

POSITION STATEMENT CARERS LIVED EXPERIENCE OF DEMENTIA in Birmingham (2024)



CONTENTS

Introduction	3		
The NHS England Well Pathway	4		
Context	6		
What is dementia?	7		
Dementia is different to Alzheimer’s Disease	7		
Types of dementia	8		
3 Stages of Dementia: Early, Middle and Late	8		
Dementia Statistics in the UK	8		
Birmingham and Solihull	8		
Birmingham and Solihull Dementia Strategy and Action Plan (2023-2028)	8		
Our Aims	9		
Our Key Principles	10		
Our Priorities	11		
Theme 1: Role of Primary Care	12		
Key Message 1.1: Carers are sometimes not taken seriously enough by their GPs when they raise concerns about challenging behaviours of the PLWD they care for.	12		
Key Message 1.2: Primary care need to be more proactive in early diagnosis of dementia and continuing care. It would be helpful for each GP practice to have a specialist.	13		
Key Message 1.3: Dementia can delay getting an early diagnosis for other illnesses.	13		
Theme 2: Role of Other Services	14		
Key Message 2.1 Better integration of services and improve continuity of care.	14		
Key Message 2.2 The assessment process for Continuing Health Care Funding should be sensitive to carer/family needs.	17		
Theme 3: Role of Carer	18		
Key Message 3.1: Support for carers who are caring for more than one family member, and those who have not accepted the diagnosis and are in denial.	18		
Key Message 3.2: Help PLWD who are self-funding their care at home.	18		
Key Message 3.3: Right support for carers caring for PLWD and psychosis at home.	20		
Key Message 3.4: Helping carers with mental health problems to care for a PLWD.	21		
Key Message 3.5: Supporting carers who are feeling isolated and lonely.	21		

Theme 4: The Role of Social Worker	22
Key Message 4.1: More help needed for carers when the PLWD refuses help, including support from Social Worker.	22
Key Message 4.2: Make the assessment process less difficult for carers, with compassion and understanding, and ensure good communication and continuity of care.	23
Summary of Lived Experience	24
3 Key Priorities	25
Discussion	26
Reflections	28
Next Steps	29
Governance and Reporting	30
Appendix	31
Reference list	34

INTRODUCTION

A Dementia Citizens Group was created to engage with people living with dementia (PLWD) and their carers to share their lived experience in Birmingham. Birmingham City Council (BCC) want to put citizens at the heart of their decisions. This group will work in co-production with the Adult Social Care Commissioning team at BCC to support the Birmingham Dementia Programme and be actively involved in service design, delivery, commissioning, and evaluation. This will ensure that dementia services will support PLWD and their carers to live better and improve outcomes.

There were 35 citizens who signed up to this group. The first meeting was held online on 29th of February 2024 (via Microsoft Teams). Eight citizens shared their lived experience with the group and why they joined the Dementia Citizen Group. They all wanted to make a difference and improve the care and experience of PLWD. There was good representation among the 3 stages of dementia: 2 people in early stage, 2 in middle stage, and 4 in late stage of dementia. A total of 4 meetings were held online.

The lived experiences of our diverse communities are not reflected in this position statement. BCC has reached out to ethnic minority communities through various avenues such as forums, dementia carer groups, and dementia training providers who engage with ethnic minority groups. Although carers from ethnic groups had signed up, there was limited representation of their lived experiences in this position statement. Further work is required to engage with people representing the complex diversity of Birmingham's population.

This position statement aims to share the group's collective voice with organisations to better understand what PLWD and their carers consider to be important to them and make a difference to their lives. The lived experiences shared in this position statement are highlighted in bold, italics and by quotation marks throughout the paper.

This position statement sets out BCC commitment to improve outcomes for PLWD and their carers to enable them to live life to the fullest, and to support them to remain active in their community for as long as they can. This document also links with other local strategies that are relevant to PLWD and their carers (see Appendix).

THE NHS ENGLAND WELL PATHWAY

The NHS England Well Pathway (see Figure 1) describes the route for a patient and their carers' dementia journey. This framework helps to support PLWD throughout their dementia journey.



Figure 1: NHS England Well Pathway

CONTEXT

WHAT IS DEMENTIA?

This position statement uses the word 'dementia'. The word 'dementia' is not a specific illness, but a term we use for a group of symptoms caused by different illnesses that damage the brain. Over time the symptoms get worse and can affect memory, problem-solving, language and behaviour.¹

Not everyone will get dementia and dementia is different from normal ageing. Everyone's experience of dementia is unique. PLWD and their carers will need to make choices about their future care and how it best meets their personal needs.



DEMENTIA IS DIFFERENT TO ALZHEIMER'S DISEASE

Dementia refers to symptoms caused when a disease damages the brain in a particular way.

The term 'Alzheimer's disease' (Alzheimer's) is used to describe a disease that damages the brain, as well as the type of dementia. Alzheimer's disease is the most common type of dementia.

Each disease affects the brain differently which is why there are different types of dementia.²

TYPES OF DEMENTIA

There are many types of dementia.

