch Community Garden, Knowle
Side by Side
Music Club, Filwood Community Centre (Bristol Beacon)
Chinese Community Wellbeing Society
Dhek Bhal Elders Group
Bristol Black Carers
Malcolm X Elders Group
Dundridge Carers Café, St George

Acknowledgements

Healthwatch Bristol would like to acknowledge all the valuable conversations carers and people with dementia shared with us. We would also like to acknowledge the Alzheimer's Society, Bristol Dementia Alliance and all the voluntary organisations providing dementia support across Bristol that invited us to facilitate these conversations and talk to staff.

Provider responses

Shane Devlin, Chief Executive Officer

Dr Ananthakrishnan Raghuram MBE, Chief Clinical Leadership and Delivery Officer (Medical)

NHS Gloucestershire and NHS Bristol, North Somerset and South Gloucestershire ICB cluster

Thank you for sharing this very helpful report with us and for the valuable insights, ideas and recommendations it has generated. We are grateful to Healthwatch Bristol and to the people living with dementia, unpaid carers, community organisations and professionals who contributed their experiences. The findings provide useful insight into the lived experiences of people with dementia and their carers and will help inform our ongoing oversight and development of dementia services across BNSSG.

The findings reflect many of the themes identified through our recent Dementia Discovery work, which reviewed the pathway from prevention and diagnosis through to post-diagnostic support and end-of-life care. The report helpfully highlights opportunities to improve consistency of access, awareness of available support, carers' experiences and equity of provision across different communities and geographical areas. These themes align with the issues identified through our wider dementia pathway review.

Diagnosis rates in BNSSG are above the England average, but we recognise that demand will increase as our population ages and that people's experiences following diagnosis are not always consistent. Existing dementia services have been extended during the ICB cluster transition, and we will incorporate this valuable feedback into our developing plans. This includes our work on prevention, earlier identification, clearer outcomes and future neighbourhood models of care. We look forward to continuing to work with Healthwatch Bristol and our partners to improve access, consistency and support for people living with dementia and their carers.

Catherine Martin, Transformation and Commissioning Lead, Bristol Adult Social Care

We welcome the findings of the Dementia Report Healthwatch Bristol September 2026 and would like to thank Healthwatch Bristol, carers, people living with dementia and community organisations who contributed their experiences and recommendations. The report provides valuable insight into the experiences of people affected by dementia across Bristol and reinforces many of the themes already being identified through our wider carers engagement and co-production work.

The feedback highlights the importance of timely information and advice, improved navigation of services, greater awareness of available support, culturally appropriate services, support for carers' wellbeing, and improved access to breaks from caring responsibilities. These themes strongly align with the priorities within Bristol's All-Age Carers Strategy and the improvement opportunities identified through our carers commissioning programme.

Adult Social Care is already progressing a number of actions that respond directly to the report's recommendations through the proposed improvements in carers support in Bristol. This includes:

- Improving access to information, advice and support through the development of a carers-focused support model at the Adult Social Care front door, helping carers navigate services more effectively and receive earlier support.
- Strengthening workforce development, co-production and lived experience involvement to improve professional practice, cultural awareness and the consistency of support provided to carers.
- Expanding wellbeing, peer support and community-based approaches that reduce isolation and improve carers' wellbeing, building on positive learning from the Accelerating Reform Fund.
- Improving carers pathways, assessment practice and links between Adult Social Care and commissioned support through the proposed Carers Practice Improvement Lead role.

The findings from the Healthwatch report will be considered alongside ongoing co-production of the Bristol All-Age Carers Strategy Action Plan and wider dementia commissioning activity. We will work with partners across health, social care and the voluntary and community sector to understand how the recommendations can inform future service development, particularly in relation to information and advice, carers' wellbeing, respite opportunities, cultural inclusion and reducing inequalities in access to support.

We remain committed to ensuring that people living with dementia and their carers are involved in shaping services and that feedback continues to drive improvements in outcomes and experiences across Bristol.

Virginia Wild, Service Manager, Bristol Dementia Wellbeing Service

The BDWS welcomes this report into dementia support in Bristol. As the population of people affected by dementia continues to grow it is important that services gain a better understanding of, and ability to address, the varied and changing needs of people living with dementia and those close to them. The service supports over 3,500 people affected by dementia in Bristol, throughout their dementia journey. The service does not discharge and is therefore able to provide continuity of support that people tell us is really important to them.

