

<p style="text-align: center;"><u>Meeting</u></p> <p style="text-align: center;">Health & Wellbeing Board</p>
<p style="text-align: center;"><u>Date and time</u></p> <p style="text-align: center;">Thursday 16th March, 2023</p> <p style="text-align: center;">At 9.30 am</p>
<p style="text-align: center;"><u>Venue</u></p> <p style="text-align: center;">Hendon Town Hall, The Burroughs, London NW4 4BQ</p>

Dear Councillors,

Please find enclosed additional papers relating to the following items for the above mentioned meeting which were not available at the time of collation of the agenda.

Item No	Title of Report	Pages
10	Dementia Strategy	3 - 40
11	Carers and Young Carers Strategy	41 - 56

Emma Powley, Emma.Powley@Barnet.gov.uk
Emma.Powley@Barnet.gov.uk

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Barnet Borough Partnership

Dementia Strategy

2023 - 2028

YOUR LIFE,
YOUR CARE,
YOUR CHOICE.

Directorate	Communities, Adults and Health
Approvers	LBB Adults and Safeguarding Committee Barnet Borough Partnership
Approval date	March 2023
Review Date	March 2025

Contents

1. Introduction.....	3
Vision	3
2. Context	4
National context and local context	4
3. We listen	5
Engagement and Co-production	5
4. Preventing Well	7
Risk of people developing dementia is minimised	7
5. Diagnosing Well	8
Timely accurate diagnosis, care plan and a review within the 1 st year	8
6. Supporting Well	10
Access to safe high-quality health and social care for people with dementia and carers	10
7. Living Well	12
People with dementia can live normally in safe & accepting communities	12
8. Dying Well	14
People with dementia can live normally in safe & accepting communities	14
9. Equality Diversity and Inclusion	15
10. Delivering change.....	16
Priorities.....	17
Outcomes	17
11. Appendices.....	18

1. Introduction

This strategy is the first Barnet Borough Partnership strategy to underpin borough-wide commitments to providing high-quality care and support for people with dementia and their carers. It builds on the progress already made in the borough to improve the lives of people living with dementia, their families, and their carers, and provides a framework for continuous action to ensure that people continue to live well and thrive.

This strategy has been coproduced and developed in partnership with people living with dementia and their carers, Adult Social Care, North Central London Integrated Care Board (NCL ICB), Barnet Enfield and Haringey Mental Health Trust, commissioned and non-commissioned organisations and voluntary and Community Sector partners (VCS).

The NHS England 'Well Pathway for Dementia', transformation framework underpins our strategy. It outlines five key elements to consider, which form the five main chapters of this strategy:

1. Preventing Well
2. Diagnosing Well
3. Supporting Well
4. Living Well
5. Dying Well

The strategy should be read alongside 'The Well Pathway for Dementia – a Barnet Perspective' attached as an appendix, in which each of these five elements is explored in more detail, alongside relevant local data and information.

Vision

Dementia is a crucial challenge for both health and social care. In Barnet, it is estimated that over 4,387 people are living with dementia, and this figure is expected to increase to 6,402 by 2035.

This strategy recognises that more can be done to improve the experience of people living with dementia and will lead to the development of an action plan to build on the progress that has been made and address the gaps identified. This means not only focusing on strengthening our current dementia pathway and services but also embedding more proactive dementia support, preventing avoidable crises, and promoting and maximising people's independence, health, and well-being.

A key driver in our approach to supporting people to live well is through providing prevention and early support. To do this, we will develop plans which are more proactive and creative in approach and offer robust support for carers, alongside an increased awareness of dementia within communities. Similarly, by ensuring that people can access early and timely diagnosis, and from there that they receive effective care co-ordination, people will enjoy an improved quality of life with a dementia diagnosis.

This strategy will inform the planning, provision, and commissioning of dementia-related services in Barnet. The associated action plan will be delivered in partnership across health and social care, wider council partners, voluntary community and faith sectors, providers of care and residents.

2. Context

What is dementia

The word 'dementia' describes symptoms that may include memory loss and difficulties with thinking, problem-solving, or language and interfere with the individuals' ability to complete daily activities. They often start with minor challenges, but for a dementia diagnosis, these are severe enough to affect everyday life. There may also be changes in mood and behaviour.

The most common types of dementia are:-

- Alzheimer's disease (60%)
- Vascular dementia (20%)
- Lewy bodies dementia (15%)
- Frontotemporal dementia (5%)

National context and local context

National Context

944,000 people are living with dementia in the UK¹ and this number is projected to increase. Although, due to the progressive nature of the disease, the early-stage symptoms, and the low diagnosis rate, it is difficult to precisely know the number of people living with the condition. It is, however, thought that one in fourteen over 65's² have dementia in the UK which makes dementia a key challenge for both health and social care and a key priority nationally and locally.

This strategy supports the visions and outcomes within the National Dementia Strategy 2009, whilst we await the publication of a new national 10-year plan to tackle dementia as announced by the Health Secretary in May 2022. It also considers key legislation and guidance, including the Care Act 2014, the NHS Long Term Plan and National Institute for Health and Care Excellence (NICE) guidance³. These key strategic documents all highlight the importance of ensuring that people with dementia and their carers can *access timely diagnosis, high-quality care, and support* and that there is an *increased awareness in our communities of dementia*.

Local context

According to the Dementia Needs Assessment undertaken by Barnet's Public Health team:

- Currently, 4,387 people over 65 are estimated to be living with dementia in Barnet, and this is projected to increase to 7,282 by 2040.
- The diagnosed dementia rate indicates what proportion of the number of people estimated to be living with dementia, have a formal diagnosis. In Barnet, the estimated diagnosed dementia rate for people aged 65+ is 65.7% and this has been falling since 2017. This suggests improvements can

¹ Luengo-Fernandez, R. & Landeiro, F. in preparation

² Prince, M et al. (2014) Dementia UK

³ <https://www.nice.org.uk/>

be made in local pathways and processes to ensure we are maximising access to diagnostic assessment.

- According to the 2021 census data, there has been a 9.3% decrease over the past 10 years of residents identifying as White, although this group still represents over half of Barnet's population. The second largest cohort are residents identifying as Asian, representing 19.3% of Barnet's population. Ethnicity data for people with dementia known to adult social care does not fully reflect this diversity, which suggests equality of access is an area for further action:

People with dementia known to adult social care by ethnicity:

Ethnicity	19-20	20-21	21-22
White	75%	75%	74%
Asian/Asian British	10%	10%	12%
Black/Black British	6%	6%	5%
Other Ethnic Groups	5%	5%	5%
Not Stated	3%	3%	2%
Mixed/Multiple ethnic groups	1%	1%	1%
Chinese	1%	1%	1%

Adult Social Care Data BIP 2022

3. We listen

Engagement and Co-production

Between 1st of June and 30th of September 2022, the commissioning and engagement teams carried out extensive stakeholder engagement with people living with dementia, their carers, health, and social care professionals, commissioned and non-commissioned services, the Dementia Friendly Partnership and the voluntary community and faith sector to understand the experiences of people living with dementia in Barnet.

We held over nine workshops and engaged over 140 people living with dementia and their carers and have captured their feedback about changes to support, or services that they feel are needed and included them directly in this strategy.

We recognise that some of this feedback may relate to pathways that already exist, changes that have been made, or changes that are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other feedback reflects gaps in our local system that we will aim to address. This will all be considered in the development of the action plan to implement this strategy.

A selection of comments from residents:

Our social worker was amazing in helping us navigate support & respite.

It was hard not being involved or asked for input by GP or MAS; I felt left out as my husband's main carer.

We want the information to be available at GP practices, pharmacies, and local groups, so it is easily accessible.

My dad is always happy when he goes to the Ann Owen Centre. Even though he doesn't remember going or what he did, he comes back chattier and really happy.

It was hard to get an appointment at the GP during the pandemic, and it's still hard.

There aren't enough culturally appropriate services. We felt a bit lost.

Age UK have really helped us cope with my mum's dementia. I don't know where we would be without them.

The training course for carers provided by the dementia specialist team was a lifeline.

My husband really enjoyed the Cognitive Stimulation Therapy sessions at the memory clinic.

I didn't know where to find information or support when my husband got a diagnosis, I felt lost.

Dr X was so thorough and kind when giving mum her diagnosis – she helped us very much. It was hard to process

If it weren't for Dementia Club UK, I would have been lost.

4. Preventing Well

Risk of people developing dementia is minimised

Why is this important?

Improved information and advice will ensure that people can make informed decisions about their health and care needs. Barnet is committed to a preventative approach that prevents, reduces, and delays the need for care.

Preventing well in Barnet

Our priority across health and social care is to ensure that we have a robust preventative approach to supporting residents, that promotes and maximises independence and well-being. Enabling everyone to live happy and healthy lives. The council's Prevention and Wellbeing team lead on this approach and local voluntary and community sector (VCS) providers, such as Age UK Barnet, deliver sessions on preventing well.



What people living with dementia and their carers feel is needed:

- Information given in advance so that people can understand how to prevent dementia.
- More support to help minoritised groups access preventative services.
- Easy access to services locally around and within communities.
- Information available at GP and local pharmacy to help people live well and access professional services quickly.
- Access to fitness programmes that appeal to those over 55's.
- More social inclusion programmes to help with isolation and loneliness.
- Varied programmes on weight management, cooking programmes, and mental health services that are culturally appropriate.