The 4 main ones are:

1. **Alzheimer's disease** is the most common type of dementia. Early signs of Alzheimer's are problems with memory, thinking, language or perception.³
2. **Vascular dementia** is the second most common type of dementia. In vascular dementia symptoms vary depending on the person, the cause and the areas of the brain that are affected. The most common symptoms during the early stages of vascular dementia include problems with planning or organising, making decisions, or solving problems, finding it hard to follow a series of steps (such as cooking a meal) and problems concentrating.⁴

Different types of vascular dementia can cause different symptoms. They often experience depression, anxiety, or apathy (a lack of feeling or emotion). As the illness progresses, they may get aggressive; find it difficult to sleep; experience delusions (persistently thinking things that are not true) and hallucinations (sensing, seeing, or hearing things that are not there). These symptoms can also be seen in other forms of dementia.

3. **Dementia with Lewy bodies disease (DLB)**. Lewy bodies are clumps of protein in the cells of the brain. Symptoms include difficulty staying focused, experiencing delusions, and problems with movement and sleep.⁵
4. **Frontotemporal dementia (FTD)**, also known as Pick's disease or frontal lobe dementia. Common symptoms include changes to personality and behaviour and/or difficulties with language. The symptoms vary, depending on which areas of the frontal and temporal lobes are damaged.⁶

A person may have more than one type of dementia based on clinical features of two types of disease and symptoms, this is known as 'mixed dementia'.

3 STAGES OF DEMENTIA: EARLY, MIDDLE AND LATE

There are 3 stages of dementia: early, middle, and late. It can be difficult to tell when a person has progressed from one stage to another. For more information see BCC dementia website

Dementia | Birmingham City Council

DEMENTIA STATISTICS IN THE UK

In the UK there are nearly a million PLWD and this number is expected to rise to 1.6 million by 2040. Around 1 in 3 people born in the UK today will be diagnosed with dementia in their lifetime. Dementia can affect a person at any age and is often more common in people over the age of 65. However, it can also affect younger people (under the age of 65) this is known as young-onset dementia. More women are affected by dementia than men.

BIRMINGHAM AND SOLIHULL

Around 13,000 people are living with dementia in Birmingham and Solihull. This figure is expected to increase to over 17,000 people by 2040. Currently there is no cure for dementia, which is why it is vital that dementia services focus on supporting people to live well with dementia.

BIRMINGHAM AND SOLIHULL DEMENTIA STRATEGY AND ACTION PLAN (2023-2028)

The Dementia Strategy (2023 - 2028) provides an overview of how health and social care will work together across Birmingham and Solihull to improve the lives of people living with dementia and their carers'. The strategy highlights the NHS England Well Pathway, which describes the route for a patient and their carers' dementia journey (see figure 1).

The strategy has identified 4 key priorities:¹⁰

1. Information focusing on the prevention of dementia, early intervention, and support.
2. Access to a timely diagnosis with support before and after.
3. Supporting people with dementia, their loved ones, carers, and communities to prevent crisis.
4. Improving the quality of personalised care and support planning for PLWD, including planning for end of life.

A refresh of the strategy and action plan for 2025-2028 will be taking place before 2025, ensuring citizens are at the heart of all discussions. This is also an opportunity to review and deliver best practice care, based on the individual needs of PLWD in Birmingham.

OUR AIMS

BCC is committed to improving the lives of PLWD and those who look after them over the next 5 years.

- Ensure the dementia services meet the needs of PLWD in the future and offers value for money.
- Ensure all PLWD live well for as long as possible.
- Tackle health inequalities for PLWD and have equitable access to services.
- PLWD and their carers lived experience can help commissioners know what matters to them, as well as help to identify issues, potential solutions, and outcomes.
- Enable PLWD and those who care for them to have the best possible health and social care support throughout their dementia journey.
- Ensure that everyone has access to information, advice and support about dementia that is simple to understand, easy to navigate and signposts to support services that are available in Birmingham.
- All health and care professionals should work together effectively as a multidisciplinary team (MDT).



OUR KEY PRINCIPLES

The core principles underlying our approach include:

Co-production: Ongoing engagement with PLWD and their carers.

Recognising people's strengths: Building on the assets that people, their families, friends, and the community can offer.

Ensuring personalised support: Building support around people rather than making people fit into rigid services and recognising that every person living with dementia is unique.

Putting the person and their family/carers in control: Services focus on being inclusive, managing behaviour and reducing risks for PLWD.

Focus on improving outcomes: Dementia affects everyone which is why we need to support family/carers and friends. Ensure PLWD are supported to remain independent for as long as possible and have good quality of life throughout their dementia journey, especially during their end of life.

Promoting equity: Challenging and removing inequality, discrimination, and stigmatisation. To champion diversity and promote cultural competence (the ability to interact effectively with people of different cultures) but also consider equity such as the individuals' socioeconomic circumstances.



OUR PRIORITIES

The priority areas identified by PLWD, and their carers are outlined below with examples of what is important to them and what they believe will make a real difference to their lives. Every effort has been made to record and understand views as accurately and sensitively as possible. The names used in this document have been changed to protect people's identity, but the stories are real.

The feedback from PLWD and their carers identified 4 key themes/areas for improvement:

1. Role of Primary Care
2. Role of Other Services
3. Role of Carer
4. Role of Social Worker.

Each theme will be discussed below in more detail.



Theme 1: Role of Primary Care

KEY MESSAGE 1.1

Carers are sometimes not taken seriously by their GPs when they raise concerns about difficult behaviours of PLWD.

