healthwatch
Gateshead

Dementia Care and Impacts on Unpaid Caregivers

Interviews exploring how providing unpaid care for loved ones with dementia affects caregivers’ wellbeing, mental health, social lives, and work-related activities.

About Healthwatch Gateshead

Healthwatch Gateshead is one of 152 local Healthwatch organisations established throughout England on 1 April 2013 under the provisions of the Health and Social Care Act, 2012.

Healthwatch Gateshead is an independent not-for-profit organisation. We are the local champion for everyone using health and social care services in the borough.

- We help people find out about local health and social care services.

- We listen to what people think of services and feed that back to those planning and running services, and the government, to help them understand what people want.

- We help children, young people, and adults to have a say about social care and health services in Gateshead. This includes every part of the community, including people who sometimes struggle to be heard. We work to make sure that those who plan and run social care and health services listen to the people using their services and use this information to make services better.

Healthwatch Gateshead is delivered by Tell Us North CIC (company no. 10394966)

Healthwatch Gateshead would like to thank everyone who generously gave their time and expertise to assist with this report.

Author: Healthwatch Gateshead

Publication date: March 2026

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Executive Summary

Unpaid caregivers looking after someone with dementia in Gateshead told Healthwatch Gateshead that they often feel overlooked and unsupported. Many are older women who put their own health, social lives, and finances aside to care for a loved one. Support services are not the same for everyone, and some are too expensive or difficult to access. People living in West Gateshead face extra challenges because of poor transport and isolation. However, our interviews show that most caregivers across Gateshead struggle to get regular respite, reliable care packages, and dementia-friendly social activities. These gaps affect the caregiver's wellbeing and daily lives.

This research set out to understand what the experiences are of unpaid caregivers looking after a person with dementia, what support they know about, and how caring affects their own health, work, and life. By sharing their stories, Healthwatch Gateshead hopes to help improve services, strengthen community support, and reduce the inequalities caregivers face.

We collected information through interviews done in person, by phone, and online. Healthwatch Gateshead used both numbers (statistics) and people’s stories (themes) to explain the findings. Caregivers were also encouraged to add more detail so we could better understand the challenges they face.

Healthwatch Gateshead spoke to fifteen unpaid caregivers. Most were older women caring for a relative in the middle stages of dementia, usually for between one and five years. No one had received proper training for dementia care, and many felt unprepared. Caring affected every part of their lives, including their physical and mental health, social relationships, money, and ability to work.

Some caregivers knew about support services like Age UK Gateshead, Admiral Nurses, and Gateshead Federation. Others did not use these services because they were too busy caring, did not know what was available, or felt uncomfortable asking for help. Not everyone had been offered respite care, showing that this important support is not consistently provided or clearly explained. Experiences with health and care professionals varied: some caregivers praised caring staff, while others felt they were not given enough information or guidance.

Overall, the findings show that unpaid caregivers play a vital role in dementia care but often at great personal cost. They need better information, training in care, easier access to support, more reliable respite options, financial help, and a stronger community network.

We recommend better joint working between health services, social care, and voluntary organisations. This could include practical dementia training, early support from a named link worker, regular health checks for caregivers, and improved access to mental health and peer support. We also suggest expanding local caregiver groups, offering clearer financial guidance, improving training for professionals, and keeping service information up to date. The Local Caregivers Strategy should be monitored through an action plan held by the Carers Partnership which would help coordinate services and formally recognise caregivers’ contributions. Although we acknowledge this is already happening, it needs to be more effectively communicated to caregivers in the community.

In summary, unpaid caregivers are essential to the dementia care system but need more consistent, accessible support to stay well and continue in their role.

Introduction

This project has been supported by the involvement of a Lead Admiral Nurse from Gateshead Health NHS Foundation Trust, (a specialist dementia nurse who provides expert support to families affected by all forms of dementia), a facilitator from Age UK Gateshead's Dementia Wellbeing Centre, and a facilitator from Gateshead Dementia Caregivers Support Group. Healthwatch Gateshead have worked with the above professionals to produce a project scoping document to better understand the current key issues with unpaid caregivers providing dementia care to friends and family members in Gateshead.

Healthwatch Gateshead gathered the information in this introduction during the early scoping work for the project and before interviewing any unpaid caregivers. This included working with various partners and professionals to review the issues in Gateshead and was done before carrying out interviews with caregivers and before the data collection began.

Dementia presents one of the most pressing health and social care challenges in the UK. As of April 2025, 498,926 patients nationally had a recorded diagnosis of dementia, with 65.5 percent aged 65 or over. A further 34,090 individuals, representing 6.8 percent of the diagnosed population were living with young onset dementia, receiving their diagnosis before the age of 65.[1] Locally, the North East and North Cumbria Integrated Care Board reported 1,983 new dementia diagnoses in Gateshead in the month of April 2025 alone.

The scale of unpaid caregiving highlights the crucial role that family members, friends, and neighbours play in supporting people with dementia. In Gateshead, approximately 18,802 residents are providing unpaid care, equating to one in ten of the local population.[2] Nationally, the estimated economic value of unpaid care has risen to £162 billion annually, almost equivalent to the national NHS budget. This makes a significant contribution to the health and social care system but is achieved at significant person

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[1] NHSE Primary Care Data 2025. Available here.

[2] Gateshead Adult Caregivers Strategy 2024-2029. Available here.

cost. Caregivers often experience negative impacts on their own health, wellbeing, employment, and financial stability. An increasing number of caregivers are now providing longer hours of unpaid care, giving up or reducing their working hours in the process to do so, along with neglecting their physical and mental health needs, placing considerable strain on those caregiving.[3]

The number of unpaid caregivers in Gateshead is likely underestimated. In particular, there is limited data on those caring for individuals with dementia, which makes this group especially invisible in research and policy. However, the Gateshead Carers Partnership are currently carrying out a piece of work to rectify this by developing a dashboard to identify carers across the borough. Background work carried out by Healthwatch Gateshead has identified referrals for dementia caregivers, such as those received by Gateshead Health NHS Foundation Trust for the memory hub, tend to originate from external limited sources, such as Adult Social Care or Dementia Links, and often only capture those fortunate enough to be connected to these services. However, from those referrals that are recorded, many of them are from the West of Gateshead. [4] The Dementia UK Gateshead Community Evaluation report for 2024 highlights that 43% of their referrals are from the West of Gateshead, this is shown in the Appendices. Many caregivers in the West of Gateshead are at greater disadvantage due to transport difficulties, geographical isolation, and fewer community-based groups.[5]

Conversations with professionals and community facilitators, including Admiral Nurses and Age UK Gateshead, have highlighted recurring issues. Caregivers, most often older women who are wives/partners or daughters of those with dementia, frequently experience their own health problems yet deprioritise their needs in order to care for their loved ones. Some face additional barriers such as cognitive or sensory impairments, which make accessing support challenging and costly. The lack of dementia-friendly social groups, the decline of sitting services, and the unreliability of formal

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[3] Carers UK, 2023. Available here.

4 L Eccleston – Lead Admiral Nurse (2025). Conversation with Jack Tinkler 10th June.

[5] I Graham – Gateshead Dementia Caregivers Support Group (2025). Conversation with Afsana Begum, 30th June.

care packages all add to their burden. Caregivers are often left without the respite they need, so their own routines are disrupted, and their own lives put on hold.

Commissioning decisions for services do consider geography and evidence of need, however as Healthwatch Gateshead we believe there is inconsistent delivery of services across Gateshead which contributes to a postcode lottery. The cost of social care is a national issue and cost to individuals will vary depending on how the service is funded and individual circumstances. Healthwatch Gateshead were told that attendance at dementia wellbeing centres is limited by affordability, with costs for attending, meals, and transport potentially creating personal financial strain. This could lead to unpaid caregivers not only under-supported but also under-recognised across the nation and not just locally[6], despite the scale of their contribution to the community and the economy.

This research aims to highlight these gaps by exploring the lived experiences of unpaid caregivers for people with dementia in Gateshead. Through in-depth interviews, the study will investigate the social, mental, and work-related impacts of caregiving, assess awareness of and access to support services, and identify barriers and gaps in provision. Importantly, the project seeks to capture caregiver perspectives on what changes are most needed within the community. By bringing forward these voices, Healthwatch Gateshead will generate evidence to inform service improvements, reduce inequalities, and advocate for more fair and sustainable support for unpaid caregivers across the borough.

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[6] Carers UK (2025) Available here

Methodology

The research objectives were defined as part of the project scoping phase and are summarised as being:

a) Explore Lived Experience

b) Assess Awareness & Accessibility

c) Identify Service Gaps

d) Understand Impact

e) Gather Caregiver-Led Solutions

f) Inform Systemic Change.

The Research Objectives and interview questions can be found in the appendices for an in-depth understanding of what this research aimed to establish.