5. Diagnosing Well

Timely accurate diagnosis, care plan and a review within the 1st year

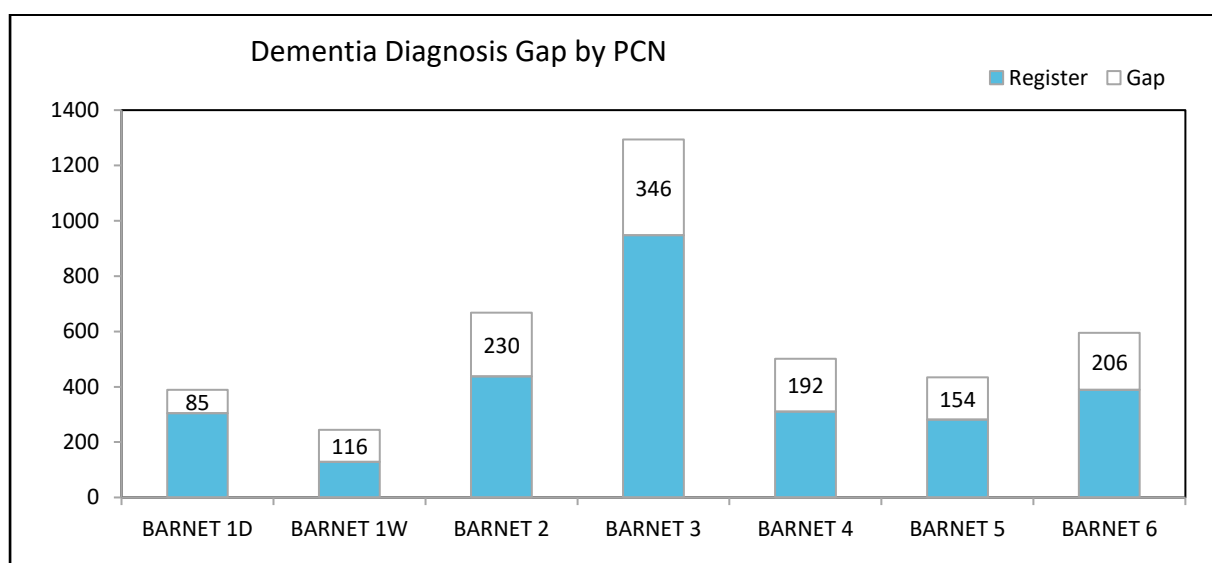
Why is this important?

Early diagnosis of dementia is a national and local priority. A timely diagnosis enables people with dementia, their carers, and healthcare staff to plan accordingly and work together to improve health and care outcomes in the longer term. When people receive a timely diagnosis, they are more likely to be involved in their care and the decisions made regarding their future. It also means they can access clinical and social interventions that enhance their care and improve their quality of life.

We want to ensure that the message of early identification and diagnosis is understood by our residents so that we can provide early support and help for those who do ultimately receive a dementia diagnosis.

Diagnosing well in Barnet

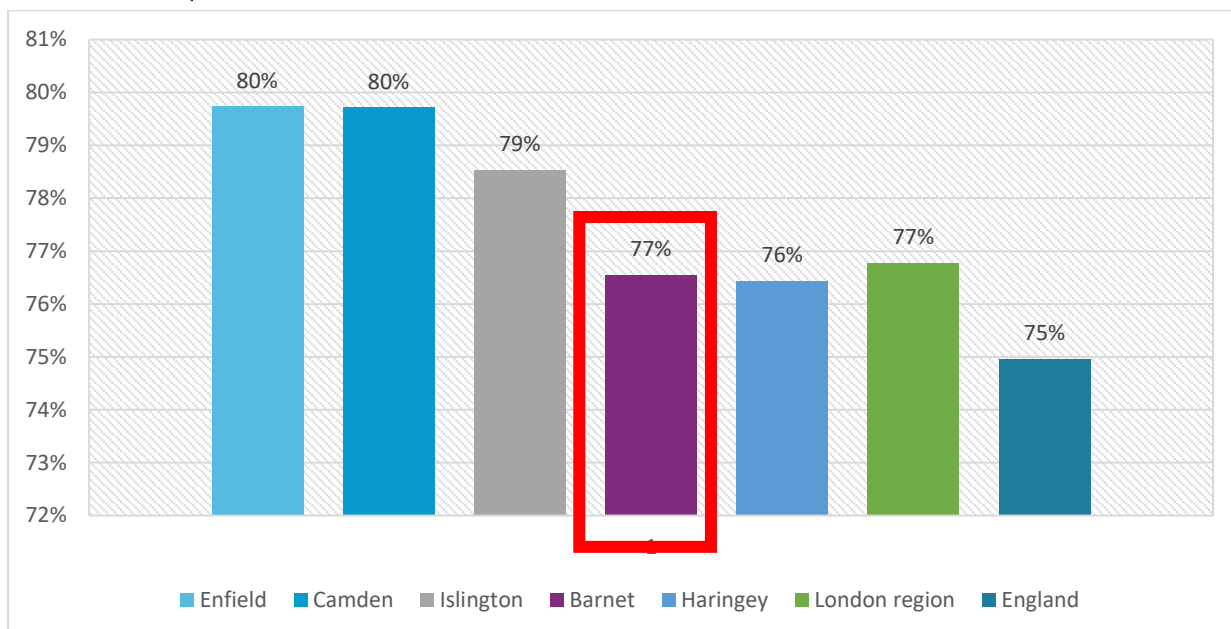
- Barnet's Memory Assessment Service is commissioned by NCL ICB and provided by Barnet Enfield and Haringey Mental Health Trust. On receipt of a GP referral, the service offers a multi-disciplinary diagnostic assessment (within a target of 12 weeks), integrated access to community support services, 12 weeks of cognitive stimulation therapy, medication stabilisation and carer support.
- GPs can also diagnose patients where they feel equipped to do so without a referral to the Memory Assessment Service
- Referrals to the Memory Assessment Service have been increasing since early 2022, following a decrease in referrals during the peak of the Covid 19 pandemic, attributed to the challenges of services working remotely. Overall Barnet's dementia diagnosis rate has dropped since 2017, which suggests improvements can be made in local pathways and processes to ensure we are maximising access to diagnostic assessment. This fall in diagnosis rate has created a 'diagnosis gap' that we can evidence at Primary Care Network (PCN) level:



Source: NHS Digital, 2020/21

- Following diagnosis, GPs are required to undertake an annual review to assess the healthcare needs of both the dementia patient and their carer(s).
The graph below shows the percentage of patients diagnosed with dementia whose care plan was reviewed in the preceding 12 months, compared with other North Central London Boroughs, London as a whole and England. Whilst Barnet is achieving a comparable percentage, there is room for improvement:

Dementia care plan has been reviewed in the last 12 months



Source: Dementia Profile - OHID (phe.org.uk)

What people living with dementia and their carers feel is needed:

- A clear dementia pathway, so people know what steps to expect especially once a referral to specialist services has been made.
- Access to GP with longer appointment times for people living with dementia.
- Regular health checks for carers as well, including regular yearly reviews
- Local information and advice appropriate at all stages of dementia.
- A better-coordinated memory assessment service that engages with the carers of the person living with dementia - some carers felt left out of the diagnosis and discharge process, which meant they could not offer the support necessary to the person during diagnosis when they needed it most.
- Early intervention and treatment, with referrals to the memory assessment service seen and a confirmed diagnosis within twelve weeks.

6. Supporting Well

Access to safe high-quality health and social care for people with dementia and carers

Why is this important?

The best place for people living with dementia is often at their home, supported and surrounded by family, friends, and the community they have been part of. We want to ensure that their choice to do so is possible even as the disease progresses.

For many people living with dementia, it is not the only health challenge they are facing, therefore, a joined-up pathway of support is necessary to ensure that they are not only able to manage their dementia diagnosis but also other long-term conditions. This requires joined-up care and support available via primary care, secondary care, and community-based services to ensure that essential needs are met and that individuals do not need to tell their story repeatedly.

We are committed to putting the person with dementia, their families, and carers at the centre of their care; accessing timely information and support as the disease progresses is essential.

Significant funding is invested across the system in supporting people living with dementia and we want to ensure that this money is being spent effectively to achieve the best possible quality of life for individuals and their families. The total cost of care for people with dementia in the UK is £ 34.7 billion⁴.

1. This is set to rise sharply over the next two decades to £ 94.1 billion in 2040.
2. The most significant proportion of this cost, 45%, is social care, which totals £ 15.7 billion.
3. In Barnet this equated to spend of £22.8 million by adult social care in 21/22 on dementia support, with the largest proportion being spent on residential care services (£12 million), followed by nursing care services (£7 million)

Supporting well in Barnet

Adult Social Care, Health services, the Memory Assessment Service, GPs, Age UK Barnet (the primary VCS provider in the delivery of dementia support services), and other VCS partners work together to deliver a joined-up offer of support and advice to those living with dementia and their carers. This includes:

- **Support in Primary Care**
 - o 'One Stop Dementia Support Clinics', a **workstream of the 'PriDem research project' by University College London⁵**, have been trialled at GP surgeries in PCN2 whereby people living with dementia and their carer(s) were proactively invited to have all their physical, social, mental well-being and information needs met in one appointment with a GP, enhanced by the addition of a Dementia focused multi-Disciplinary team. Feedback was positive, with 98% attendance and 94% extremely likely to recommend to friends and family. Given the positive outcomes achieved, it should be explored whether this approach is mirrored across Barnet in future.

⁴ [What are the costs of dementia care in the UK? | Alzheimer's Society \(alzheimers.org.uk\)](#)

⁵ [Dementia and Cognitive Impairment | Institute of Epidemiology & Health Care - UCL – University College London](#)

- o The Aging-Well Multi-Disciplinary Team is commissioned to work with patients in primary care across Barnet. For eligible patients, the team offers holistically assessment, coordination and personalisation of patient care to build resilience, reduce crisis and minimise the risk of hospital admission.
- **Wider Healthcare Services**
 - o Support after diagnosis with mental health or behaviour challenges is available from the Community Mental Health Teams. There is an identified gap in psychological support for people living with dementia.
 - o Admiral nurses are based at the memory assessment service and provide specialist support and guidance to the person living with dementia and their carer in managing a dementia diagnosis.
 - o Community and acute health services are expected to ensure their staff are appropriately trained to support people with a dementia diagnosis who are accessing their services and that reasonable adjustments are made so that services are accessible and inclusive.
 - o Short-stay emergency inpatient admissions are proven to be particularly distressing for people living with dementia who can struggle with changes to their environment. Reducing emergency admissions through holistic and well-coordinated care is a priority area.
- **Adult Social Care**
 - o Adult social care undertake statutory functions under the Care Act, including assessment of need, care and support planning and safeguarding. Adult social care promote well-being and independence by using a strengths-based approach to preventing, reducing, or delaying needs from developing or escalating.
 - o Barnet's adult social care team also includes a Specialist Dementia Support Service which aims to:
 - Support and maintain the health and wellbeing of people living with dementia
 - Supporting carers to continue in their caring role
 - Support people with dementia to remain living in the community
 - Improve the knowledge, confidence, and skills of carers to make a positive difference in their lives and to the lives of those for whom they care
 - Maximise the use of preventative community support services for carers.
- **Commissioned Services**

Where the need for a formal service is identified, adult social care can explore a range of commissioned services:

 - o Care at home - Barnet has an 'approved provider list' of high quality domiciliary agencies and it is a priority to ensure that all relevant staff have dementia training
 - o Care technology, such as a GPS watch
 - o Equipment to support independence in the home
 - o Intermediate care services to support hospital discharge
 - o A range of suitable housing options:
 - Extra care – the Council is part-way through an investment programme in extra care, to deliver an additional 178 units by 2024

- Residential care and nursing care - it is estimated that 70% of people with dementia may eventually require long-term residential care. Barnet has a significant number of care homes, but overall bed capacity is falling. There is an under-provision of care homes that can provide complex care for conditions such as dementia, particularly where people have complex behavioural needs. A dedicated Care Home Support Team has been piloted in early 2023 to increase the mental health support available to homes as part of plans to expand complex care provision. At time of writing, initial outcomes are positive and further review is needed to inform future commissioning intentions.