Sarah's Lived Experience Sarah's husband Bob has Alzheimer's since 2021 and his personality has changed. She worked in a care home as a manager for over 20 years	
Negative experience	"Bob was aggressive, restless, and neurotic." Sarah would ask her doctor for a referral, but the doctor did not help. "Only when Bob assaulted a neighbour early one morning did it prompt a referral to the Mental Health team where he was then diagnosed with dementia and paranoia."
Positive experience	"After Bob was diagnosed, she was able to manage him better and get him the help he needed. Now he is calm".
Comment	Sarah said, "GPs should take carers seriously especially when they raise concerns about PLWD aggressive behaviour."

Ayan Lived Experience Ayan recognised the signs of dementia but felt that she was not taken seriously by the GP.	
Negative experience	Ayan recognised that her mom shows signs of dementia, but she is not being heard by her GP and feels let down, frustrated and anxious. "How can I help my mom get a diagnosis?"

Alice's Lived Experience – Initial consultation with the GP	
Positive experience	"Joe told his GP that he was worried about dementia, she did some memory tests, confirmed our suspicion, and referred him to the local memory clinic. From this point on he was not 'in denial'. He immediately gave up his work, re-did our wills and made lasting power of attorney (LPA) whilst he still had capacity." This initial consultation was a positive experience.

KEY MESSAGE 1.2

Primary care needs to be proactive in early diagnosis of dementia and continuing care. It would be helpful for each GP practice to have a specialist.

Alice's Lived Experience	
Negative experience	"By June 2021, Joe was walking less, I arranged physiotherapy. He had 'accidents' and was becoming incontinent; I bought incontinence pants. He needed help dressing and undressing. He forgot how to shave; I bought an electric shaver. Where was the GP in all this? The answer is nowhere."
Comment	<i>Alice said, "if it hadn't been for my advocacy, we would have had no support. Joe was supposed to have at least yearly check-ups with the GP."</i>

KEY MESSAGE 1.3

Dementia can delay getting an early diagnosis for other illnesses.

Alice's Lived Experience – Dementia delayed diagnosis for other illnesses.	
Experience	"Joe was eating poorly and losing weight, at first this was blamed on his dementia and /or the medication. Eventually the GP did some tests, referred him to hospital and a dietician. Several appointments, scans, and tests later it turned out he had prostate cancer which had already spread to his bones. I believe that the delay in this diagnosis contributed to the rapid decline in his Alzheimer's."

Theme 2: Role of Other Services

There are a wide variety of services such as NHS, Local Authority, and voluntary organisations that people living with dementia use, as shown below:

- Birmingham Community Healthcare Trust (BCHCT): Physiotherapy, Occupational Therapy, Speech and Language Therapy, Dietetics, Podiatry.
- Memory Assessment Service (MAS): Birmingham and Solihull Mental Health NHS Foundation Trust
- District Nurses and End of Life Care
- Consultant in Old Age Psychiatry
- Alzheimer’s Society, Birmingham Carers Hub, and Carers Emergency Response Service (CERS); Admiral Nurses
- Local Authority, Medequip Community Equipment Services

“Right from the start I felt I had to organise everything myself with little or no help from statutory agencies. We had no contact with the Local Authority.”(carer)

“It can be a nightmare for carers to navigate all these services” (carer)

KEY MESSAGE 2.1

Better integration of services and improve continuity of care.

Alice’s Lived Experience with Memory Assessment Service (MAS)	
Positive experience	<p><i>“Joe was seen relatively quickly in the Memory clinic. The psychologist was very helpful and did a thorough assessment. We came away knowing there was a real problem, with information leaflets and some helpful advice.</i></p> <p><i>However, this service then had to refer to another part of the Mental Health Trust for medication to be prescribed.”</i></p> <p><i>“It was probably 6 months from going to the GP to getting the medication. If early intervention is important then this process needs to be quicker. We need better integration of services.”</i></p>

Alice's Lived Experience - Consultant in Old Age Psychiatry provided continuity of care.	
Positive experience	<i>"Joe had regular appointments (every 6 months) with the same consultant who prescribed and reviewed his medication. Initially face to face and then by phone. This same consultant was always contactable by telephone to discuss new symptoms. e.g., disturbed sleep and always responded quickly. A member of his team was also able to do home visits when indicated. This medical input was far more helpful than that provided by our GP. It provided a continuity of care which was very important."</i>

Helen Lived Experience - Alzheimer's Society and continuity of care.	
Positive experience	<i>"The Memory Clinic initially put us in touch with the Alzheimer's society. An advisor phoned me regularly and more often as Jim's illness progressed. It was always the same advisor which was very helpful. This was particularly important during lockdown."</i> <i>"However, at some point the service changed and there were only intermittent calls and not always the same person – so this was not as helpful. "</i>

Simran Lived Experience - Admiral Nurses Simran's mental health was starting to suffer.	
Positive experience	<i>"I had wonderful support from the Admiral nurse for my mental health as a carer. After an initial home visit this consisted of phone calls, which could last for up to an hour, weekly or fortnightly, for almost 3 years. She acted as my "key worker" she listened and made practical suggestions and signposted me to other services. She liaised with other services on my behalf. This is a wonderful service."</i>