Healthwatch Gateshead initially recruited four participants through opportunity sampling to take part in interviews for this project. Each interviews lasted approximately 1.5 hours.

This sample size was chosen in recognition of the challenges faced by unpaid caregivers, such as limited time to step away from caregiving duties to provide interviews, and lack of appropriate respite. In using a small sample, we were able to spend more time with each caregiver to gather rich qualitative insights during interviews, that helped to reveal complex experiences, feelings, and views such as the impacts unpaid caregiving had on caregivers' overall quality of life. Additionally, this enabled us to carry out purposeful sampling in which we were able to speak to those who were significantly relevant to the study, and it further supports the depth of case-oriented analysis of data. We felt that the quality of the data from each caregiver was more important than the number of respondents, as the emphasis was on gathering meaningful, detailed information that directly addressed the research questions we asked caregivers.

Healthwatch Gateshead's Engagement and Involvement Officers recruited participants through drop-in sessions at locality venues during community outreach. In addition, we contacted key partner organisations that supported the project scoping stage and invited their service users and clients to share their views, if they were willing; (see acknowledgements for a list of partners).

We aimed to make our approach person-centred, thereby tailoring the interviews to the needs of the caregivers, so that they felt supported and accommodated. For example, telephone interviews, in-person interviews at homes, workplaces, and community spaces were offered.

The engagement and data collection was undertaken within a 6-week time period, between the 11th of August 2025 and the 19th of September 2025.

However, due to the small sample size of four unpaid caregivers, Healthwatch Gateshead did an additional engagement period starting on the 1st December 2025 until the 15th December 2025 to attain further feedback from more unpaid caregivers. We once again implemented a person-centred approach offering interview methods that would accommodate their needs whether that be in person, online or by telephone.

Following this extended engagement period, we gathered feedback from an additional 11 unpaid caregivers, resulting in a total of 15 responses across the two engagement periods.

A total of fifteen unpaid caregivers shared their experiences and views via interviews. Five interviews were held in-person, eight interviews were held over the telephone, and another two were held via a virtual/online meeting over Zoom or Microsoft Teams. Interviews were conducted according to each caregiver's preferences, ensuring a flexible and person-centred approach that recognised the limited time unpaid caregivers could offer to share their experiences, all whilst committedly caring for a loved one.

The Engagement and Involvement Officers recorded the conversations using Dictaphones (devices used to record spoken word) and also made some written notes during the interviews that took place with the caregivers. Although the formal process of recording interviews was exercised, the Healthwatch Gateshead team ensured that the discussions were more conversational rather than structured questions and then answers, to help caregivers feel comfortable enough to share their experiences and make sure their voices were being heard.

Recorded and written notes were then put into a word document to be used for data breakdown, and for recording key statements provided by the caregivers. Healthwatch Gateshead's Research and Data Officer also created a copy of the interview questions on SmartSurvey to be used internally, as it allowed for further analysis once exported onto a Microsoft Excel spreadsheet. All data gathered was then combined to illustrate a bigger picture of the key points caregivers had to share.

The data analysis used a mixed methods approach where quantitative (statistical – e.g. percentages) data, and qualitative (thematic – e.g. Mental health) data were studied and explored to help present findings.

Results and Discussion

Survey responses have been sorted under the following categories:

- Demographics and Participant Profiles
- Experiences and Confidence in Caring
- Impact on Caregivers' Wellbeing
- Support and Resources
- Additional Information

Demographics and Participant Profiles

Healthwatch Gateshead acknowledged the difficulties unpaid caregivers face in finding time to participate, particularly those providing full-time care who cannot easily step away from their responsibilities. Although the intention was to gather responses from at least 6–8 caregivers through in-depth qualitative interviews, Healthwatch Gateshead were able to interview 15 unpaid caregivers in total during the two engagement periods.

Firstly, we asked participants where they reside in Gateshead, as we wanted to see if data reflects the issues West of Gateshead, as highlighted in our background research for project scoping. Figure 1 & Figure 2 displays the geographical spread of the caregivers that took part across Gateshead.

It must be noted that 2 caregivers were categorised as Out of Area (NE1 & SR6) but provide regular unpaid care for a loved one in Gateshead and opted to take part in interviews and were therefore included in the data set as we aim to demonstrate the unpaid caregiving landscape in Gateshead.

Number of respondents	Postcode	Locality responding to postcode
6	NE10	East
2	NE16	West
2	NE8	Central
3	NE9	South
2	NE1/SR6	Out of Area

***Figure 1**: Table outlining respondents' postcode locations.*

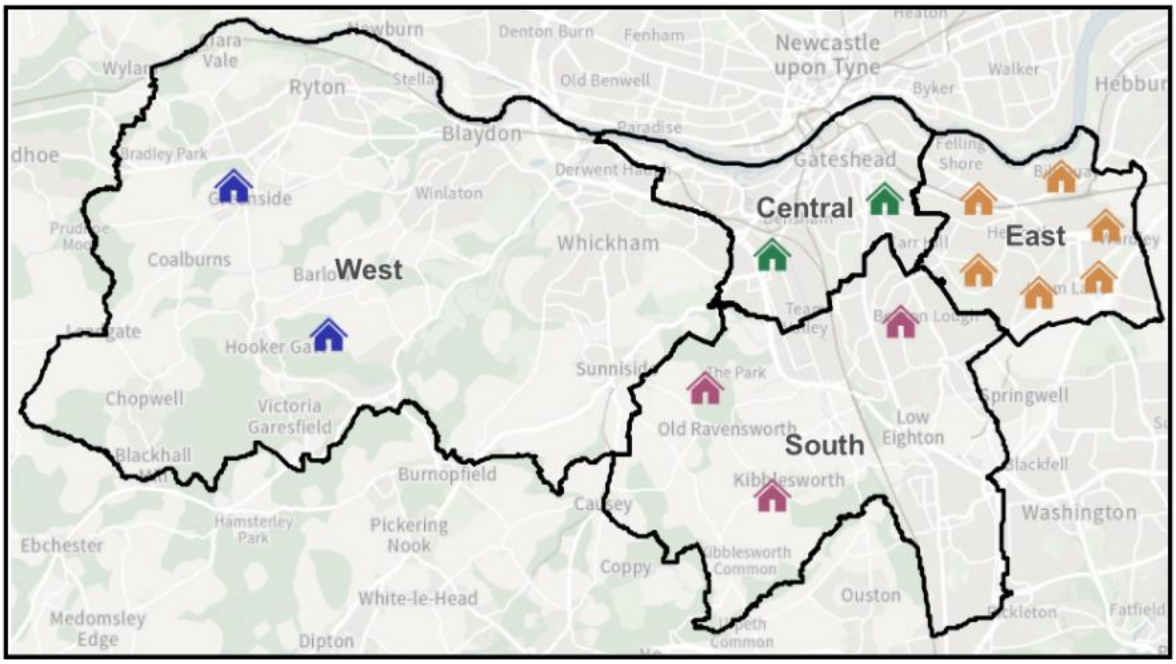

***Figure 2**: Map of Gateshead showing number of caregivers who look after someone with Dementia who lives in Gateshead based on the first part of their postcode.*

Of the fifteen caregivers, fourteen identified as female and one as male when asked to provide this information. We aimed to capture a mix of caregivers who either identified as a male or female, however the majority of these were female caregivers.

When asked to select their age range from 18 to 65+, three caregivers reported being between 45 and 55 years old, six were between 56 and 65, and six were aged 65 or over. No participants under the age of 45 were identified as providing unpaid care.

Number of respondents	Age range
3	46-55
6	56-65
6	65+

Figure 3: Table showing respondents' age ranges.

We asked caregivers about their relationship to the person with dementia they supported. Ten were a child looking after their parent (66%) three looked after their spouse (20%), one looked after their aunt (7%) and another looked after their friend (7%). Figure 4 shows this as pie chart.