What people living with dementia and their carers feel is needed:

- Information and advice to be timely and accurate at the point of need so that people can continue living in the community and maintain their well-being.
- Services to be better coordinated to meet the needs of those living with dementia and their carers.
- Improved quality of care for people with dementia, where they are treated with dignity and respect when admitted to the hospital.
- Access to safe, high-quality health and social care services for people living with dementia.
- More funding for community organisations to keep offering support
- Care agencies should have dementia-trained staff so that carers can feel safe leaving their family members.

7. Living Well

People with dementia can live normally in safe & accepting communities

Why is this important?

As the numbers of people living with dementia increases, we have a responsibility as a society to ensure that our communities are accepting and supportive; ensuring people feel included and valued. People living with dementia should receive coordinated care and have access to appropriate leisure activities which facilitate social inclusion.

In 2020/21⁶ it was estimated that around 6% of the UK population, around 4.2 million people, are providing informal care, and around 60% of carers are women. Barnet carers strategy 2023-2028 (*appendix*) sets out the borough's vision for carers to enable them to live their lives with the support, confidence, knowledge, and training that they need. We recognise the role, and value carers bring into improving the

⁶ <https://www.gov.uk/government/collections/family-resources-survey--2>

lives of people living with dementia in Barnet and their role in maintaining the health and well-being of the person they care for.

Living well in Barnet

- **Dementia-Friendly Barnet**
 - Barnet is committed to creating a sustainable dementia-friendly community and was recognised as a community that is ‘working to become dementia friendly’ by the Alzheimer’s Society in October 2022
 - Barnet’s Dementia Friendly Barnet Partnership is formed of over 40 local organisations and holds a comprehensive action plan to increase the number of dementia-friendly venues in the borough
 - The partnership is also expanding the local training offer to increase the number of Dementia Friends in Barnet (currently over 12,000) who have a key role in raising awareness and creating a safe community for people living with dementia.
- **Social prescribers** are based in primary care and provide information and support to patients with social and economic issues that affect their health and well-being.
- **Dementia advisers**, currently commissioned from Age UK Barnet, provide information and advice to help people diagnosed with dementia find the right support for them.
- Barnet also has a commissioned **day opportunities** service for people with mild to moderate dementia, currently delivered by Age UK Barnet, as well as other leisure and social inclusion opportunities available through the Council’s leisure provider, VCS providers and other partners. It is recognised that more could be done to ensure there is a varied leisure and social inclusion offer for people living with dementia who have more complex are and support needs.

Support for Informal Carers

Support for carers of people living with dementia is an increasingly important part of the offer. Ensuring that carers are supported and valued in their role enables them to continue providing support, preventing hospital admissions, and prolonging the time that people can remain living independently in their own homes.

The current commissioned provider for carers, Barnet Carers Centre, provides support for carers of those living with dementia. More information about the support available to carers is outlined in the Barnet Carers and Young Carers Strategy 2023-2028.

What people living with dementia and their carers feel is needed:

- More access to dementia advisors
- Better access to information and advice in the community locally to them when they need it.
- More day opportunities spread out in the community.
- Better co-ordination of services, so people do not have to keep telling their stories repeatedly.
- More respite opportunities and funding so carers can have regular breaks and the person living with dementia can be safe and looked after, including within their own home.
- Respite vouchers that meet the cost of care in residential homes that are known to families.

8. Dying Well

People with dementia can live normally in safe & accepting communities

Why is this important?

People living with dementia want to die with dignity in the place of their choosing; this can only be done if our services can identify and meet those needs. People with dementia want to be confident that their end-of-life wishes will be respected.

A survey conducted by Sue Ryder⁷ discovered that the top priorities for people at the end of their lives were:

- Being in a familiar surrounding
- Having dignity and privacy
- Surrounded by loved ones and
- Being pain-free

It is essential to have conversations with people living with dementia and their carers early on so that they can plan for their future whilst they are still able to and can have their wishes considered instead of when things are in a crisis.

Dying well in Barnet

We must ensure that people living with dementia and their carers receive the right support to plan for the end of their life and to choose where they die, whether at home, in a hospital setting, in a hospice or in a care home.

In Barnet, GPs are given the training to enable them to have difficult conversations about dying. Our later life planning service, currently run by Age UK Barnet, also provides information and advice around decision making, from legal matters and ensuring that Power of Attorney arrangements are in place, to knowing that each choice matters.

What people living with dementia and their carers feel is needed:

- Information available about pain management and palliative care, particularly the support available from primary care
- For people with dementia to be in a caring environment when they die, instead of being in a hospital setting – this was heightened during the pandemic.
- Access to bereavement counselling and support as the person nears the end of their life and after they have passed
- Good quality end of life dementia care in residential and nursing homes.

⁷ Sue Ryder, A time and place: what people want at the end-of-life 2013

9. Equality Diversity and Inclusion

This section will explore the demographic considerations that we should make to ensure that our dementia offer is equitable and accessible to all residents of Barnet and meets the needs of the local population.

By age, in Barnet, the highest proportion of the population from white ethnic backgrounds is found in the older age groups. The highest proportion of people from ethnic minority backgrounds is found in the younger age groups. Barnet's population is projected to become increasingly diverse as the white British population is projected to decrease in proportion to the total population (from 61.3% in 2015 to 58.4% in 2021 and 56.4% in 2030)⁸.

People from ethnic minority backgrounds and dementia

High levels of stigma and lower levels of awareness of dementia are prevalent in some communities. In Barnet, people from ethnic minority backgrounds are under-represented in dementia services and tend to present in services later. There needs to be more activity on how we continue to reach people around prevention and early detection so that support is available earlier and that services are designed to be culturally sensitive and suitable.

We have an opportunity to ensure that our service provision meets the needs of our ethnic minority communities and that the services are culturally sensitive and appropriate.

Learning disabilities and dementia

In 2020, there were predicted to be 7,231 adults aged 18+ living with a learning disability in Barnet. At present, the most significant proportion of people aged under 65 living with learning disabilities falls into the 25-34 years old age group (26.4%). People with learning disabilities are also likely to be diagnosed with dementia.

As the population increases, the number of adults (aged 18+) with learning disabilities in Barnet is predicted to increase to 8,869 by 2035.

Barnet Learning Disabilities Service (BLDS) supports the care pathway for people with learning disabilities and dementia. BLDS consists of psychiatrists, psychologists, physiotherapists, social workers, speech and language therapists, occupational therapists, and nurses. BLDS uses a multi-disciplinary approach to diagnosing and treating the condition as well as providing information and support to carers as well as the person. Additionally, BLDS signposts people to other services available in the borough. While there are some services available for this cohort, with a recent addition of a dementia nurse into the team it is recognised that there are gaps in services, and much work needs to be done to develop appropriate services which meet the needs of individuals with learning disabilities and dementia.

Early onset dementia

The number of people with early onset (under 65 years old) dementia is projected to increase. Between 2020 and 2040, the number of younger people living with early-onset dementia will rise from 55 to 71 for males and 40 to 46 for females. With more men living with young onset dementia than women.

Getting a diagnosis for a younger person can take longer. Currently, the National Hospital for Neurology and Neurosurgery (University College London Hospital NHS Trust) runs the Cognitive Disorders Clinic with

⁸ Joint Strategic Needs Assessment 2015 to 2020

a multi-disciplinary team that assesses patients. It provides expertise in young onset dementia and has a national referral base.

There is a general lack of age-appropriate services concerning the needs of younger people with dementia. Dementia support services are available for older people, and these activities are generally unsuitable for younger adults. Although the current numbers of people living with young onset dementia are not immense, we need to develop services to ensure that our local offer has more support for people with young onset dementia in the next 15-20 years in line with the diagnosis rate.

10. Delivering change

The implementation of this strategy will be planned in consideration of good practice principles, to ensure the associated action plan is accessible, co-produced, timely and tailored to deliver meaningful outcomes to people living with dementia and their carers.

To deliver the action plan we will work across health and social care, with wider council departments, education, housing, and the voluntary and community sector. We will also develop relationships across the wider community, including employment and business sectors as part of this approach, and will continue to put people living with dementia and their carers at the heart of this process.

We have captured feedback from residents about changes to support or services that they feel are needed and included them directly in this strategy. We recognise that some of this feedback may relate to pathways that already exist, changes that have been made, or changes that are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other feedback reflects gaps in our local system that we will aim to address. This will all be considered in the development of the action plan to implement this strategy.

An important strand of our action plan will be addressing challenges relating to under-representation or disproportionality, following further interrogation of demographic data - notably census data that has recently become available.

The action plan will focus on priorities for the next two years and will be overseen by the Joint Commissioning Team. Progress will be reported to the Barnet Borough Partnership Board and other boards/committees as requested. After two years, a review will be undertaken to agree next steps.