Aisha Lived Experience - Carers Emergency Response Service (CERS)	
Positive experience	<i>"Before I had regular carers, I couldn't leave Ali on his own. CERS provided me with free care for Ali when I attended hospital appointments and would have provided emergency care if I had been taken ill. Knowing this gave me peace of mind."</i>

Yasmin Lived Experience – Birmingham Carers Hub	
Positive experience	<i>“Someone (always the same person) phoned me about 4 times a year. She did a carers assessment and provided me with a Wellbeing payment that enabled me to attend pottery classes. She also encouraged me to apply for the attendance allowance, council tax reduction etc.”</i> <i>“Without her I would not have known about these things.”</i>

Monica Lived Experience - Medequip Community Equipment Service	
Positive experience	<i>“When Malcolm’s mobility got worse, Monica contacted Adult Social Care and after a telephone assessment a lovely man came to fit a handrail up the stairs. This was done quickly. When Malcolm came home from hospital having had COVID and deteriorated a lot the necessary equipment was delivered quickly.”</i>

Emily’s Lived Experience – Aids and Adaptations Emily cared for her husband Charles, who has dementia.	
Negative experience	<i>Emily was angry, “It’s been 2 years of waiting for adaptations. Early intervention is important and should not be delayed.”</i>

Nicola Lived Experience – Self-funding more major adaptations e.g., converting a downstairs room to a bedroom.	
Comment	<i>“People who are fortunate enough to have money/resources can get adaptations done themselves more quickly. This highlights an inequality in experience and outcomes.”</i>

Both the voluntary sector and NHS services play a vital role in supporting and helping carers'.

"The voluntary sector is life saving and memory clubs, it mattered! They are vital and gave me a sense of friendships and support." (carer)

"Most of the support was from memory clinic, psychiatrists and Admiral nurses which are NHS services" (carer)

KEY MESSAGE 2.2

The assessment process for Continuing Health Care Funding should be sensitive to carer/family needs.

Alice's Lived Experience of Applying for Continuing Health Care Funding	
Negative experience	<p><i>"Joe often refused to get out of bed till the carer had gone. Leaving me with all the personal care. He was becoming aggressive; mobility was decreasing, and he needed a lot of help with feeding."</i></p> <p><i>"The district nurse, who had been visiting, suggested I apply for the Continuing Health Care Funding. The assessment process for this was one of the worst experiences of our whole journey. It reduced me to tears."</i></p>
Comment	<p><i>Alice said, "CHC should be sensitive to carer/family needs when reviewing the assessment process."</i></p>

Theme 3: Role of Carer

KEY MESSAGE 3.1

Supporting carers who are caring for more than one family member who has not accepted the diagnosis and is in denial.

Tina's Lived Experience Tina faced additional pressures as she was also caring for her dad who has dementia but is in denial.	
Negative experience	<i>"Dad also had dementia in 2018 and was aggressive and in denial, hallucinating, and getting no answer from doctors. After lockdown his condition got worse. How do you help someone like my dad who is in denial to access support?"</i>

KEY MESSAGE 3.2

Help PLWD who are self-funding their care at home.

Jessica's Lived Experience Jessica is caring for Mona, her mother-in-law who has vascular dementia. Jessica has lasting power of attorney for Mona and is also supporting Tim, her father-in-law.	
Negative experience	<i>Jessica feels isolated and alone because her in-laws were self-funders. She was left to search for help online and feels left on her own to get on with it. She now realised the effects her mother-in-law illness has had on her father-in-law. He was not getting any support from family or from social services.</i>

Abigail Lived Experience of self-funded carers.

Positive experience	<i>"My Admiral Nurse realised I was struggling. By now I couldn't leave Desmond alone in the house. I contacted Home Instead and had a carer twice a week (self-funded) this enabled me to have some respite from caring and have some time to do some activities for myself. This gave me some resilience."</i>
Comment	<i>"Abigail said, "I had the help of wonderful carers both 'live in' and 'hourly' without whom I would have not been able to cope."</i>

Mary's Lived Experience – Self funding care

Mary has been caring for her husband Adam who has dementia for the last 11 years.
Adam had to retire early from work. Mary has been self-funding his care.

Negative experience	<i>Mary said, "It was hard work! I feel frustrated and had to do things myself. I attended a wedding and had to organise someone to take care of Adam. It cost me £1000 a week to care for Adam, just so I could attend a wedding." Mary asks, "What could I do?"</i>
----------------------------	--

Nicola Lived Experience – cost of private ‘live in care’ to get a break.

Roy had private physiotherapy every week virtually until his death. This level of input was not available through the NHS.

Things declined with Roy who became less and less cooperative, becoming aggressive and needing more and more help. Nicola needed a break.

Negative experience

“Nicola had a holiday, this cost £6000 for 6 days care as it was charged at the hourly rate, but I had no alternative. When Roy needed full time care from someone other than me and we agreed to having ‘live-in’ care. I was fortunate in that my father had this, so I knew how to go about it. ”

KEY MESSAGE 3.3

Right support for carers caring for PLWD and psychosis at home.

Diane’s Lived Experience

Diane was caring for her mom Jane at home. Jane was recently diagnosed with Alzheimer and psychosis and was becoming aggressive, confused and paranoid.

Negative experience

Diane said, “There was no one who could tell her how to manage her mom’s behaviour. Her mom was not sleeping well, and she was afraid to leave her alone at home. There was no one to turn to for help.” Diane told us that, “if she had the help to manage the psychosis and aggression, she would have liked to have cared for her at home for as long as possible”.