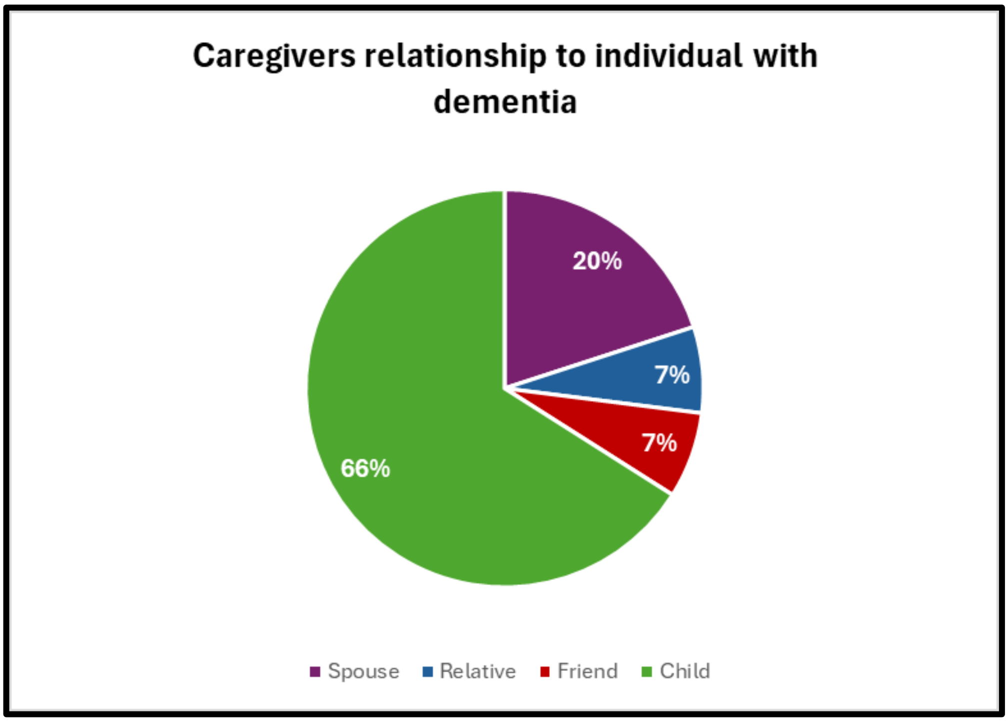

Figure 4: Pie chart demonstrating the relationship between the caregiver and the individual they were providing care for.

Caregivers were also asked how long they had been providing unpaid care, with options of less than one year, 1–5 years, 6–10 years, or more than 10 years. Fourteen participants reported that they had been caring for their loved ones with dementia for between 1-5 years, with one caregiver reporting they had been caring for 6-10 years.

Additionally, caregivers were given four options when asked which stage of dementia their loved one was currently experiencing: 'Early (Mild) Stage', 'Middle (Moderate) Stage', 'Late (Severe) Stage', and 'Not Sure'. Seven caregivers stated that the person they care for is currently experiencing the 'Middle (Moderate) Stage', four stated it was the 'Late (Severe) Stage', whilst the remaining four caregivers selected 'Not Sure'. In the middle stage of dementia, symptoms become more noticeable, and the person usually needs more support in managing daily life, needing frequent reminders and some help to wash and dress (for example, having their clothes laid out for them). This stage of dementia is often the longest. On average it lasts about two to four years.[7]

National data suggests that there is a higher percentage of women identifying as caregivers in Gateshead, 59% at the most recent census. Our findings for demographics suggest that unpaid dementia caregiving in Gateshead is primarily carried out by (older) women. The majority of participants identified as female and were aged 45 or above, reflecting broader national patterns that highlight the gendered nature of unpaid care.[8] This raises important questions about the gender split and impact of long-term caregiving on caregivers' health, wellbeing, and financial security. This will be explored in more depth later on.

Again, most caregivers reported providing unpaid support for between one and five years, indicating that dementia care is often a sustained and demanding responsibility rather than a short-term role. Most were caring for loved ones in the middle (moderate) stage of dementia, a period typically associated with increasing dependency and emotional strain. Four participants were unsure of the stage of dementia, suggesting possible gaps in communication or understanding about the condition.

Experiences and Confidence in Caring

Healthwatch Gateshead were interested in whether caregivers were given the right guidance to help support the person they care for, and if this enabled them to be prepared in providing the support.

They were asked what information on dementia, and what training they had received that was specific to the needs of the person they care for.

All fifteen caregivers reported that they were provided no training specific to the person they cared for. In terms of receiving information nine respondents said they had received information in some format (60%), four did not receive any information (27%) and two did not specify if they had received information (13%).

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[7] Alzheimer's Society – Dementia Stages and Symptoms. Available here.

[8] Office for National Statistics – The Gender Gap in Unpaid Care Provision. Available here.

Of those caregivers who stated they received information, one respondent specifically mentioned they received an information pack from Alzheimer's Society with information of how dementia can progress, what to expect and also details of services that are available, along with dementia support groups their loved one could go to. Another respondent mentioned that they received three books with information but did not specify where they were from. They did however mention that the books did not tell them how to provide care to someone with dementia. Three caregivers said they received information from the Memory Clinic/Hub with one of them specifying that the information booklet they received from the Memory Clinic/Hub was quite lengthy and tone was difficult to read as they are dyslexic. Another caregiver mentioned they received information from professionals if they asked questions and added if they felt they had any further questions regarding their loved one with dementia they had a professional to direct questions to.

From the caregivers who stated they did not receive any information, one caregiver said that it takes a long time to receive information for their loved one, due to their diagnosis. Another said that they had to actively look for a social worker due to a lack of support or information by professionals, whilst another respondent said they wouldn't get any information unless they asked questions to a professional.

From the two caregivers who did not specify if they had received information, one stated they were trained by the previous caregiver of the person with dementia, not by a professional.

The information suggests that unpaid caregivers of people with dementia receive minimal training or generic support when it comes to understanding how to care for their loved ones. While 60% of participants were given information about dementia and local services, there is a clear absence of tailored training and practical guidance that addresses the specific needs of the person they support

This lack of person-centred training leaves caregivers underprepared to manage the complex and evolving challenges associated with dementia care. It may also contribute to feelings of uncertainty, stress, and isolation among caregivers, as they are often left to learn through their own experience or seek advice independently.

The finding highlights a gap in professional communication and structured caregiver education, pointing to a need for more consistent, accessible, and perhaps personalised dementia care training for unpaid caregivers.

Impact on Caregivers’ Wellbeing

We also aimed to explore how providing unpaid care affects caregivers’ overall wellbeing, focusing on its impact on their physical and mental health, social life, finances, and employment where relevant.

So, we asked caregivers to explain the challenges they face in caring for the person with dementia – if any. Responses were categorised using the following groupings. See Figure 5:

Categories	Caregiver Responses	Impact
Physical Health	Seven of the fifteen (46%) caregivers stated that their physical health has been affected by caring for the person with dementia. This includes feeling very tired; fluctuations with blood pressure; anxiety; back strain; burnout; becoming quickly aged due to stress. One stated that they find it difficult to do any physical work for the person they care for such as shopping and hoovering so have to ask other family members to do this. Another said that their caregiver role is *“physically demanding, resulting in caregiver injury”.*	This highlights how the physical demands of caregiving can exceed individual capacity, particularly for older caregivers.
Mental Health	Ten of the fifteen respondents (66%) said that their mental health was affected. Five respondents said that they get anxiety. Other factors affecting mental health included tiredness, acute	This suggests that prolonged emotional strain, worry, and lack of respite contribute to a decline in mental wellbeing, echoing wider evidence that unpaid

	stress; exhaustion and emotional burnout. This has led to depression for two respondents and causing panic attacks in one respondent. One said that they are on anti-depressant medication.	caregivers are at higher risk of mental ill health.
Social Life	Twelve of the fifteen caregivers (80%) stated that their social life is impacted in some way. This includes having to move away from family/friends to take care of their loved one, having to cancel planned holidays and finding it difficult to spend time outside of the home without another person to take care of their loved one while they go out. One respondent did say that during Covid-19, they did talk to a counsellor in order to speak to someone but felt as though the counsellor wasn't communicating very well on the phone call and there were only six sessions that they could attend which wasn't very much to help them.	This points to a broader need for accessible and ongoing social and psychological support for unpaid caregivers.
Finances	Four respondents (27%) said that they are managing financially although they do lose money due to their caregiving responsibilities. One caregiver did elaborate that although they are managing financially, their loved one with dementia is unaware that they need to pay for things. By providing care to their loved one, the caregiver's expenses	This underlines how caregiving can have an impact on financial stability, even when caregivers feel they are coping, especially when additional costs arise from the person's loss of financial capacity.

	have gone up by £200-£400 a month. Two respondents found a great impact of financial strain due to their caring responsibilities especially as the condition of their loved one progresses.	
Occupational	Two respondents mentioned that they do work which they find difficult to balance the care and support that they provide to their loved one as well as fulfilling their own needs such as grocery shopping, housework etc. One of the respondents also mentioned, that their loved one repetitively calls them whilst at work which causing them to feel worried.	This demonstrates the tension between employment and caregiving responsibilities, and how caregiving can affect productivity, work-life balance, and emotional wellbeing.

Figure 5: *Table highlighting the overall impacts of unpaid caregiving.*

The data paints a clear picture of the heavy burden unpaid caregivers carry, affecting their physical health, mental wellbeing, social connections, finances, and ability to work. These overlapping pressures indicate that unpaid caregivers for people with dementia are at high risk of burnout and social isolation, emphasising the urgent need for respite provision, mental health support, financial assistance to sustain their wellbeing and caregiving capacity, and perhaps flexible work/employment arrangements.

Support and Resources

In addition to the above, Healthwatch Gateshead wanted to further explore whether caregivers were offered any tools or provision to help support them to care for their loved ones with dementia.