Priorities

We have coproduced the following 3 priorities to guide our action planning:

1. Improved information and advice (Before diagnosis, at diagnosis, and after diagnosis) to ensure that people can make informed decisions about their health and care needs.
2. Improved awareness and identification; early and timely diagnosis.
3. Individualised and tailored support that promotes independence and well-being (At diagnosis and after diagnosis)

Outcomes

The outcomes we will achieve through this strategy include:

1. Barnet residents understand what actions they can take to reduce their risk of getting dementia
2. The dementia diagnosis gap is reduced and ultimately eliminated, with equal and timely access to diagnosis
3. People living with dementia and their carers have timely access to high quality information and advice in order to make informed decisions about their health and care needs
4. People living with dementia and their carers have a coordinated, high-quality experience of health and care services, where they are treated with dignity and respect by professionals who have the appropriate skills and experience to understand and respond to their needs
5. People living with dementia and their carers feel empowered, listened to and in control of their own care and support
6. Everybody living with dementia receives a holistic annual review within primary care
7. People living with dementia and their carers feel included as part of society
8. People living with dementia feel confident that their end of life wishes will be respected

11. Appendices

- The Well Pathway for Dementia – a Barnet Perspective
- Dementia Friendly Barnet Partnership: [Dementia | Barnet Council](https://www.barnet.gov.uk/adult-social-care/specialist-support/dementia)
<https://www.barnet.gov.uk/adult-social-care/specialist-support/dementia>

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The Well Pathway for Dementia – a Barnet Perspective






YOUR LIFE,
YOUR CARE,
YOUR CHOICE.

The Well Pathway for Dementia – NHS England Transformation Framework

The Well Pathway for Dementia is NHS England's framework to support the transformation of dementia care and support. It covers five key areas:

1. Preventing Well
2. Diagnosing Well
3. Supporting Well
4. Living Well
5. Dying well

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p>	 <p>Access to safe high quality health & social care for people with dementia and carers</p>	 <p>People with dementia can live normally in safe and accepting communities</p>	 <p>People living with dementia die with dignity in the place of their choosing</p>
"I was given information about reducing my personal risk of getting dementia"	"I was diagnosed in a timely way"	"I am treated with dignity & respect"	"I know that those around me and looking after me are supported"	"I am confident my end of life wishes will be respected"
"I feel included as part of society"	"I am able to make decisions and know what to do to help myself and who else can help"	"I get treatment and support, which are best for my dementia and my life"	"I feel included as part of society"	"I can expect a good death"
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ , BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ , Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽³⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ , Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
<small>References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.</small>				

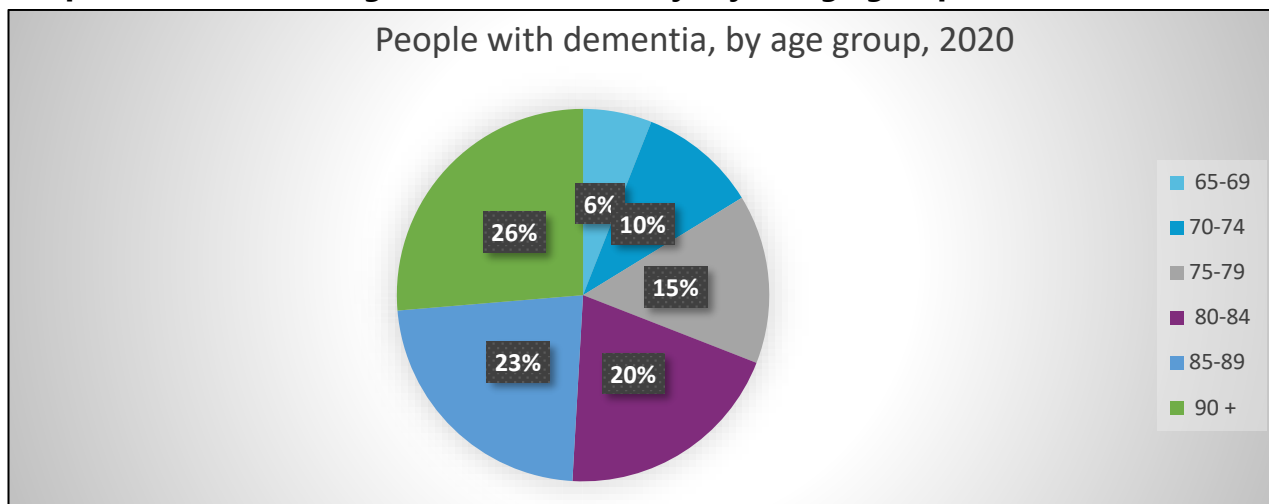
This report will go on to explore each area in more detail, providing relevant data and summarising some of the progress in Barnet.

1. Preventing Well

Risk of people developing dementia is minimised

According to Alzheimer's society, whilst not all older people have dementia, the most significant risk factor for dementia is ageing. This is supported by the Barnet data presented below, where older age groups account for larger proportions of the dementia population:

People with dementia aged 65+ in Barnet, by 5-year age group, 2020



Source: Barnet Public Health Dementia Needs Assessment 2022/23

The risk of getting dementia can also be increased by:-

- Gender and Sex
- Lifestyle
- Other health conditions
- Air pollution
- Ethnicity

About a third of Alzheimer's diseases are estimated to be attributable to potentially modifiable risk factors¹. The Lancet Commissions on Dementia Prevention, Intervention and Care identified that 35% of dementia was attributable to a combination of the following risk factors²:

- Midlife hearing loss can increase stress on the brain and social isolation. It is estimated that hearing loss can be responsible for 9.1% of the risk of dementia onset.
- Cardiovascular risk factors for dementia include hypertension, diabetes, and obesity.
- Lifestyle and psychological risk factors include depression, smoking, lack of physical activity, and alcohol consumption.
- Preventative factors include educational and occupational attainment and social isolation.

¹ *Lancet Neurology* (2014)

² *The Lancet* (2017) 390

- Smoking doubles the risk of developing dementia. Smoking prevalence for adults in Barnet has decreased from 15.6% in 2012 to 11.1% in 2019, which is lower than London's 12.9% and England's 13.9%.
- Excess weight in adults is recognised as a significant determinant of premature mortality and avoidable ill health.
- Drinking more than the recommended limit for alcohol increases a person's risk of developing common types of dementia, such as Alzheimer's disease and vascular dementia. Reliable figures of the number of people with alcohol-related brain disorder (ARBD) in Barnet are unavailable, and the condition is likely to be underdiagnosed. This is partly because having problems with alcohol still carries a stigma within society, so people may not seek help. Awareness of ARBD, even among professionals, also varies widely.

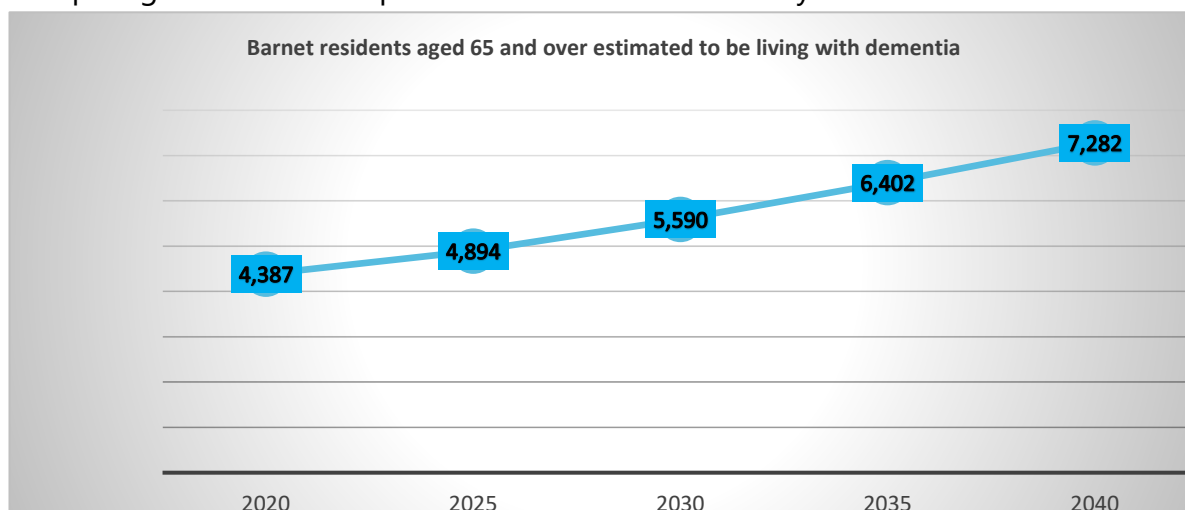
2. Diagnosing Well

Timely accurate diagnosis, care plan, and a review within the first year

Dementia Projections

Currently, 4,387 people aged over 65 are estimated to be living with dementia in Barnet, and this is projected to increase to 7,282 by 2040.

People aged 65 and over predicted to have dementia by 2040

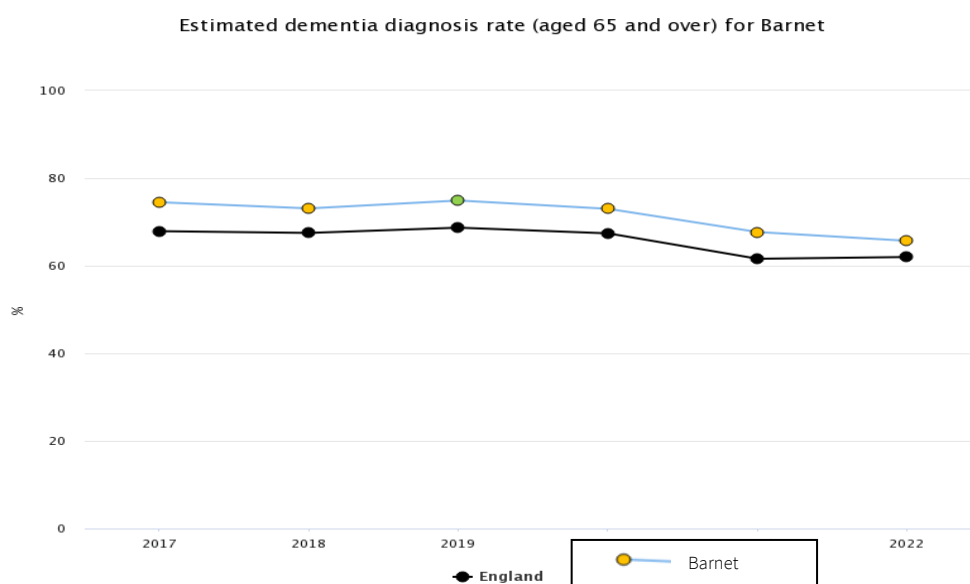


Source: POPPI (based on ONS data). Available at: <http://www.poppi.org.uk/>

Estimated Diagnosis Rate

In 2022, the estimated percentage of older people (aged 65+) living with dementia in Barnet who have a formal diagnosis is 65.7%. This is slightly lower than London's 66.8%, but higher than England's 62%. Islington has the best diagnosis rate (82.4%) in North Central London and London.