Comment

Diane “recognised Alzheimer Society are good at referring everywhere but there is no practical support. No one had the skills to do that.”

KEY MESSAGE 3.4

Helping carers with mental health problems to care for a PLWD.

John's Lived Experience John's mom has dementia and lives in a council house. John has his own mental health problems but stepped in to help his mom to move out of her council house.	
Negative experience	<i>"Mom went into residential care home for two weeks. I was on my own; I felt isolated, lonely, and stressed and had my own mental health problems. I was left to handle my mom's council house. I didn't know what to do or where to go. I had no support from any family members."</i>
Positive Experience	<i>"The Council showed compassion and had sent me a letter giving me extra time to move my mother's belongings."</i>
Comment	<i>John said, "there needs to be more support for carers with mental health problems who become carers for a parent living with dementia."</i>

KEY MESSAGE 3.5

Supporting carers who are feeling isolated and lonely.

Aliyah Lived Experience Aliyah cared for her husband Hassan, who has dementia. She doesn't have time for herself and is feeling isolated and lonely because she had lost contact with her friends over the years, or they died.	
Negative experience	<i>Aliyah said, "I have one day off a week; and have lost touch with friends, or they have died." Hassan can't be left alone; she monitors him and is not using caring services because he doesn't trust them.</i>
Comment	<i>Aliyah told us that carers need support. She said, "It's important to know how carers are coping and feeling and to find out what support they need. This can lead to feelings of isolation and loneliness".</i>

Theme 4: The Role of Social Worker

KEY MESSAGE 4.1

More help needed for carers when the PLWD refuses help, including support from Social Worker.

Ed's Lived Experience	
Ed told us, "A social workers would come out to see his mom, but his mom would refuse support".	
Negative experience	<i>"In hospital there was a lack of social workers. The social worker in hospital was not helpful. I was told by a social worker that mom was moved to a care home across the city."</i> Ed had travelled by bus to the care home only to find out that his mom was still in hospital. He said, <i>"I was never informed that mom was still in hospital."</i>
Comment	<i>Ed said, "there is plenty of advice and direction from organisations but no practical help when PLWD refuse help or don't want to go. More needs to be done."</i>
Positive Experience	<i>"Only when mom moved to a care home was, she then assigned a social worker, and she is doing better now."</i>

Tina's Lived Experience – Shortage of social workers	
Tina faced additional pressures as she was also caring for her dad who has dementia but was in denial. He had experienced multiple failures while he was admitted to hospital because there was shortage of social workers.	
Negative experience	<i>There was no social worker available to discuss discharge from hospital. While he was waiting Tina dad had a fall and broke his hip and had to have a hip replacement.</i> <i>"There are more challenges for a PLWD when they are not mobile."</i>

KEY MESSAGE 4.2

Make the assessment process less difficult for carers, with compassion and understanding, and ensure good communication and continuity of care.

Alice's Lived Experience with social worker (Assessment for Continuing Health care funding)	
Negative experience	<p><i>"A social worker, who had never seen Joe and who only joined the meeting by phone, did not agree with the family or others who knew him. I was covered in bruises but felt I would have needed to be in A & E before she took this aggression seriously (it is of course the illness not the person). The whole process was traumatic."</i></p> <p><i>" It was the only contact I had with a social worker, and it was not a good experience."</i></p>
Negative experience	<p><i>"Having to chase the social worker who doesn't get back to you or having to repeat again with the new social worker is frustrating. It takes time and energy and you hit a brick wall every time."</i></p> <p><i>"You try to get support only to find out support is not there anymore. Waiting 5 to 6 weeks before they get back to you because of their big caseloads, putting further strain on the health and social care system."</i></p>

SUMMARY OF LIVED EXPERIENCE

- Support and encourage PLWD to get a diagnosis and access services early, especially when they are in denial.
- GP and social workers play an important role for PLWD and their carers and they need to listen to carers and take them seriously.
- Both carers and PLWD who have mental health problems will need additional support to live well.
- Carers who are caring for more than one PLWD will need additional support from health and other professionals including health and social care systems such as respite and day care centres.
- PLWD achieve their preferred place of care. Getting good care at home to be able to stay in their own homes or a care home for as long as possible, but it comes at a financial cost.
- Carers are feeling the pressures to cope and don't have time to take care of their own health and wellbeing. Offer better support for carers to avoid carer breakdown.
- Help carers who self-fund care to be offered choices to support PLWD with a personalised care and support plan.
- Help carers to receive adequate breaks and funding that meets their individual needs.



"We need better communication, coordination and cooperation."

- carer

"The voluntary sector is life saving and memory clubs, it mattered!

They are vital and gave me a sense of friendships and support." - carer

"Most of the support was from memory clinic, old age psychiatrist and Admiral nurses which are NHS services"

- carer

3 KEY PRIORITIES

After a long discussion with carers, the carers focused on the top 3 priorities that are important to them that would make a real difference to their lives. A consensus was reached, and the group identified the top 3 key priorities, where change needs to happen. These are shown in table 3 below.

Table 3: Top 3 Priorities

Top 3 Priorities	
1	Better integration of services to speed up early diagnosis and improve continuity of care.
2	Primary care needs to be proactive in early diagnosis of dementia and continuing care. Someone in each practice should have this as a speciality, to drive change and become a "dementia friendly practice".
3	Help/support PLWD who are self-funding their care at home.