We asked them if they were aware of any resources and support services for caregivers of people with dementia.

Nine caregivers mentioned Age UK Gateshead as a place that they can seek support or to attend a dementia day care centre, a service commissioned by Gateshead Council and accessed via Adult Social Care.

Support groups such as the Dementia Network and a group at Dunston were also mentioned. One respondent also mentioned that they were aware of a day centre running at Blaydon but they didn't feel comfortable with the idea of it.

One caregiver also mentioned that they know they can seek resources and support at the Memory Clinic/Hub at Bensham.

Other professionals and organisations mentioned included: Admiral Nurse from the Queen Elizabeth Hospital (Gateshead Health NHS Foundation Trust), GP, Rapid Response Team, and having paid carers from Gateshead Council to support. House on the hill was also mentioned by one of the respondents, which is the name of a council commissioned Dementia Day Centre provided by Age UK.

Responses indicate that caregivers are aware of some local sources, specialist and community-based group support, showing that some informal and social support options exist within the area. However, the caregiver who expressed discomfort about attending a local day centre in Blaydon, is suggestive of the view that perhaps not all caregivers or their loved ones find day care services suitable or appropriate for them.

Overall, this suggests that awareness of support varies, and that personal preferences, comfort levels, and perceived service quality may influence whether caregivers engage with available support. It also highlights a need to ensure that dementia-related services are welcoming, flexible, and tailored to meet both caregivers' and care recipients' needs.

Caregivers were then also asked what types of support they are currently in receipt of, if any.

Five respondents (33%) said that they receive support from Age UK Gateshead including their dementia day care centre. Five respondents

(33%) also said that they can use respite care for support. Of these respondents, two specified that they have six weeks of respite care to use and one said they were not satisfied with the previous respite facility their loved one went to, so are reluctant to use respite again.

Three respondents (20%) said they currently do not receive any support from any organisations. Figure 6 depicts where the interviewed caregivers received support from.

Current support	Number of respondents receiving
Age UK Gateshead	5
Carers Federation	2
North East Counselling Service	1
Memory Clinic/Hub	1
Admiral Nurse	1
Social Worker	1
Respite (when required)	5
No support at all	3

Figure 6: Table showing where the interviewed caregivers currently receive support from

Some services are commissioned through the ICB, LA, NHS as service provision. These includes Carers Federation, social workers and counselling services. While other services are funded via charitable funds and others not for profit.

The data suggests that support uptake among unpaid dementia caregivers is inconsistent, with some caregivers stating they have received support, whilst others none at all. While some caregivers are actively engaging with services, others are not currently accessing any form of help. Notably, two caregivers reported declining offers of support which may indicate barriers such as not being appropriate from a timing perspective, emotional readiness, or confidence in service effectiveness.

Overall, these findings point to a mixed picture of engagement, where availability of support does not always translate into uptake. This underscores the need for more proactive, flexible, and personalised outreach, ensuring that unpaid caregivers are both aware of and feel comfortable accessing the support channels that are available to them.

We also asked caregivers how satisfied or dissatisfied they were with the current level of support they receive. The breakdown of what caregivers responded with can be shown in Figure 7.

Level of satisfaction	Number of respondents
Very satisfied	1
Somewhat satisfied	2
Neither satisfied nor dissatisfied	3
Somewhat dissatisfied	4
Very dissatisfied	5

Figure 7: *Table showing how caregivers reported their level of satisfaction with support they receive*

One caregiver was "Very satisfied" with current support due to their loved one enjoying going to the dementia day care centre.

Two caregivers said they were "Somewhat satisfied". One of the caregivers explained that there was a long waiting time for their loved one to be diagnosed with dementia from Bensham Memory Clinic/Hub and believed an earlier diagnosis and medication would have prevented severe progression of their condition.

The other caregiver said they were satisfied with the current provision of support and was available when needed, however they did also mention *“if you go to council or social workers, it takes too long, even to change (paid) carers. If you want to change any days etc-it takes too long via Age UK Gateshead. Respite is in place, I don’t feel like I can take it”*

Of the three caregivers who were “neither satisfied nor dissatisfied”, one of the respondents said they had different feelings with different aspects of support. They explained that they were Satisfied with Memory Clinic/Hub, neither satisfied nor dissatisfied with Admiral Nurses, dissatisfied with health service generally and charities, which resulted in their neutral response. Another caregiver mentioned they keep themselves healthy, have friends in similar positions to lean on and will contact the council soon to see what they can be offered. The final caregiver said they were not actively looking for support at the moment so could not comment.

Of the four caregivers who responded with “Somewhat dissatisfied”, two of those said that they lacked awareness of what support was available and didn’t know who to contact. One caregiver expanded on this by saying a social worker is the best professional to seek help from, however they are only available to support for 6-8 weeks and they had to wait 6 months to just be assigned one. The third caregiver gave this rating because they were unable to get a GP appointment, either in person or over the phone, to discuss Power of Attorney for their loved one. The final caregiver stated they were somewhat dissatisfied as they had no support from any organisation for their loved one and only been given medication to relieve symptoms of dementia without any further information or support.

The remaining five caregivers who selected “Very dissatisfied” chose this rating because they did not have any support from any organisations or professionals to improve their caregiving circumstances. One further added that they had a break in communication with their support worker, which caused further complications as they are already working on a busy schedule looking after their loved one.

Overall, this highlights large inconsistencies in service accessibility and awareness, with the caregivers feeling unsupported or uncertain about where to turn for help, pointing to a need for clearer communication, stronger service coordination, and improved access pathways.

Furthermore, we asked caregivers what additional support or resources would be helpful or could be improved to better support unpaid caregivers of people with dementia.

Figure 8 is a list of what the caregivers mentioned and suggests what would be helpful or could be improved in relation to support or resources:

Area of Support	Support needs identified by carers
Coordinated and Ongoing Support	• A named link worker or assigned social worker from the beginning • Regular check-ins and ongoing advice, with face-to-face availability • A change in the healthcare system to place greater focus on carers as well as patients
Information, Guidance and Planning	• A guidebook outlining available support and how to care for someone with dementia • Clear information on the stages of dementia and what care is appropriate at each stage • Support with legal matters such as wills and Power of Attorney
Emotional and Mental Health Support	• Dedicated mental health support for carers • Recognition of the emotional impact of being an unpaid carer
Financial Support and Recognition	• Increased funding and financial support for unpaid carers personal finances

	• Greater recognition of carers' contributions to the Health and Social Care system • Improved benefits and protections for carers, particularly around financial losses linked to residential care
Respite and Practical Help	• Support to care for their loved one at home while the carer is away • Help to enable carers to have time for themselves and maintain independence
Social Connection and Peer Support	• Opportunities for carers to connect, share experiences, and exchange information • Discounts for social activities and public transport to help carers and their loved ones maintain a social life

Figure 8: Table showing what caregivers would find helpful or would like to be improved to support their caregiving role.

To capture more in-depth feedback, we asked caregivers if they have been offered respite care, and if so, was there availability of respite care when they needed it.

Six of the fifteen (40%) respondents said that they have been offered respite care. One mentioned that they used 2 weeks but were later told that they would have to pay £200 subsidy which they weren't aware of and has now made them reluctant to take on respite care again. Another respondent said that their loved one went for respite for a couple of days but fell down, so they don't feel comfortable with using respite services again.

Other respondents that were offered respite care said that it was either not the right time or they are currently looking at their options.

Eight respondents (53%) said they had not been offered respite care. Two said that they would be reluctant to take on respite care due to hearing experiences from other people who have utilised respite care or because of the financial implication of paying for respite. One respondent mentioned that respite care is not something that they had considered yet.

Access to respite care was mixed, with just under half of the respondents being offered it and others expressing reluctance to use, due to economic strain or the emotional hesitation to entrust their loved one's to be cared for by others. This could suggest that respite care it not being effectively integrated or communicated within existing support systems leaving unpaid caregivers without essential relief that could protect their wellbeing. However, it should be noted that not all caregivers are eligible for respite care and this could explain why not all respondents reported being offered this support. This finding highlights a potential gap in the knowledge of caregivers around accessing respite care and their hesitancy to take up respite for their loved ones with dementia.

Overall, their feedback underscores the need for holistic, caregiver-centred policies and resources that prioritise wellbeing and recognition.

Additional Information

Finally, towards the end of the interviews with the caregivers, we asked them to provide any additional information they wished to share about being an unpaid caregiver for a loved one with dementia.

They all shared varied views that seemed important to them to mention. Below are some of the opinions they shared:

(the remaining additional information comments that the caregivers provided but are not included in this section can be found in the appendices)

One had positive feedback regarding the professionals that they have come across particularly at Bensham Hospital.

"The professionals that I have come across such as consultants at hospital have been brilliant by being very patient and listening to what we say. Staff at Bensham Hospital were so lovely they're just amazing and they make time to listen to me as well…they get the views of both sides, and they find out from the person themselves if they can recognise any changes themselves and then they'll ask."