In Barnet, across London and England-wide, the estimated diagnosis rate has been falling since 2017:



Our recent needs analysis shows that in Barnet, dementia diagnosis rate has gone down from 74.5% in 2017 to 65.7% in 2022.

Getting a diagnosis

Barnet's Memory Assessment Service (MAS) is commissioned by NCL ICB and provided by Barnet Enfield and Haringey Mental Health Trust (BEHMHT). The service offers:

- Early holistic assessment for people with memory problems
- A multi-disciplinary service, that follows National Institute for Health and Care Excellence³ (NICE) guidelines and has now achieved Memory Service National Accreditation Programme (MSNAP) standards.
- Integrated community support for people living with dementia and their carers at the point of diagnosis, working closely with the VCS-provided dementia advisor service, who are based at the clinic and accept referrals directly from the team.
- Diagnosis within 12 weeks of referral to the MAS by their GP, meeting one of the Barnet Health and Wellbeing Board (HWBB) targets.
- Cognitive stimulation therapy for twelve weeks post-diagnosis for those with mild to moderate dementia
- Support for carers via the START (StrAtegies for Relatives) programme. This programme has been proven⁴ to reduce depression and anxiety for families of people living with dementia.
- Initial management of those newly diagnosed before follow-up care is handed over to the GP once the medication regime for those that are eligible is established and the individual is stable.

³ <https://www.nice.org.uk/guidance>

⁴ [START-Intervention-Summary.pdf \(modern-dementia.org.uk\)](#) pg 2

According to MAS statistics, since January 2022, there has been an increase in referrals to the service, following a decrease in referrals during the peak of the Covid 19 pandemic:

Barnet Memory Assessment data on referrals received and types of dementia diagnosis

Memory Assessment Service	2018/19	2019/20	2020/21	21/22
Total Referrals received (all sources)	857	792	577	858
Patients diagnosed with any form of dementia	520	448	333	386
Patients diagnosed with Alzheimer's	441	382	281	314
Patients diagnosed with vascular dementia	31	28	21	24
Patients diagnosed with young onset dementia	10	5	14	8

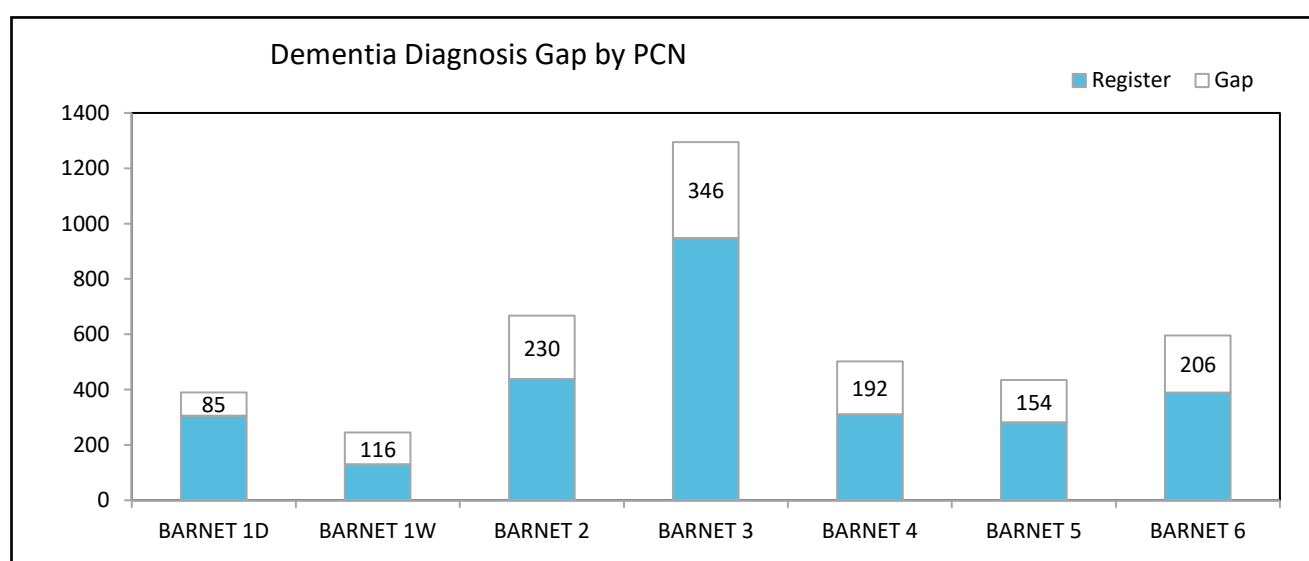
Source: Memory assessment service 2022

GPs can also diagnose and manage patients within their primary care networks (PCN), where they feel equipped to do so without a referral to MAS.

Some diagnoses are also made in secondary care where an inpatient has been hospitalised for another ailment; in such cases, the GP is informed when the patient is discharged.

The Diagnostic Gap

The graph below shows the gap in diagnosis rate against prevalence data, within each Primary Care Network (PCN):



Source: NHS Digital, 2020/21

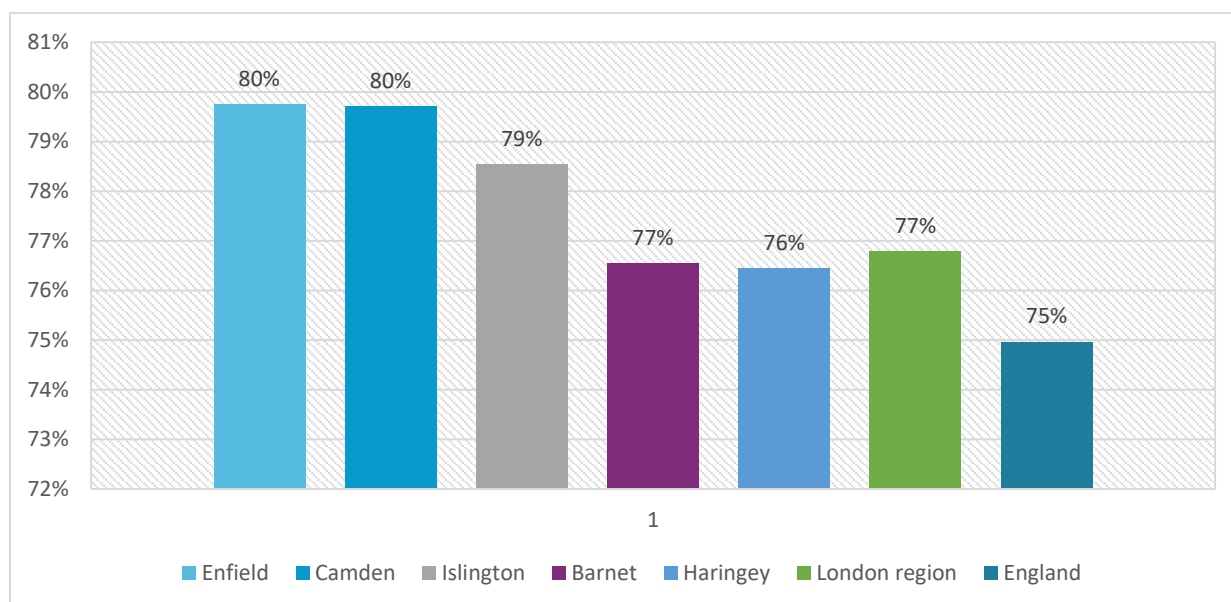
Annual care plan reviews with the GP

A face-to-face review of the healthcare needs of both dementia patients and their carers is an essential element of their holistic care plan. The annual review with the GP should address four key issues:

- An appropriate physical and mental health review for the patient
- If applicable, the carer's needs for information commensurate with the stage of the illness, as well as the patient's health and social care needs

- If applicable, the impact of caring on the carer and
 - communication and co-ordination arrangements with secondary care (if applicable).
- National templates are available to support GPs, but these aren't always used.

The graph below shows the percentage of patients diagnosed with dementia whose care plan was reviewed in the preceding 12 months. Barnet had a lower rate of patients whose care plan had been reviewed by their GP in the last 12 months than Enfield, Camden and Islington, similar to London and slightly higher than Haringey and England:



Source: [Dementia Profile - OHID \(phe.org.uk\)](https://www.phe.org.uk/dementia-profile)

3. Supporting Well

Access to safe high-quality health and social care for people with dementia and carers

Supporting people living with dementia and their carers in primary care

- The Aging-Well Multi-Disciplinary Team is commissioned to work with patients in primary care across Barnet. For eligible patients, the Multi-disciplinary Team holistically assesses, coordinates, and personalises patient care to build resilience, reduce crisis and unplanned care incidents and improve quality of life.
The original pilot for this service found that nearly 80% of the patients identified as most in need of holistic case management were people living with dementia. Consequently, the most recent additions to the Aging-Well Multi-disciplinary team are two Admiral Nurses (specialists in dementia care).
- **‘One Stop Dementia Support Clinics’**, A workstream of the **‘PriDem research project’** by University College London⁵ testing an evidence-based, primary care led approach to

⁵ [Dementia and Cognitive Impairment | Institute of Epidemiology & Health Care - UCL – University College London](https://www.ucl.ac.uk/dementia-and-cognitive-impairment)

post-diagnostic dementia care.

PriDem Clinical Dementia Lead Robyn Barker worked with GP surgeries in PCN2 to improve care systems, including introducing PriDem annual dementia review templates, which teams adapted to suit local needs. Robyn supported Oakleigh Rd North Clinic and Brunswick Park Medical Centre to deliver 'One Stop Shop' annual dementia review clinics

People living with dementia and their chosen family members were proactively invited to have all their physical, social, mental well-being and information needs met in one appointment with a GP, enhanced by the addition of a Dementia focused multi-Disciplinary team. All the non-medical surgery staff involved received level 1 Dementia Awareness training beforehand.