DISCUSSION

Dementia should be everyone's business and responsibility.

Carers told us:

- There needs to be a better understanding of the dementia journey right from the start and not just at the end which was good for some people.
- How important it is to have a named person who can support carers/PLWD to access the right help and support at the right time. The named person identified may be dependent upon the person situation and could be any member of the health or care team or possibly a dementia advisor. The role of a dementia advisor is to offer support, advice and information, and connect carers/PLWD to face-to-face services in your area such as 'Singing for the Brain'; activity groups and peer support for people with dementia; information and support groups for carers.
- Carers want to see further improvements to continuity of care and better communication between professionals (GP, social worker, dementia advisor etc). One way would be to encourage health professionals/named person to download the Alzheimer's Society 'My appointments booklet' which is a record of appointments with health and social care professionals. This would help PLWD to have contact details and have a record of professionals they have been in contact with. For more information see link:
<https://www.alzheimers.org.uk/get-support/publications-factsheets/my-appointments>

Priority 1: Better integration of services

- Carers shared that there is a real disconnect from the original assessment to prescribing medication early. Carers would like to see integrated services that are joined up smoothly from GP practice to memory clinic service to consultant psychiatrist who prescribe medication. This process needs to be quicker and more joined up.

Priority 2: Primary care needs to be much more active in dementia care.

- Someone within each practice should have dementia as a speciality. They would be the named person at the GP practice, this could include a dementia advisor that is attached to the GP practice or a health professional.
- Encourage GP practices to hold a training forum with all primary care staff to reflect on the position statement and to understand how staff are perceived by dementia carers, and how they can improve lived experience of PLWD and their carers in Birmingham.
- Encourage more GP practices to become "dementia friendly practice".

Priority 3: Self- Funding your own care

Carers raised concerns around self-funding care. Carers felt angry and frustrated when being left on their own to put the right package in place. They felt that too often there was no help or support from anyone. This needs to change so carers can talk to someone who can help them put a personalised care package in place and advice to help PLWD to stay independent at home for longer.

Carers clearly told us:

- As the PLWD condition progresses the carer becomes exhausted, tired, and overwhelmed in caring for their loved one.

“The lack of family support and being isolated to care for PLWD can be very challenging to provide their care needs, particularly when the dementia is starting to be progressive. I found the experience very draining both physically and emotionally. I think it is important that people have emotional support particularly if they are carers who are on their own to provide the care their relatives need.”(carer)

- How a professional can support carers by giving them information about what is available and then helping them to access it. For example, doing the “handholding” by recommending options and have their consent to refer to a service based on the needs of the carer.

“They want to talk to someone who will not just make them feel better but also provide the help they need! To be listened to and not just be signposted to a service but to be helped to access that service.” (carer)

REFLECTIONS

Carers have clearly told us what they want and what would make the most difference to PLWD and their carers now and in the future.

Carers joined the Dementia Citizen Group because they all wanted to make a difference to improve dementia care and the experience of PLWD.

Here are some reflections from the group.

"I got a lot out of it and the city council have certainly been trying to help carers in Birmingham. It was good to build relationship with other carers and learn about the commissioning side of it too. It was a valuable experience for me to gain further knowledge around support for carers. It is a positive step forward." (carer)

"From a carer's perspective, there needs further acknowledgment that many carers dedicate their lives in looking after loved ones. The huge struggles we all face with people living with dementia is needed to be at the forefront of delivering the best care in the city of Birmingham."

"It's a very impressive statement that covers a lot of very important issues. I think it will help carers already looking after family members and those who started experiencing a family member who is struggling with memory issues. I wish this was available when I knew my mother had dementia." (carer)

NEXT STEPS

Our top three priorities have been identified in this position statement. This position statement gives valuable insight from PLWD and their carers. The themes identified in the position statement will feed into the Birmingham Solihull Joint Dementia Strategy refresh (2025-2028) for further development. We will continue to supplement this position statement with other lived experience from PLWD and their carer voices.

Recent reports have also highlighted similar themes. For example in report by Dementia Carers Count said, "there must be better coordination between health and social care services as well as with charities, voluntary groups, and others, so that family dementia carers are promptly identified and directed to appropriate support following a dementia diagnosis."¹¹ The report also shares that, "carers should be given a named point of contact who they can approach for support and information" and also stated that "carers who pay for care tell us they feel discouraged from approaching health and social care professionals even for guidance." When carers were given generic information, this left them feeling confused and isolated. They had no advice or support but just a diagnosis.¹²

views and experience of over 2,000 people affected by dementia to understand what support they need after diagnosis. This report recommends "everyone diagnosed with dementia has access to a dementia support worker or similar service, which should be commissioned as part of a 'stepped' model of care."¹³ If PLWD don't get the right care at the right time this has a negative impact on their quality of life and has a big impact on health and care system.

Age UK also reported that carers want good care at home.¹⁴

We want decision makers to understand the challenges PLWD and their carers face and how they can have meaningful conversation with the Birmingham Dementia Steering Group to improve dementia services in Birmingham. This position statement will also be published on the Birmingham City Council Dementia website.