Another respondent again expressed their positive experiences particularly with Gateshead Council supporting the independence of their loved one. A referral was made to Gateshead Council's Prime Team for the first 4-6 weeks, and they could see a positive change in their loved one, looking more aware and healthier. Age UK Gateshead were also mentioned to have been great with picking and dropping off their mother from home to their lunch club, along with the GP being brilliant help.

One however described their frustration and surprise at the lack of guidance from services in terms of care, medicinal side effects, and offer of alternative care.

"I'm really surprised at the lack of any guidance or governance of anything. You end up guessing. As a person you have to go and find it and seek it and I could probably do more and list all those things at the back of my mind."

One described frustration around pharmacy services.

"Frustration with pharmacy services – many are closing or have reduced hours, making it hard to manage complex medication schedules. After switching to a different pharmacy, I encountered repeated errors, delays, and poor service, including a pharmacist prioritising a vaccine over resolving a prescription issue. I felt deeply let down and took my mother to confront the pharmacy directly. I now actively discourage others from using that pharmacy, leveraging my public-facing job to spread awareness."

One added that they always travel in a taxi and receive carers allowance, for her husband that she cares for, but is quite content overall.

"No, I'm quite all right as long as I have my family, as long as he's able to go out, he doesn't walk far. We get taxis everywhere. Get carers allowance for

that. We taxi everywhere. He's doesn't talk. He's very really nonverbal now, doesn't have any conversation, but lonely sometimes. But I'm a type of person that's quite content to be honest. I would sharp shout for help if I needed it. But he's not got any angriness in him or anything like that."

This qualitative feedback offers valuable insight into the diverse and deeply personal experiences of unpaid caregivers for people with dementia. It highlights that while some caregivers encounter positive and compassionate professional support, others experience frustration with systemic shortcomings in health and social care.

The positive account of staff at Bensham Hospital shows the importance of empathy, communication, and inclusion of both the patient and caregiver in care decisions, showing how such interactions can build trust and reassurance. Again the other positive experience that another caregiver had with support services such as Gateshead Council, Age UK Gateshead and their GP highlight that when accessed, these support networks are beneficial and assist the caregiver's role.

On the contrary, other caregivers' comments reveal gaps in information, guidance, and coordination, leaving them to navigate complex care and medication systems largely on their own. The frustration expressed around pharmacy errors and limited access to medicines further reflects service fragmentation and the added stress placed on caregivers.

Finally, one caregiver's contentment, despite both social and geographical isolation with reliance on taxis, illustrates that coping mechanisms and family support can mitigate some emotional strain, though loneliness remains a persistent theme. Overall, these reflections suggest that while individual professionals can make a meaningful difference, systemic improvements are needed to ensure consistency, reliability, and person-centred support across all aspects of dementia care.

Key Themes:

In reference to the data and findings presented above, Healthwatch Gateshead have determined the following themes as the key points of focus, based on what caregivers have reported to us:

1. Lack of Training and Tailored Information – Unpreparedness and lack of person-specific guidance.

- All caregivers reported no training specific to the person they care for.
- While some received general information (e.g. about dementia, support services), there was a clear lack of practical guidance on how to actually care for someone with dementia.
- Caregivers often had to proactively ask questions to get information from professionals or seek information independently.

What this means: Caregivers are often thrust into their roles with minimal preparation, leading to uncertainty and stress.

2. Significant Impact on Physical health, Mental Health– Caring takes a toll on physical and emotional well-being, along with social life of caregivers

- Physical health: Common issues included fatigue, high blood pressure, and physical limitations in caregiving tasks.
- Mental health: Caregivers reported anxiety, stress, and depression. One caregiver reported being on antidepressant medication.
- Increasing effect: The physical and emotional burden of caregiving is high and under-addressed.

What this means: There is a clear need for holistic health support for caregivers, not just for the person with dementia.

3. Isolation and Sacrifice of Social Life – Social withdrawal and emotional isolation.

- Large proportion of respondents reported negative effects on their own social lives, including, moving away from friends/family, cancelling personal plans like holidays, and feeling unable to leave the house without someone to provide care.
- Even when accessing counselling, support was felt to be limited and insufficient.

What this means: Social isolation is a recurring issue that could contribute to poor mental health and burnout.

4. Financial and Occupational Strain – Financial burden and work-life conflict.

- Some caregivers are managing financially but still face increased out-of-pocket expenses (£200–£400/month).
- Employment is difficult to balance with caregiving duties:
- Struggles with time management and fulfilling their daily needs such as housework or grocery shopping.
- Interruptions at work (e.g. calls from the person with dementia).

What this means: Caregiving creates hidden economic costs and work-related stress, especially for those caregivers trying to stay in employment.

5. Limited Awareness and Uptake of Support Services – Knowledge gaps and barriers to accessing support.

- Some caregivers are aware of support services like Dementia Network, Rapid Response Team, Admiral Nurses or Age UK Gateshead and their Dementia Day Care Centres.
- However, actual uptake to services is low: three caregivers received no current support; some declined what was offered.
- Reasons include not feeling comfortable using services (e.g. day centres), lack of follow-up from support services or proactive outreach from services.
- Caregivers recognised that some services were universally available and others required eligibility, however this affected the support they needed.

What this means: Access to support is inconsistent, and services may not meet caregivers emotional or practical needs.

6. Mixed Satisfaction with Existing Support – Inconsistent experiences and unmet needs.

- Overall satisfaction ranged across the board with ratings of very satisfied from one caregiver, to very dissatisfied for five caregivers.
- Some caregivers acknowledged certain services as helpful (e.g. Memory Clinic/Hubs and dementia day centres), but others expressed dissatisfaction due to poor communication and limited availability of appointments (e.g. with GPs). Whilst another expressed there was a long waiting time to be assigned support (social workers). This is demonstrating a lack of carer-focused attention in the system.

What this means: Existing services have disjointed communications and fail to centre on the caregiver's perspective.

7. Clear Calls for Systemic and Practical Support Improvements – Desire for recognition, respite, and tailored help.

Some suggestions made by respondents included:

- Increased financial support and benefits for unpaid caregivers.
- Recognition of their contributions (e.g. housing concerns if loved one enters care or providing support with wills & Power of Attorney).
- A link worker or point of contact for consistent guidance.
- Respite options so caregivers can take breaks and have time for themselves.
- A shift in healthcare focus to include both patients and caregivers

What this means: Caregivers are asking for tangible, structural and practical support.

8. Inconsistencies for Respite Care – Lack of respite opportunities and concerns about cost.

- Only some of the caregivers reported that they had been offered respite care, however we are unsure if all caregivers were eligible for this support.
- Even among those who could afford it, there is reluctance to pay or uncertainty around availability.

What this means: Respite care is viewed by caregivers as being not appropriate, unaffordable, and is not proactively offered, leaving caregivers without essential relief.

9. Experiences with Healthcare Services Vary Greatly – Disparity in experiences with professionals and services.

- One caregiver shared positive feedback about Bensham Hospital, whilst another shared positive experiences of Gateshead Council, Age UK Gateshead and their GP.
- Others expressed frustration with a lack of guidance, medication side effects and pharmacy issues.
- Another caregiver expressed poor communication from professionals.

What this means: The quality of professional support is inconsistent and depends heavily on individual experiences.

Conclusion and Recommendations

Overall, the findings reveal that unpaid caregivers for people with dementia in Gateshead play a vital yet undervalued role, often at great personal cost. From our interviews with fifteen unpaid caregivers of people with dementia and/or dementia related diseases in Gateshead, our finding reveals that the caregivers spoken to is largely undertaken by (older) women, most of whom have been providing care for between one and five years to loved ones in the middle stage of dementia.

Caregivers reported receiving no individualised training or very little guidance on how to support someone with dementia, often relying on limited general information from clinics or their own initiative.

The impact on wellbeing was significant across all domains, with most reporting deteriorating physical and mental health, social isolation, financial strain, and challenges balancing employment and care.

Awareness and uptake of local support services, such as those provided by Age UK Gateshead, Admiral Nurses, and Carers Federation, were inconsistent, with some caregivers declining support due to time pressures, financial constraints or discomfort with using these services.

Not all caregivers had been offered respite care, which could highlight a communication gap around eligibility and service provision not being communicated effectively. This is also based off the assumption that all caregivers are eligible for respite care. While some caregivers praised compassionate healthcare staff, others expressed frustration with poor communication and limited practical guidance.

In conclusion, unpaid caregivers are a critical but fragile pillar of the dementia care system. To maintain their essential role, there must be greater consistency and accessibility of support, clearer communication and guidance from professionals. There should be a focus on promoting and advertising the current support that is being invested into by partners and coordinated through the Caregivers Strategy, so unpaid caregivers are aware of the support there for them to utilise.