Dementia Navigator

The Dementia Navigator is a unique role within the service that aims to provide continuity of support through a person-centred approach, tailored to the needs of the person living with dementia and those close to them. Their focus is on enabling independence, quality of life and wellbeing. The practical and emotional support that this role provides has been consistently identified in user feedback as being highly valued.

We recognised that people's experiences of the role can vary due to the individualised approach and as such defining the role to carers is not always straightforward. The service will work with its PPI engagement forums to identify ways we can improve consistency, clarity and communication about the role.

Information

This feedback as being consistent with other feedback we have received about Wellbeing Plans. Some of the feedback that we have received reflects that a significant amount of information soon after a diagnosis can be overwhelming.

Both the function and form of these wellbeing plans are reviewed on a regular basis with the support of our PPI engagement forums. We acknowledge the need to balance consistency of information, whilst ensuring that information is provided at the right time and is proportionate.

Cultural competence

As a service we acknowledge the health inequalities that exist and the responsibility of services like ours to proactively respond to these. Since the start of the service, we have invested in the unique role of our Dementia Community Development Coordinators to work in partnership with communities across Bristol to better understand and address the needs and barriers specific to accessing Dementia services. Part of this role includes supporting BDWS staff awareness and cultural competence and we recognise the need for an ongoing commitment to this.

Access to mental health support

The BDWS model is underpinned by the provision of continuity of support through the whole dementia journey, to both people living with dementia and those close to them, including unpaid carers. The service has an ongoing commitment to

regular contact (at least 6 monthly) and understands the importance of staying in touch and being readily accessible at times of change or increased need.

Carers, both unpaid and paid, play a vital role in supporting people living with dementia throughout their journey. Part of the navigator role includes offering direct support to carers and signposting them to appropriate community and peer support.

Dementia progression

As a service that does not discharge, the BDWS is well placed to provide information, advice and support where and when it is needed. The service provides continuity through regular contact and runs a dedicated Access line that facilitates rapid needs based support and interventions that is responsive to changing needs.

The service has been improving access to its tailored post diagnostic interventions which have a focus on maintaining wellbeing, planning for the future and increasing understanding of dementia including for carers and loved ones.

Prevention

The BDWS is identifying ways to increase understanding and awareness of modifiable risk factors relating to dementia. We recognise that BDWS has a role to play, alongside wider health system partners in furthering the dementia prevention agenda.

References

Dementia Care in BNSSG, Discovery Report, August 2025

Healthwatch Thurrock, *Delving into dementia,* April 2025
www.nds.healthwatch.co.uk/reports-library/delving-dementia

Local Healthwatch research (Delving into Dementia), April 2025

JNSA data (September 2025, Bristol City Council) on dementia prevalence

www.bristoldementiawellbeing.org/ (Accessed May 2026)

Appendices

Healthwatch Bristol Dementia Support Project – July 2026

Questions for carers

1. After diagnosis

- Has the person you care for had a dementia diagnosis?
- Did they feel supported straight after diagnosis?
- If so, how?
- What do you think would have been most helpful after diagnosis?

2. Understanding the navigator role

- Have you heard of the Bristol Dementia Wellbeing Service?
- Or the Dementia Navigator service? (Part of the Bristol Dementia Wellbeing Service)
- Have you/the person you care for had contact with this service?
- Did anyone explain their role clearly?
- Do you feel clear about what your navigator is there to help with?

3. Practical vs emotional support / Where do you receive support? What type of support – practical and emotional support?

- Who helps you with:
    - Practical things (services, benefits, appointments), or

    - Emotional support?
- What kind of support has been most useful to you?
- How helpful did you find your Dementia Navigator?

4. Changes over time (important for dementia)

- Has the support changed as things have progressed?
- Do you feel the support keeps up with your needs?

5. Access & inequalities

- Has anything made it harder to access support?
  (e.g. transport, language, confidence, cultural issues, knowing who to contact)
- Do you think some people might find it harder than others to use this service?

6. Awareness of wider services

- Have you been connected to:
    - Support groups
    - Community services
    - Financial or care support
- Were these helpful?

7. Other support

- Where do you get most support?
- Are you aware of the Dementia Lead at your GP practice?
- Have you had any contact with the Dementia Lead or other support at your GP practice? Please describe this support.

8. Changes over time (important for dementia)

- Has the support changed as the dementia of the person you care for has progressed?
- Do you feel the support responds to your needs as a carer?
- Do you feel the support responds to the needs of the person you care for?

9. If you could make changes to the support or services you have received, please could you tell us what these would be? How could the services be improved and work better for carers and people with dementia in your community?

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