GOVERNANCE AND REPORTING

The Dementia Citizen Group is part of the dementia strategy and action plan for Birmingham to improve outcomes for people living with dementia and their families/carers. The findings from this group will feed into a Birmingham Dementia Steering Group. This steering group monitors progress made on the dementia action plan.

The governance of the dementia program consists of:

- Birmingham Dementia Steering Group meets monthly to drive progress towards actions led by BCC in the Dementia Strategy. Progress on the strategy is reported as part of the Council Plan.
- Birmingham and Solihull (BSOL) Dementia strategy Task & Finish Group meet monthly with colleagues attending from Birmingham and Solihull (BSOL) Integrated Care Board (ICB), Solihull MBC and BCC to coordinate and share developments on the action plan and share learning and practice across the system.
- BSOL Dementia Interface Steering Group meets monthly and is a wider partnership group including the third sector to provide strategic direction/forum and oversight of the dementia strategy and action plan. Cares are also represented in this group.

APPENDICES 1 TO 5

Appendix 1: Lived experience of PLWD and their carers' in Birmingham

Date	Event	Method
29/ Feb/2024 03/May/2024 06/Jun/2024 11/Jul/2024	<i>Birmingham Dementia Citizen Group meeting</i>	<i>Online Microsoft Teams meeting</i>

Appendix 2: Examples of relevant local strategies

Local Strategies	Links
Joint Birmingham and Solihull Dementia Strategy 2023-2028	<i>Joint Dementia Strategy Birmingham City Council</i>

Appendix 3: Definitions

Dementia is a **progressive, irreversible clinical syndrome** with a range of cognitive and behavioral symptoms including memory loss, problems with reasoning and communication, change in personality, and reduction in the person's ability to carry out daily activities.¹⁵

Carer – A carer is anyone, including children and adults who looks after a family member, partner or friend who needs help because of their illness, frailty, disability, a mental health problem or an addiction and cannot cope without their support.¹⁶

Appendix 4: Examples of Services in Birmingham for PLWD

Admiral Nurses

You can find dementia support from specialist dementia nurses called Admiral Nurses who can support you as a carer. Phone the Admiral Nurses dementia helpline: **0800 888 6678** [Find out more about Admiral Nurses and how to book an appointment.](#)

Alzheimer's Society

Alzheimer's Society dementia advisers provide one-to-one support for anyone living with dementia or worried about their memory. [Find out more about support available from Alzheimer's Society.](#)

BCC Dementia website

The website offers citizens access to information and advice on how to reduce your risk of dementia, signpost you to get the right care, support, and information throughout a person dementia journey. Raise awareness of dementia and how to plan for your future and the importance of personalized care and support planning.

[Dementia | Birmingham City Council](#)

Birmingham Carers Hub

Birmingham Carers Hub offers a wide range of support and services for unpaid carers including, information and advice, statutory carer's assessments, and much more.

[Find out more about Birmingham Carers Hub](#)

Carers Emergency Response Service (CERS)

The service operates 24 hours a day, 7 days a week and can provide support for up to 48 hours (72 hours on Bank Holidays), after which, longer term care can be arranged if necessary. Birmingham Carers Hub runs the Carers Emergency Response Service known as 'CERS'. Find out more here:

[Carers Emergency Response Service \(CERS\)](#)

Birmingham Community Healthcare (BCHC)

One of the largest community-based NHS Foundation Trusts in the country, BCHC provides access to the support you may need as a carer.

[Find out more about BCHC and the support they offer](#)

Forward Carers

Forward Carers offer peer support groups, which give you the chance to offload and talk about what is going on and learn from the lived experience of others.

[Find out more about how forward carers can support you](#)

Dementia Carers Count (DCC)

DCC works with Birmingham Carers Hub to provide advice just to carers, so you can share your experiences confidentially. If you are a carer registered with Birmingham Carers Hub you can talk to other carers and access five, free online sessions. You will also be able to book face-to-face sessions.

To book a session, **phone: 0333 006 9711.**

[Find out more about Dementia Carers Count.](#)

Memory Assessment Service (MAS) Birmingham and Solihull Mental Health NHS Foundation Trust (bsmhft.nhs.uk)

The MAS is open to adults (25+ from Birmingham and 18+ from Solihull) that have been experiencing memory problems or other “thinking” difficulties for at least 6 months. The primary focus of the Memory Assessment Service is to assess people who are experiencing memory or cognitive difficulties in the context of a suspected dementia.

The service promotes the early identification of dementia as we know that getting an early or timely diagnosis can help people to live well with the condition. For more information: [Memory Assessment Service \(MAS\) - Birmingham and Solihull Mental Health NHS Foundation Trust \(\[bsmhft.nhs.uk\]\(http://bsmhft.nhs.uk\)\)](#)

Neighbourhood Network Schemes

The purpose of Neighbourhood Network Schemes is for people to access community-based support which can promote well-being and a better quality of life. NNS aims to do this through better co-ordination of community-based prevention & early intervention services. Social Work teams have meetings and drop-in surgeries in local libraries and cafes.

Find out more on [how Neighbourhood Networks Works | Prevention and Communities | Birmingham Connect to Support](#)

Birmingham Connect to Support Directory

The Community Directory lists groups, organisations and activities that will support you to lead a happy, healthy life in your own home and community. They can be accessed for free or at low cost. The Directory is managed by your local Neighbourhood Networks Scheme on behalf of Adult Social Care.