Recommendations

The findings from our research, namely the key themes and outcomes, have allowed us to propose recommendations as a Healthwatch.

These recommendations are based on what we learned from our partner organisations by reflecting their input gathered through earlier engagement, information provided by the 15 unpaid caregivers we interviewed, and internal discussions within the Healthwatch Gateshead Research and Engagement Team.

We present the following evidence-based set of recommendations below, each matched with a responsible organisation or service in Gateshead:

- Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) should better promote the existing dementia-specific training and information sessions for unpaid caregivers, including practical guidance on day-to-day care, communication, and behavioural changes. These sessions could be improved by more co-production with caregivers and offered as both online and in person options.

- In partnership with Primary Care Networks (PCNs), Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) could also create an 'Early Intervention Package' for new caregivers, including a 'Named Caregiver Link Worker' as a single point of contact for coordination, follow-up, and signposting.

- NHS North East and North Cumbria Integrated Care Board (NENC ICB) and GP Practices (via the support of CBC Health Federation) should introduce routine caregiver health checks and ensure easy access to mental health and wellbeing support, such as counselling and peer support groups.

- The Carers Partnership could improve their role as advocates for caregivers across the system by:

    - Working with VCSE organisations to expand dementia-friendly caregiver groups across different geographies in Gateshead including drop-ins, flexible meeting times, and virtual options (e.g. Dementia Network, Age UK Gateshead, Gateshead Carers Association, Caregivers Connected Gateshead). This would ensure there is a good spread of accessible and varied services in all localities that meets the needs of local caregivers.

    - Working as a partnership to communicate more widely the 'Local Caregivers Strategy' and to formally recognise unpaid caregivers, as well as set out commitments around training and involvement them in service co-design.

    - Better promotion of existing information about financial entitlements for caregivers. Also to support employers to adopt "caregiver-friendly" workplace policies such as flexible hours and carer leave, including information on carer's rights.

    - *Organisations within the Carers Partnership should also look to proactively promote and advertise their support services and outline what is currently available for unpaid caregivers in the community.*

    - *The Carers Partnership should undertake a review of the current respite provision to identify potential communication gaps, as well as gaps in accessibility and suitability for unpaid caregivers, with a consideration around caregivers' eligibility for this support.*

- Gateshead Council (Adult Social Care Commissioning), NENC ICB, and independent care providers should consider increasing investment in affordable, accessible respite care, both in-home and community based. Also to ensure all caregivers are proactively offered respite during care planning and if not eligible signposted onto alternatives.

- Gateshead Health NHS Foundation Trust, NENC ICB, and the Local Pharmaceutical Committee should provide mandatory dementia and caregiver-support training for frontline healthcare professionals to improve communication, empathy, and joined-up care.

- In general terms, GP Practices and support organisations should have their websites and information pages of staff details updated with their 'specialisms' outlined. So, members of the public can be informed of who to speak to for specific support for dementia and caregiving issues.

Overall, the responsibility for improving unpaid dementia caregiving in Gateshead is shared across the partners under the Caregivers Strategy and implemented through it's action plan. Through this partnership approach Healthwatch Gateshead would like to see more joined up delivery of services, improved communication between professionals and involving local caregivers in the production of services going forward. This coordinated approach ensures that more caregivers are not just recognised but meaningfully supported in maintaining both their wellbeing and their vital contribution to dementia care.

Although Healthwatch Gateshead has provided an evidence base, key findings, and recommendations for services and organisations, we acknowledge that the research has certain limitations. We have therefore highlighted the main issues observed throughout the project and outlined considerations for future research to help address these limitations. Please see Appendix for more details on these limitations and how we could improve future research.

Response Statements

The following statements have been provided by our key partners, and some of the organisations and services identified in the recommendations. These responses are intended to acknowledge, engage and address the research findings that have been presented by Healthwatch Gateshead.

Gateshead Dementia Caregivers Support Group Facilitator

"I have read the attached document, and I find the content to be correct so far, even with the small number of caregivers represented.

Gateshead council carried out a Caregivers Charter a few years ago. I was one of the Caregivers in the discussion group. It took two years at least for the charter to be finalised. Due to staff leaving and the charter being shelved. When it was published, they may have just published another council's documentation. It was supposed to be a live document with regular updating and discussion on recommendations being met. There hasn't; not to my knowledge anyway. So good luck with that idea. We caregivers don't have any confidence in the local authorities in that respect.

I would like to suggest maybe carrying out a larger study, including the Sandwich Caregivers. I have new members (not many) that their cared for are in there 70's. So some of them are caring for their parents and children at the same time. Putting even more stresses on them. Because it affects their work, thus their finances, the lives of their children, via poor finances and the health of their parents' poor physical health and mental health. Even when their cared-for eventually need to have residential care. But your conclusions still ring true. If there was more holistic support the cared for could live a better quality of life, therefore the caregivers' lives become bearable.

The services that are available at the moment are helpful but have been very slow in addressing needs. Two members have been waiting for months to receive a caregiver's assessment.

The Wellburn Group have given me a room, beverages and biscuits free of charge. Very grateful to them. An improvement service, private and *voluntary groups working together in Gateshead. It wouldn't have happened without the Gateshead Dementia Network. The Facilitator is trying so hard, without funding to keep it going. If we lose the Network, I believe Gateshead Dementia Support Services will go back to the black hole it was in 2 or 4 years ago. It's a shame you couldn't do something about saving the network. You would think the health authority and local authorities would back it, as it does do much good for, and awareness about Dementia."*

North East & North Cumbria Integrated Care Board (NENC ICB)

Chief Operating Officer

Thank you for sending us your latest report, which provides lived experience and insight from caregivers on their concerns regarding unpaid care for people with dementia. We know how vital unpaid caregivers are for people with dementia and to the wider system. We recognise from the feedback that there are challenges regarding support for caregivers, including access to support and communication of the support offer.

	Recommendation	Comments
1.	Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) should better promote the existing dementia-specific training and information sessions for unpaid caregivers, including practical guidance on day-to-day care, communication, and behavioural changes. These sessions could be improved by more co-production with caregivers and offered as both online and in person options.	*This is with our partners for their due consideration*
2.	In partnership with Primary Care Networks (PCNs), Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) could also create an 'Early Intervention Package' for new caregivers, including a 'Named Caregiver	*This is with our partners for their due consideration*

	Link Worker' as a single point of contact for coordination, follow-up, and signposting.	
3.	NHS North East and North Cumbria Integrated Care Board (NENC ICB) and GP Practices (via the support of CBC Health Federation) should introduce routine caregiver health checks and ensure easy access to mental health and wellbeing support, such as counselling and peer support groups.	The commissioned carers support service in Gateshead provides peer support through individual and group activity. Other carers support services in Gateshead also have a peer support offer. Those carers who require support with their mental health/wellbeing who would benefit from counselling can access support through Talking Therapies provided through South Tyneside and Sunderland NHS Trust. It is good practice for GPs to keep a register of carers and certainly adds valuable context if a GP is aware someone has caring responsibilities. Practices are flexible and if advised that someone has caring responsibilities and require some reasonable adjustments e.g. appointments times Reception teams look to accommodate. There are currently no plans to introduce routine caregiver health checks in Gateshead over and above the regular offer of NHS health checks, screening, annual reviews etc The ICB are currently working with the Carers Federation who have developed a letter for Carers to

		take to GP highlighting their caregiver status, requesting that practices record this on Carers records and take account of this while offering support.
4.	The Carers Partnership could improve their role as advocates for caregivers across the system by: • Working with VCSE organisations to expand dementia-friendly caregiver groups across different geographies in Gateshead including drop-ins, flexible meeting times, and virtual options (e.g. Dementia Network, Age UK Gateshead, Gateshead Carers Association, Caregivers Connected Gateshead). This would ensure there is a good spread of accessible and varied services in all localities that meets the needs of local caregivers. • Working as a partnership to communicate more widely the 'Local Caregivers Strategy' and to formally recognise unpaid caregivers, as well as set out commitments around	The ICB has been and continues to be an active member of the Carers Partnership.