Initial outcomes:

- Post Diagnostic care, closer to home by own GP.
- Collaborative, holistic, personalised Dementia Care Planning between organisational silos.
- 98% Attendance.
- 94% extremely likely to recommend to friends and family.
- Carers and people living with dementia received emotional support and practical information, and social care referrals were made where needed
- Proactive prevention of social crisis such as carer stress breakdown.
- Preventative health care opportunities, blood pressure checks, diabetic checks, and vaccines.

Supporting people living with dementia and their carers in wider healthcare services

- Post-diagnosis, the Community Mental Health Teams (CMHTs) work with families in the community in four geographical teams within the borough and are open to people who already have a diagnosis of dementia but may be presenting with challenging behaviour because of their progressing dementia.
- The **Admiral Nurse service** is specifically designed to support the needs of carers for someone with dementia. Admiral nurses are specialist nurses with expert knowledge of the difficulties facing people looking after a friend or a relative living with dementia. They are based at the memory assessment service and work closely with the Dementia Advisers provided by Age UK Barnet and the Specialist Dementia Support Team within Adult Social Care. Referral is via the GP.
- **Community Health Services - CLCH Dementia Care Strategy, 2022 – 2025** *(see Appendix)*
The Central London Community Health NHS Trust provides community health services to more than two million people across eleven London boroughs and Hertfordshire, including Barnet.
In 2022 they published a dementia care strategy which focuses on improving public and professional awareness, understanding of dementia and the stigma associated with it addressed by developing an informed and effective workforce for people with dementia.

- **Acute Inpatient Services**

Out of every 100 people diagnosed with dementia on GP registers in Barnet, 50.1% were admitted to acute hospitals as inpatients during 2019/20. This figure is lower than both London's 52.8% and England's 51.8%, and a reduction from 55% in Barnet in 2018.

Changes in the surrounding environment can increase anxiety and stress levels. People with dementia can be more susceptible to these changes, which can cause additional distress. Therefore, short-stay emergency inpatient admissions (of one night or less) should be avoided wherever possible.

Barnet's rate of short-stay emergency admissions for those aged 65+ was 33.1% in 2019/20. This is slightly higher than statistical neighbours at 32.2% and England at 31.4%, but this is not statistically significant⁶.

Adult Social Care

In Barnet there is a single point of entry to adult social care for anyone newly diagnosed, caring for someone living with dementia or whose circumstances have changed and who needs support to access services or support. Adult Social Care promote well-being and independence by using a strengths-based approach to preventing, reducing, or delaying needs from developing or escalating. Care Act Assessments are used to assess needs for services such as care at home and accommodation-based services, talked about in more detail below. Social care can also offer direct payments for individuals and families to direct their own care and support.

There is also a Specialist Dementia Support Service which aims to:

- Support and maintain the health and wellbeing of carers and of people living with dementia
- Supporting carers to continue in their caring role
- Support people with dementia to remain living in the community
- Improve the knowledge, confidence, and skills of carers to make a positive difference in their lives and to the lives of those for whom they care
- Maximise the use of preventative community support services for carers.

Care At Home

- As dementia progresses, a person can require additional care and support to enable them to continue living at home. Good quality domiciliary care and access to community activity and engagement are essential for the person's independence, as well as reducing isolation and hospital admissions and preventing or delaying permanent admissions into care homes.

Barnet has good quality domiciliary agencies that support in meeting the needs of residents who need care and support.



















⁶ Dementia Profile - OHID (phe.org.uk)

- Care technology can be instrumental in helping people continue living well with dementia. Often as dementia progresses, an intervention such as a personal alarm, 24-hour personal emergency monitoring service or a GPS watch can help the person with dementia maintain their independence whilst giving the carer or family members confidence that they will be alerted if necessary.
- Residents can also access equipment to improve the home environment, such as toilet seat raisers, kitchen aids, talking clocks and grab rails, or be supported with major structural alterations such as level access showers or ramps.

Housing and Accommodation-based Services

- Accommodation providers play a key role in making Barnet a Dementia Friendly Community, one that is safe and enabling for those living with dementia and their families.
Suitable housing is necessary for the changing needs of those living with dementia, and Barnet is working to develop new models of accommodation and support, ensuring that there is sufficient and diverse housing and support provided to meet the needs of adults with dementia.
- Extra care housing is one of those options for people living with dementia who want to continue living on their own with the comfort of knowing that there is the security of staff at hand. A new Council-owned 53-unit extra care scheme, Ansell Court, opened in early 2019. This scheme has been designed to focus on the needs of people with dementia to meet the growing demand for services. Sites for two more extra care schemes have been identified, and construction is underway, providing a further 125 properties. These are Stagg/Atholl House in Burnt Oak, which is due to open in early 2023, and Cheshire House in Hendon, due to open in 2024
- It is estimated that 70% of people with dementia may eventually require long-term residential care. Barnet has a significant number of care homes, but a growing need has been identified for care homes that can provide complex care for conditions such as dementia, particularly where people have complex behavioural needs.
- A dedicated Care Home Support Team has been piloted in early 2023 to increase the mental health support available to homes as part of plans to expand complex care provision. At time of writing, initial outcomes are positive and further review is needed to inform future commissioning intentions.
- Positively, the graph below shows that 83.9% of residential and nursing home beds in Barnet suitable for older dementia patients (aged 65+), were rated as "Good" or "Outstanding" by the Care Quality Commission in 2020. This was significantly higher than England's 74.1% and statistical neighbours' average of 76.7%.

% of residential care and nursing home beds for people aged 65+ with a CQC rating of good or outstanding, 2020

Area ▲▼	Value ▲▼		Lower CI	Upper CI
England	74.1		74.0	74.3
Neighbours average	76.7*		76.1	77.4
Harrow	97.8		96.6	98.6
Richmond upon Thames	95.9		94.0	97.2
Kingston upon Thames	91.6		89.7	93.3
Merton	89.6		87.0	91.7
Redbridge	88.7		86.3	90.7
Wandsworth	86.0		83.9	87.8
Barnet	83.9		82.2	85.5
Bromley	82.1		79.7	84.3
Croydon	77.3		75.3	79.1
Hounslow	74.2		70.4	77.7
Brent	71.9		68.5	75.1
Enfield	71.6		69.1	74.1
Sutton	70.3		67.3	73.2
Hillingdon	63.0		60.2	65.7
Ealing	55.2		52.2	58.1
Bexley	47.5		44.7	50.3

Source: Care Quality Commission

- Unfortunately, since 2017 Barnet's bed capacity per 100 persons registered with dementia (aged 65 +) has reduced from 70% to 67.7%.in 2020. This is significantly higher than London 51.9% but lower than England 75.3%:

4. Living Well

People with dementia can live normally in safe and accepting communities.

Dementia-Friendly Barnet

Barnet is committed to creating a sustainable dementia-friendly community and has formed the Dementia Friendly Partnership Barnet, whose primary purpose is to work collaboratively to ensure that people living with dementia are understood, respected, and supported.

A Dementia Friendly Community is a place where people living with dementia are understood, respected, and supported; an environment where people living with dementia will be confident that they can contribute to community life.

The Dementia Friendly Barnet Partnership is formed of over 40 local organisations with a joint leadership where the CEO of Barnet Carers and the CEO of Age UK Barnet, UK are driving the work forward alongside Public Health.

There is a straightforward programme of action, including working with local organisations, businesses, culture venues, leisure centres, faith groups, and residents to share responsibility in helping people with dementia (PLWD) to live independently and safely in Barnet. It will also tackle stigma, promote opportunities for people with dementia and their carers to live well and raise awareness of the importance of planning end-of-life in advance.

The Dementia Friendly Barnet Partnership is formed of over 40 local organisations and has a programme of action that includes working with local organisations, businesses, culture venues, leisure centres, faith groups, and residents to share responsibility in helping people living with dementia feel supported, respected and empowered by their local community.

The partnership successfully applied to the Alzheimer's Society to gain recognition as a borough working towards becoming dementia friendly – this was accepted in October 2022.

The partnership is also expanding the local training offer to increase the number of Dementia Friends in Barnet (currently over 12,000) who have a key role in raising awareness and creating a safe community for people living with dementia.

The partnership has successfully gained "Working to become Dementia Friendly" status through Alzheimer's Society in October 2022. The following venues are accredited as Dementia Friendly Venues through The Mayor of London scheme for public spaces. They are:

- Royal Air Force Museum
- Arts Depot
- Copthall Leisure Centre

- Colindale Community Trust

Currently, there are 12,295 Dementia Friends in Barnet, and the partnership plans to recruit an additional 1,000; this will help in raising awareness of dementia as well as creating a safe community for people living with dementia.

We also have dementia-friendly swimming in Barnet, where a fully qualified swimming teacher leads swimming sessions to support individuals living with dementia to enhance their psychological and cognitive well-being. The initial 8-week swimming sessions were funded by Swim England and the London Marathon Charitable Trust and supported by Dementia Club UK. These will be sustained as part of the centre's programme and run each week at the Lido Leisure Centre and are free for people living with dementia and their carers.

Coordinated Care

- **Social prescribers** provide information and support to patients with social and economic issues that affect their health and well-being for adults over 18, are registered with a GP and have consented to the referral. This service is currently provided by Age UK Barnet and has helped people living with dementia and their carers access local well-being services.
- **Prevention and wellbeing coordinators** support adults with disabilities, mental health illness, older people and their families and carers to remain independent and maximise their wellbeing. Access to the coordinators is via adult social care.
- **Dementia advisers** provide information and advice to help people diagnosed with dementia find the right support for them. Information is provided on all aspects of living with dementia, and signposting and support in accessing local services. The service is currently commissioned from Age UK.