Birmingham Connect to Support is the council’s main source of advice and information about care and support for adults in Birmingham:

[Visit Birmingham Connect to Support](#)

Appendix 5 - Additional Resources for self-funding care

- Age UK Factsheet on [How to get care and support \(\[ageuk.org.uk\]\(http://ageuk.org.uk\)\)](#)
- A simple guide created to help you navigate life with dementia. [Download guide](#)
- **Care and Support Services Directory** gives the contact details of care homes in BSOL. Tips about what to look for when choosing a home.

The Care Quality Commission (CQC) inspect every care home and assesses the quality of care it provides. You can see reports for Birmingham care homes on the CQC website www.cqc.org.uk

REFERENCE LIST

¹ Alzheimer's Society (2022). What Is dementia? | Alzheimer's Society. [online] www.alzheimers.org.uk. Available at: What is dementia? | Alzheimer's Society (alzheimers.org.uk) [Accessed 17 May 2024].

² Alzheimer's Society (2022). What is dementia? | Alzheimer's Society. [online] Available at: <https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia#2>. [Accessed 17 May 2024].

³ Alzheimer's Society (2023). Alzheimer's disease. [online] Alzheimer's Society. Available at: <https://www.alzheimers.org.uk/about-dementia/types-dementia/alzheimers-disease>. [Accessed 17 May 2024].

⁴ Alzheimer's Society. (2022). Symptoms of vascular dementia. [online] Available at: <https://www.alzheimers.org.uk/about-dementia/types-dementia/symptoms-vascular-dementia#content-start>. [Accessed 17 May 2024].

⁵ Alzheimer's Society. (2021). Symptoms of dementia with Lewy bodies. [online] Available at: [Symptoms of dementia with Lewy bodies \(DLB\) | Alzheimer's Society \(alzheimers.org.uk\)](http://www.alzheimers.org.uk/about-dementia/types-dementia/symptoms-dementia-with-lewy-bodies). [Accessed 17/05/2024]

⁶ Alzheimer's society (2019). Frontotemporal dementia: What Is it? [online] Alzheimer's Society. Available at: <https://www.alzheimers.org.uk/about-dementia/types-dementia/frontotemporal-dementia>. [Accessed 17/05/2024]

⁷ Birmingham City Council. (2024). About dementia. [online] Available at: [About dementia | Birmingham City Council](http://www.birmingham.gov.uk/about-dementia) [Accessed 17 May 2024].

⁸ Alzheimer's Society (2024) Our vision is a world where dementia no longer devastates lives Alzheimer's Society (alzheimers.org.uk) Accessed 17/05/2024

⁹ NHS Birmingham and Solihull (2023) Our Dementia Strategy :: NHS Birmingham and Solihull. [online] Available at: [BSICS_Dementia_Strategy_2023-2028_FINAL_MAR23.pdf \(icb.nhs.uk\)](https://www.nhs.uk/our-dementia-strategy) [Accessed 17 May 2024].

¹⁰ **NHS Birmingham and Solihull (2023)** Our Dementia Strategy :: NHS Birmingham and Solihull. [online] Available at: [BSICS_Dementia_Strategy_2023-2028_FINAL_MAR23.pdf \(icb.nhs.uk\)](https://www.nhs.uk/our-dementia-strategy) [Accessed 17 May 2024]. [Accessed 17 May 2024].

¹¹ Dementia Carers Count (2024) Our Manifesto for Dementia Carers. [online] Dementia Carers Count. Available at: [https://Dementia-Carers-Count \(DCC\) Manifesto 2024 GE \(dementiacarers.org.uk\)](https://www.dementiacarers.org.uk/manifesto) June 2024. Online [accessed 06/08/2024]

¹² Dementia Carers Count (2024) Our Manifesto for Dementia Carers. [online] Dementia Carers Count. Available at: [https://Dementia-Carers-Count Count \(DCC\) Manifesto 2024 GE \(dementiacarers.org.uk\)](https://www.dementiacarers.org.uk/manifesto) June 2024. Online [accessed 06/08/2024]

¹³ Alzheimer's Society (2022) Left to Cope Alone The unmet support needs after a dementia diagnosis. [online] Alzheimer's Society. Available at: [https://left-to-cope-alone-after-dementia-diagnosis-report-summary.pdf \(alzheimers.org.uk\)](https://www.alzheimers.org.uk/left-to-cope-alone-after-dementia-diagnosis-report-summary.pdf) [accessed 06/08/2024].

¹⁴ Age UK (2023) Why Can't I get Care. [online] Age UK. Available at: [https://why-cant-i-get-care-report.pdf \(ageuk.org.uk\)](https://www.ageuk.org.uk/why-cant-i-get-care-report.pdf) [accessed 06/08/2024]

¹⁵ National Institute for Health and Care Excellence (NICE) (2022). Dementia: What is it? [online] NICE. Available at: [Definition | Background information | Dementia | CKS | NICE](https://www.nice.org.uk/guidance/NG107) Accessed 17 May 2024].

¹⁶ NHS England (n.d.). NHS commissioning. Who is considered a carer? [online] Available at: <https://www.england.nhs.uk/commissioning/comm-carers/carers/#:~:text=A%20carer%20is%20anyone%2C%20including>. [Accessed 17 May 2024].