	training and involvement them in service co-design. - Better promotion of existing information about financial entitlements for caregivers. Also to support employers to adopt "caregiver-friendly" workplace policies such as flexible hours and carer leave, including information on carer's rights. - *Organisations within the Carers Partnership should also look to proactively promote and advertise their support services and outline what is currently available for unpaid caregivers in the community.* - *The Carers Partnership should undertake a review of the current respite provision to identify potential communication gaps, as well as gaps in accessibility and suitability for unpaid caregivers, with a consideration around caregivers' eligibility for this support.*	
6.	Gateshead Council (Adult Social Care Commissioning), NENC ICB, and independent care providers should consider	The ICB regularly reviews and updates its commissioning intentions often in partnership with the local authority. The ICB

	increasing investment in affordable, accessible respite care, both in-home and community based. Also to ensure all caregivers are proactively offered respite during care planning and if not eligible signposted onto alternatives.	recognises the value of carer breaks and will continue to offer support on a person-centred basis.
7.	Gateshead Health NHS Foundation Trust, NENC ICB, and the Local Pharmaceutical Committee should provide mandatory dementia and caregiver-support training for frontline healthcare professionals to improve communication, empathy, and joined-up care.	The ICB currently has no plans to introduce mandatory dementia and caregiver support training for frontline health care professionals.
8.	In general terms, GP Practices and support organisations should have their websites and information pages of staff details updated with their 'specialisms' outlined. So, members of the public can be informed of who to speak to for specific support for dementia and caregiving issues.	Every GP is an *expert generalist*, trained to care for people of all ages and bring care together when health needs overlap. Practice websites may also share staff members' areas of interest, to help people find the right support more easily
9.	Overall, the responsibility for improving unpaid dementia caregiving in Gateshead is shared across the partners under the Caregivers Strategy	The ICB does and will continue to support the development of this work through the Carers Partnership and its ongoing work

	and implemented through it's action plan. Through this partnership approach Healthwatch Gateshead would like to see more joined up delivery of services, improved communication between professionals and involving local caregivers in the production of services going forward. This coordinated approach ensures that more caregivers are not just recognised but meaningfully supported in maintaining both their wellbeing and their vital contribution to dementia care.	with the commissioned carers support service.

Thank you very much for sharing this report and we look forward to reading the next one.

Gateshead Council

As a Local Authority we recognise the vital role that caregivers play in sustaining wellbeing, independence and quality of life across our communities. We welcome this research to understand how we can better support caregivers locally, and how it can further support our delivery of the Caregivers Strategy.

	Healthwatch Recommendation	Gateshead Council Response
1.	Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) should better promote the existing dementia-specific training and information sessions for unpaid caregivers, including practical guidance on day-to-day care, communication, and behavioural changes. These sessions could be improved by more co-production with caregivers and offered as both online and in person options.	We are committed to improving the information available to caregivers and use a range of approaches to promote opportunities for dementia training and information sessions. This includes the Council's website, the Dementia page on OurGateshead, the Gateshead Exchange and through one-to-one advice and signposting through our commissioned service with Carers Federation. To improve caregivers' involvement in shaping services, we have commissioned an Expert Panel for Young Carers and Adult Caregivers.
2.	In partnership with Primary Care Networks (PCNs), Gateshead Health NHS Foundation Trust (Admiral Nurses) and Gateshead Council (Adult Social Care) could also create an 'Early Intervention Package' for new caregivers, including a 'Named Caregiver Link Worker' as a single point of	As part of the Caregivers Strategy delivery plan, Carers Federation are creating a Welcome Pack which will be distributed to caregivers in a range of settings. Caregivers can also access the support of a Carer Wellbeing Facilitator who can provide coordination, support and signposting, by registering with Carers Federation.

	contact for coordination, follow-up, and signposting.	
6.	Gateshead Council (Adult Social Care Commissioning), NENC ICB, and independent care providers should consider increasing investment in affordable, accessible respite care, both in-home and community based. Also to ensure all caregivers are proactively offered respite during care planning and if not eligible signposted onto alternatives.	We know how important it is for Caregivers to be able to have a break from their caring role and recognise that high-quality, flexible respite is essential to preventing breakdown and enabling Caregivers to continue their role. We offer a range of respite opportunities and are focused on ensuring Caregivers understand the full range of options available to them following Care Act and Carers Assessments. This includes via financial assessments, though it is important to recognise that the ability to access funded respite care is shaped by the national statutory charging framework which determines how councils must assess financial contributions. To help Caregivers maximise their income we have commissioned specialist information, advice and guidance on income and benefits, provided by the Carers Federation.
4.	The Carers Partnership could improve their role as advocates for caregivers across the system by: • Working with VCSE organisations to expand dementia-friendly caregiver groups across different	The Council (as convenor of the Carers Partnership) will propose a review of the membership, terms of reference and activities of the partnership. We would invite Healthwatch to take an active role in preparing for and facilitating the

	geographies in Gateshead including drop-ins, flexible meeting times, and virtual options (e.g. Dementia Network, Age UK Gateshead, Gateshead Carers Association, Caregivers Connected Gateshead). This would ensure there is a good spread of accessible and varied services in all localities that meets the needs of local caregivers. • Working as a partnership to communicate more widely the 'Local Caregivers Strategy' and to formally recognise unpaid caregivers, as well as set out commitments around training and involvement them in service co-design. • Better promotion of existing information about financial entitlements for caregivers. Also to support employers to adopt "caregiver-friendly" workplace policies such as flexible hours and carer leave, including information on carer's rights. • *Organisations within the Carers Partnership should also look to proactively promote and advertise their*	review, based on the learning from this project.

	support services and outline what is currently available for unpaid caregivers in the community. - *The Carers Partnership should undertake a review of the current respite provision to identify potential communication gaps, as well as gaps in accessibility and suitability for unpaid caregivers, with a consideration around caregivers' eligibility for this support.*	
9.	Overall, the responsibility for improving unpaid dementia caregiving in Gateshead is shared across the partners under the Caregivers Strategy and implemented through it's action plan. Through this partnership approach Healthwatch Gateshead would like to see more joined up delivery of services, improved communication between professionals and involving local caregivers in the production of services going forward. This coordinated approach ensures that more caregivers are not just recognised but meaningfully supported in maintaining both their wellbeing and their vital contribution to dementia care.	Whilst we would not disagree with the sentiment, we do not feel this is a measurable action and feel it needs to be reworded so that we can demonstrate whether the recommendation has been achieved.

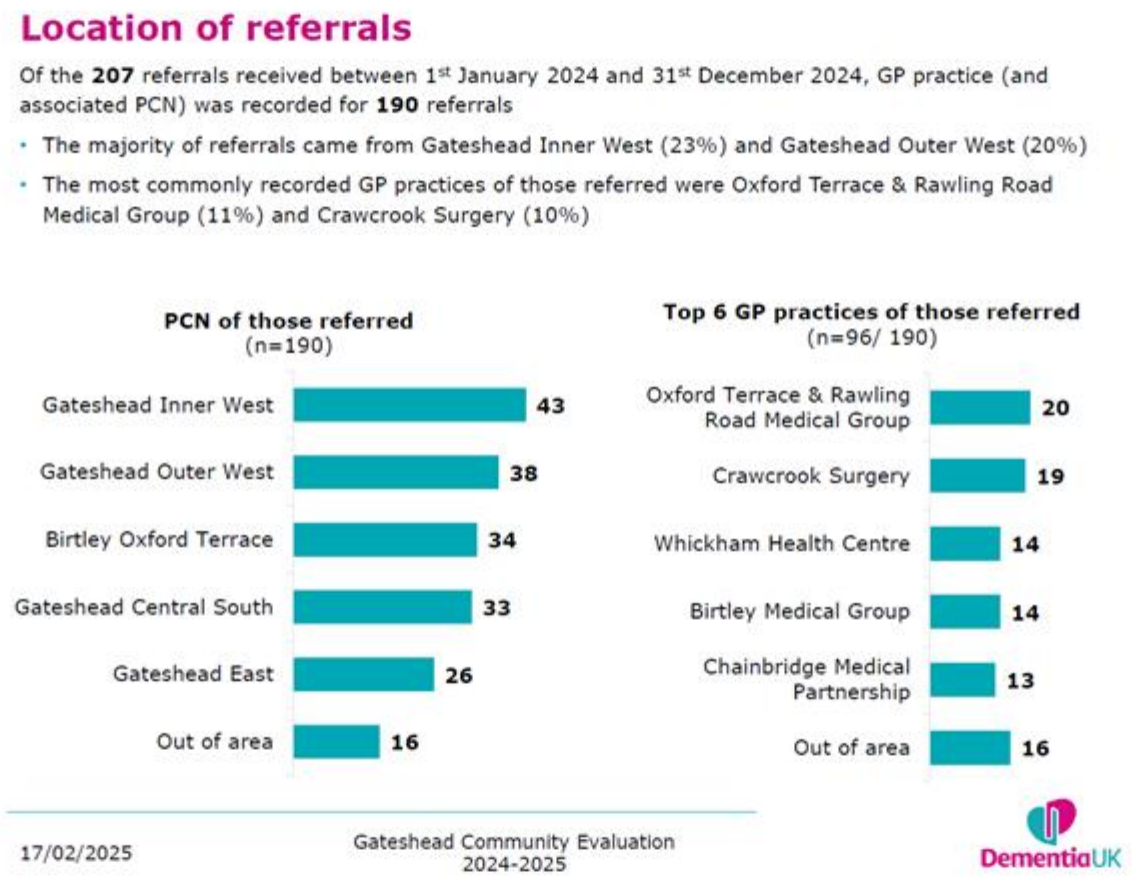
Acknowledgements

Healthwatch Gateshead would like to extend our gratitude and thanks to the caregivers who were able to contribute some of their time to speak with us and provide their lived experiences. We would also like to acknowledge the following partners and organisations in the list below for providing us with the support and information we needed to complete this project. Without this feedback we would not have been able to capture such important data, that helps to amplify people's voices, inform the public, and help suggest wider system improvements.