The following table shows the number of referrals to the service, those accessing the service and those receiving one-to-one support:

Dementia Advisor Service April 2018 – April 2022

	Year End March 2018	Year End March 2019	Year End March 2020	Year End March 2021	Year End March 2022	Total
Referrals received	561	962	853	332	770	3,478
No accessing service	561	962	853	332	770	3,075
No receiving 121 support	402	not reported	450	326	589	1,767

Leisure and Social Inclusion

- AgeUK Barnet is currently commissioned to deliver the **living well service** to provide day opportunities for people with mild to moderate dementia across two sites in the borough, one at the Ann Owen Centre in East Finchley and the other in Hendon. It offers a range of cognitive, physical, and social activities for people with dementia in a safe and welcoming environment with trained staff and volunteers. Individuals are encouraged and

supported to maintain their skills and remain a part of their communities.

AgeUK Barnet has teamed up with Barnet Carers Centre to offer a support group for those caring for someone living with dementia. A chance to meet others, share tips, and gain information about the condition and the services available in the area.

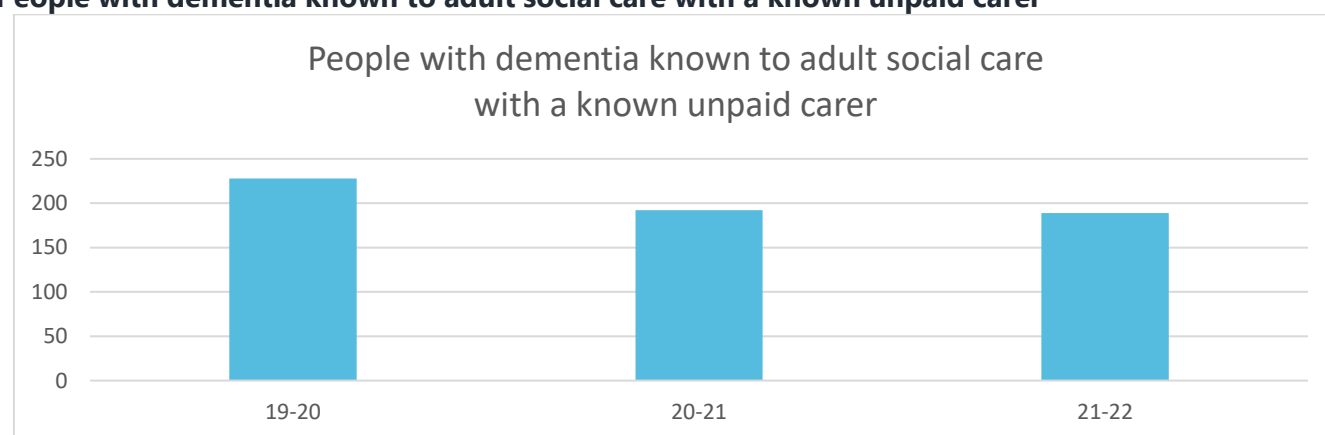
- AgeUK Barnet also runs a **Dementia café** that serves both people living with dementia and their carers. The cafe is an informal social point at which people living with dementia and their carers can come together, share views, obtain mutual support, gather information, and participate in arts and crafts activities.
- **Dementia Club UK** also welcomes people living with dementia alongside their carers, friends, and families to attend their clubs which can be found dotted around Barnet. They provide people with another lifeline, giving care and support, professional advice, fun daily activities, and above all, hope.

Support for Unpaid Carers

Support for carers of people living with dementia is an increasingly important part of the offer. Ensuring that carers are supported and valued in their role enables them to continue providing support, preventing hospital admissions, and prolonging the time that people can remain living independently in their homes.

As per the graph below, the number of people caring for people living with dementia known to adult social care has been falling over the last few years. Given that the number of people diagnosed with dementia is increasing, these figures are likely to be underrepresenting carers of people with dementia.

People with dementia known to adult social care with a known unpaid carer



Source: Adult Social Care data BIP team.

The current commissioned provider for carers, Barnet Carers Centre, provides support for carers of those living with dementia. This includes offers personalised support, training, and facilitation of peer groups and networks. Dementia-specific programmes for carers aim to provide them with the skills required to carry out their caring role. More information about the support available to carers is outlined in the Barnet Carers and Young Carers Strategy 2023-2028.

5. Dying Well

People living with dementia die with dignity in the place of their choosing.

What is already happening in Barnet?

In Barnet, GPs are given the training to enable them to have difficult conversations about dying. Our later life planning service, currently run by Age UK Barnet also provides information and advice around those crucial decisions, from legal matters and ensuring that Power of Attorney arrangements are in place, to knowing that each choice matters. Planning ensures that individuals have identified advocates who can support them with their plans when the time comes and ensure that their wishes are considered.

The data below shows the place of death of people aged 65+ with dementia. Barnet vs. London and England, 2016-2019.

	Barnet	London average	England average
Care home	48.9%	43.6%	58.4%
Own home	15.7%	15.8%	11.2%
Hospital	32.8%	28.7%	38.4%

Source: [Dementia Profile - OHID \(phe.org.uk\)](https://dementia.org.uk/ohid/)

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London Borough of Barnet

Carers and Young Carers Strategy

2023 - 2028

YOUR LIFE,
YOUR CARE,
YOUR CHOICE.

Directorate	Communities, Adults and Health Family Services
Approvers	Adults and Safeguarding Committee, Children Education and Safeguarding Committee
Approval Date	
Review Date	

Foreword

Foreword to be added prior to publication.

Contents

Foreword	2
1. Introduction.....	2
Scope of this strategy.....	3
2. Context.....	3
Carers in Barnet.....	4
3. We listen	5
Engagement & Co-production	7
4. Existing Offer and Services	9
5. Delivering Change	10
Priorities.....	11
Outcomes	11
Review	12
6. Further reading	13

1. Introduction

A Carer is a person over the age of five who provides unpaid care and support to a parent, partner, child, relative, friend, or neighbour who is unable to manage on their own because of a disability or impairment, poor health, frailty, or use of drugs or alcohol. This includes:

- Adult carers: an adult aged eighteen and over who is caring for another adult such as a spouse, parent, partner, friend, neighbour, relative or adult child.
- Parent Carers: A parent or guardian who provides care to their child (of any age) to a degree greater than would be normally expected in a parenting role.
- Carers of multiple people: Those who care for more than one person and include different generations.
- Young Carers: A person under eighteen who provides or intends to provide care for another person (of any age, except where that care is provided for payment, pursuant to a contract or as voluntary work).
- Young Adult Carers: An adult aged between 18 and 25 who is caring for another adult or child.

The framework for how we intend to support carers of all ages in our borough is outlined in this strategy, which is a declaration of our commitment to carers and young carers in Barnet.

Supporting carers and young carers has been defined as a priority for the council and the NHS, and supporting unpaid carers is one of the objectives included in the council's manifesto. This strategy supports the Barnet Joint Health and Wellbeing Strategy, Barnet's Children and Young People's Plan and Child and Family Early Help Strategy, and the Adult Social Care Reform priorities for unpaid carers. It has been developed with the direct involvement of over three hundred Barnet Carers through the co-production and engagement work led by our commissioned provider, Barnet Carers Centre, and in partnership with colleagues across the Council, Health, and the voluntary sector.

This strategy will help the council to carry out its duties to support carers in their caring role. This includes helping to prevent young carers from carrying out inappropriate caring and ensuring that carers of all ages can achieve the outcomes that they desire. Enabling carers helps to support and promote the independence of people with care and support needs. This means considering the needs of carers at various times in their caring role, such as providing support early on, support to maintain care, and support at the end of a caring role or, when moving from Family Services to Adult Social Care. By working closely across the Council and with the wider community we aim to achieve the outcomes defined within this strategy.

The next step is to translate this strategy into action so that it makes a real and lasting difference to the lives of carers of all ages.

Scope of this strategy

This strategy will:

- set out to carers how we will support them in carrying out their caring role.
- set out to young carers how we will support them and help to prevent them from carrying out caring activities that aren't appropriate for them as young people, sometimes called inappropriate caring.
- set in motion a governance structure and action plan for all organisations to work together to support carers and young carers within Barnet.

2. Context

The caring relationship can be rewarding but it can also be challenging with some carers experiencing stress, social isolation, financial hardship, ill health, and minimal time for themselves. Building resilience in carers relies on having informal and local support and knowing where to access help when needed.

The Care Act 2014 put into place a consolidated legal framework for carers and means that carers are recognised in law in the same way as those that they care for. The Children and Families Act 2014 introduced a 'whole family' approach to assessment and support. Local authorities must offer an assessment where it appears that a child is involved in providing care¹. This legislation is aligned with similar provision in the Care Act 2014² requiring local authorities to consider the needs of young carers if, during the assessment of an adult with care needs, or of an adult carer, it appears that a child is providing, or intends to provide, care. Both the Care Act and the Children and Families Act were designed to complement each other and promote a "whole family approach" and joined up working where needed, which avoids the need for multiple assessments. The legislation stresses the importance, of considering the outcomes that everyone may be seeking.

In Barnet, young carers assessments are undertaken via an Early Help Assessment. Assessments must consider whether the care being provided by a child is excessive or inappropriate; and how the child's caring responsibilities affects their wellbeing, education, and development. A local authority should consider how supporting the adult with needs for care and support can prevent the young carer from undertaking excessive or inappropriate care and support responsibilities.

This strategy builds on the previous Barnet Carers Strategy Action Plan and supports achieving the outcomes set within the Joint Health and Wellbeing Strategy 2021 – 2025, the Children and Young People's Plan 2023-2027 and the Child and Family Early Help Strategy 2023-2027. In addition to local documents, this strategy has been shaped by the Adult Social Care Reform White Paper, which identifies unpaid carers as a priority area, the National Carers Action Plan (2018-2020), NHS Long Term Plan (2019), and takes into account key legislation, as outlined above.

¹ Children Act 1989: section 17ZA 1(a) [inserted by section 96 Children and Families Act 2014]

² Care Act 2014: section 63(1).

Carers in Barnet

The 2021 Census advises that Barnet has 28,808 Carers, which makes up 7.9% of total Barnet population.³ This is a reduction from the 2011 census, which reported 32,256 Carers (9% of total population in 2011).

Further information around carer population is collected from our commissioner provider, Barnet Carers Centre, who report 3,703 Adults Carers, and 787 Young Carers known to them.