- Age UK Gateshead Dementia Wellbeing Centre Facilitators
- Gateshead Carers Federation
- Gateshead Council (Adult Social Care Team)
- Gateshead Dementia Caregivers Support Group
- Gateshead Dementia Network
- Gateshead Health NHS Foundation Trust Lead Admiral Nurse
- Gateshead MECC
- HOPE Network

Appendices

Data cited from *Dementia UK Gateshead Community Evaluation Report January 2024 – December 2024*



Location of referrals

Of the **207** referrals received between 1st January 2024 and 31st December 2024, GP practice (and associated PCN) was recorded for **190** referrals

- The majority of referrals came from Gateshead Inner West (23%) and Gateshead Outer West (20%)
- The most commonly recorded GP practices of those referred were Oxford Terrace & Rawling Road Medical Group (11%) and Crawcrook Surgery (10%)

17/02/2025

Gateshead Community Evaluation 2024-2025

DementiaUK

Research Objectives:

a) **Explore Lived Experience:** understand the daily realities, pressures, and emotional toll faced by unpaid caregivers of people with dementia in Gateshead.

b) **Assess Awareness & Accessibility:** examine unpaid caregivers' awareness of and access to existing support services, with special focus on availability in the West of Gateshead.

c) **Identify Service Gaps:** map the current dementia-related services and highlight gaps, particularly in relation to respite care, social support, and equitable access.

d) **Understand Impact:** investigate the mental, social, and occupational impacts of unpaid dementia caregiving, including effects on employment and wellbeing.

e) **Gather Caregiver-Led Solutions:** engage caregivers in identifying practical improvements and priorities for dementia care service delivery in their local area.

f) **Inform Systemic Change:** provide evidence-based recommendations to health, social care, and community stakeholders to reduce postcode-based disparities and better support caregivers.

Interview Questions:

General Information and Demographics:

1) What is the first part of your postcode that you currently reside? (e.g., NE1)

2) What is your gender identity?

3) What is your age range?

4) What is your relationship to the person with dementia? (e.g., spouse, child, friend)

5) How long have you been providing unpaid care for the person with dementia?

6) Which stage of dementia does the person you are caring for currently have?

Experience and Confidence in Caring:

7) What training or information were you provided with, specific to the person you care for?

Impact on Caregiver's Well-being:

8) What are the challenges you face in caring for the person with dementia? (This can include impacts on physical health, mental health, social life, financial and occupational well-being).

Support and Resources:

9) What access to resources and support services for caregivers of people with dementia are you aware of?

10) What types of support do you currently receive? (e.g., respite care, counselling, support groups)

11) How satisfied or dissatisfied are you with your current level of support? And why?

12) What additional support or resources would be helpful or improved to better support unpaid caregivers of people with dementia?

13) Have you been offered respite care? And if yes, was there availability of respite care when you needed it?

Additional Feedback:

14) Is there anything else that you would like to share about your experience as an unpaid caregiver for someone with dementia?

Additional Feedback Comments, Question 14:

Positive

- One respondent add that they always travel in a taxi and receive carers allowance
- One said that their family was their support network to help them through caring for their loved one
- Spending more time within their family home and watching their "little ones grow"
- Everyday is a new day to learn about their loved one and adjusting to them

Negative

- Found doctors to be dismissive
- Lack of communication from professional and long waiting times for support

- Have a lot of strain as caring for both parents with different complicated needs
- *"Social services are just not interested in anyone suffering with dementia, they think it's somebody else's problem so they think I can just deal with it and do the caring."*
- Caregivers' personal needs are not being met.
- There was an issue when Gateshead boundaries had changed and commissioned service had got removed out. They therefore had to through a different payment option for carers. The payments due kept on changing which was quite stressful. But as the caregiver had worked in social care in the council before, they were aware that it was a systems issue whereas no one else would know that as a regular carer who has not worked in this department of the council.
- Mother receives low rate of attendance allowance and it is quite difficult to navigate through the system. Caregiver mentioned that it should be a more centralised at local government level rather than at national level.
- Worried if they try to seek financial support, that it will affect the support that their loved one.

Limitations

1) Small sample size:

Even after an extended engagement period only a small number of caregivers participated. This limits the ability to generalise findings to all unpaid dementia caregivers in Gateshead and does not capture the full diversity of experiences.

2) Limited demographic representation:

The research did not include a broad range of demographic groups (e.g. younger caregivers, caregivers from ethnic minority communities, working caregivers, male caregivers etc.). The majority of the responses came from caregivers who identified as older women, as a result, some experiences and views may be underrepresented, and findings cannot be fully generalised to the wider population.

3) Self-selection bias:

Caregivers volunteered to take part, meaning those with stronger opinions, often more negative or positive may be overrepresented.

4) Geographic spread not fully captured:

Although some differences were noted across areas of Gateshead, the sample was not large enough to compare experiences by locality e.g. West of Gateshead, where discussions with partners in the initial scoping stage of the project highlighted there were more pertinent issues.

5) Focus on mostly qualitative themes:

The research set out to capture qualitative responses via in-depth interviews with caregivers, although with the limited quantitative data the ability to benchmark findings against wider data sets is restricted. This, however, can be attributed to the small sample size.

6) Lack of input from professionals or wider stakeholders:

The findings focus solely on caregiver perspectives as we did not gather views from healthcare professionals, social care staff, or support organisations, limiting the ability to cross-check service-related issues.

7) Limited exploration of decline services:

Although some caregivers decline support services, we did not explore in depth why they were declined or how services could be redesigned or improved to encourage uptake.

How can we improve Future Research?

Future research should aim to include a larger, more diverse group of caregivers, ensuring representation across different age groups, ethnic backgrounds, types and stages of dementia and different areas of Gateshead. Using targeted outreach through community hubs, VCSE organisations, GP practices may allow us to capture more data from unpaid caregivers who may be harder to engage, thereby strengthening engagement with underrepresented groups. However, this would change the methodology from detailed interviews to wider questions in a survey.

Although Healthwatch Gateshead did employ a mixed-methods approach, future research could consider combining qualitative interviews with quantitative tools such as caregiver burden scales, or mental wellbeing questionnaires etc. This could strengthen the evidence base and allow comparison with regional and national data.

Perhaps carrying out a longitudinal research projects e.g. a follow-up study over 6-12 months, could reveal how caregiver needs change over time, particularly as dementia progresses, which may help to analyse why caregivers decline services, and explore barriers to accessing respite and cultural or personal factors that influence service use. Furthermore, future work could assess the effectiveness of existing services e.g. Memory Clinic/Hubs, caregiver groups, counselling, helping to pinpoint what works well and what needs improvement.

Future research could also include gathering feedback via surveys from GPs, Admiral Nurses, Adult Social Care Teams, VCSE groups, as it would help to triangulate (overlook/share) findings and identify system-wide gaps.

Signposting

- Age UK
  Telephone: 0800 055 6112
  www.ageuk.org.uk

- Alzheimer's Society
  Telephone: 0333 150 3456
  www.alzheimers.org.uk

- Caregivers Connected Gateshead
  Telephone: 0808 801 0350
  https://caregiversconnectedgateshead.co.uk/

- Carer's Trust – Gateshead Carers Association
  Telephone: 0191 490 0121
  www.gatesheadcarers.com

- Carers Trust - Tyne and Wear
  Telephone: 01207 549780
  https://carerstrusttw.org.uk/

- Citizen's Advice – Gateshead Dementia Advice Service
  Telephone: 0191 4785100
  www.citizensadvicegateshead.org.uk

- Dementia UK
  Telephone: 0800 888 6678
  www.dementiauk.org

- Gateshead Council – Adult Social Care (Resources and Guidance for Caregivers)
  Telephone: 0191 433 7033
  https://www.gateshead.gov.uk/article/35418/Resources-and-guidance-for-caregivers

- Gateshead Dementia Caregivers Support Group
  Telephone: 07850 051822
  irenegraham.gdcsg54@gmail.com

- Mind UK – Coping while caring for someone else
  Telephone: 0300 123 3393
  www.mind.org.uk

- The Silver Line
  Telephone: 0800 4 70 80 90
  www.thesilverline.org.uk

healthwatch
Gateshead

Healthwatch Gateshead
c/o Tell Us North CIC
Milburn House, Suite E11 Floor E
19 Dean Street
Newcastle upon Tyne
NE1 1LE

Website: www.healthwatchgateshead.co.uk
Phone: 08000 385 116
Email: info@healthwatchgateshead.co.uk