Although the Census provides useful information, it is widely acknowledged, both nationally and locally, that it is likely to underreport the number of carers, as many carers view their caring responsibilities as part of another role, such as that of a parent, partner, child, relative or friend. It is clear we need to identify and support carers earlier before there is a risk of carer breakdown, or carers are no longer able to care.

The Covid 19 pandemic has adversely impacted many carers and young carers in our communities. The Council recognizes the importance of working closely with its partners and the community and voluntary sector in responding to the needs of carers and young carers to ensure that we are appropriately supporting carers and young carers in our communities to maintain their health and wellbeing and achieve the outcomes that they desire.

Recognising the demographic changes in Barnet, we acknowledge the need to ensure that support and services are accessible to, and appropriate for, the diverse group of people who are carers. Some of the key demographic considerations that inform our action plan are as follows:

- We have an aging Carer population that presents with a myriad of physical health needs.
- The Covid 19 pandemic and the subsequent economic crisis has adversely impacted many carers and young carers in our communities, and there is a greater need around moderate to severe mental health challenges.
- Carers have long had concerns about their own mental health and the mental health of the people they care for. In a recent survey 46% of carers cited their mental health in their top two concerns for 2023. Almost 80% of those responding to the survey placed the mental health of the person they care for in their top two concerns for 2023.
- According to the latest census findings, proportionately more of Barnet's residents are now children and young people or older adults compared to 2011. The numbers of older adults in Barnet will continue to increase, putting increasing demand on adult social care and creating more caring roles.
- Barnet has the highest recorded prevalence of dementia across North Central London and as of 2020 has the largest population of all London boroughs.
- There has been a 9.3% decrease over the past 10 years of residents identifying as white although this group still represents over half of Barnet's population followed by those identifying as Asian representing 19.3% of Barnet's population. The ethnic group showing the highest level of growth over the last 10 years has been those who identify as Other Ethnic Groups now representing 9.8% of the population.
- Over a third of Barnet's population self-reported as Christian with those reporting as having no religion being the next most common consisting of 20.2% of Barnet's population. Overall, 14.5% of

³ [Unpaid care, England, and Wales - Office for National Statistics \(ons.gov.uk\)](https://ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/conditionsanddiseases/articles/unpaidcareenglandandwales/2019)

Barnet's population self-reported as Jewish, however the Jewish population in Barnet represents 39% of London's Jewish population.

- The latest census finding has reported that Barnet has a growing number of migrants settling in the borough and staying for the longer term.

3. We listen

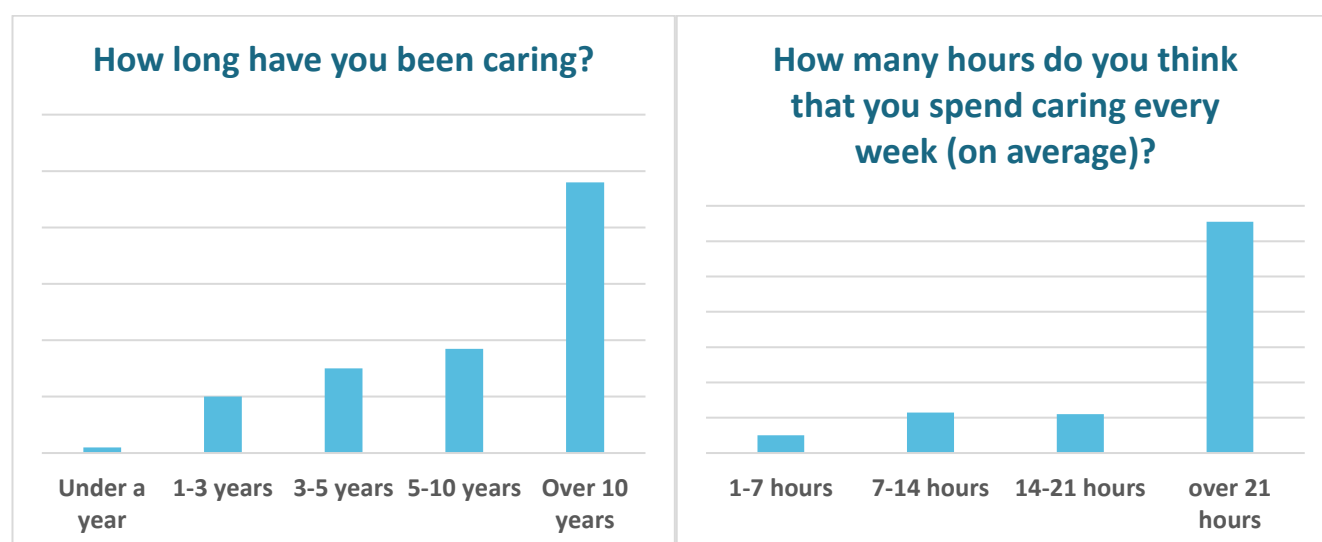
Barnet Council, and its key partners across health and social care, are committed to empowering carers to share their views and to work in partnership in the shaping and delivery of services.

This strategy, the priorities and the outcomes identified have been codesigned with young and adult carers across the borough. Over three hundred carers have been engaged via a combination of focus groups and online surveys. Six focus group discussions were delivered by Barnet Carers Centre and took place in person and remotely. An online survey was sent to all Adult Carers known to the Barnet Carers Centre; and promoted via the council's engagement and consultation website, Engage Barnet.

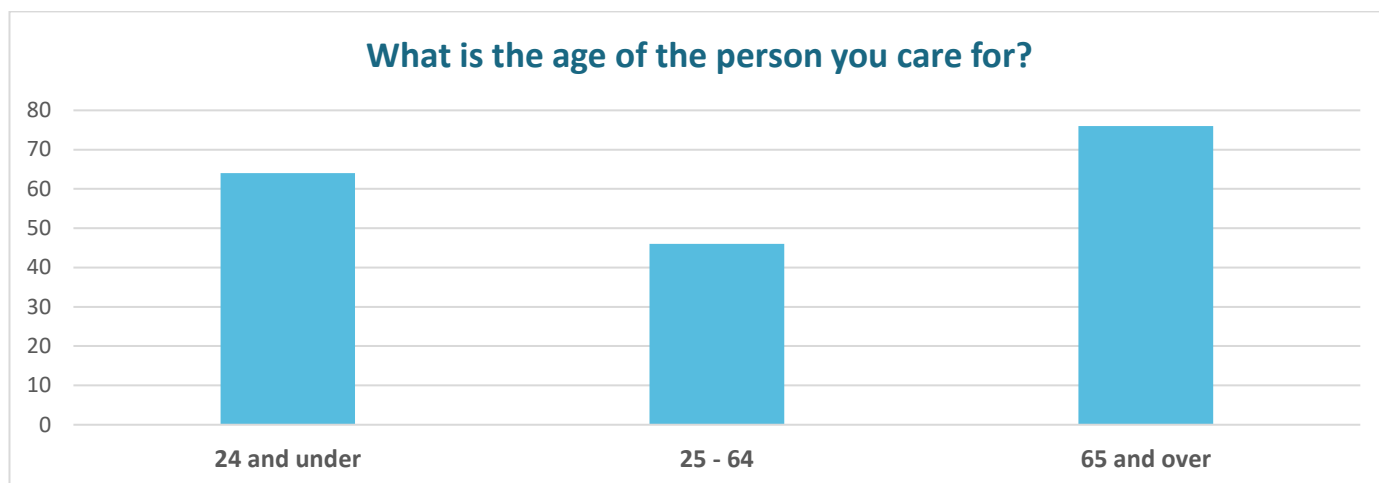
Furthermore, this strategy incorporates feedback collected from carers via the Survey of Adult Carers, conducted biannually by local authorities across the country, and makes important considerations of the hardships recorded as faced by carers during the Covid 19 Pandemic.

Some key findings from the engagement activity and feedback collated are as follows:

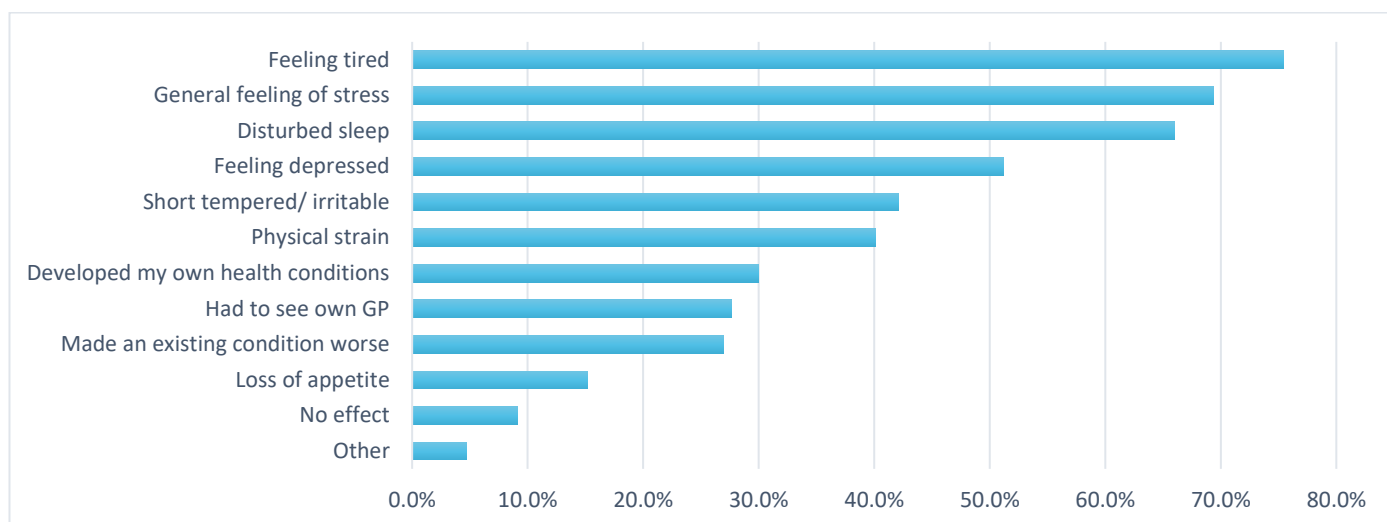
1. A majority of respondents to the survey specific to this strategy have been caring for over 10 years and spend over 21 hours on average in a week in their caring role (Carers Strategy Survey)



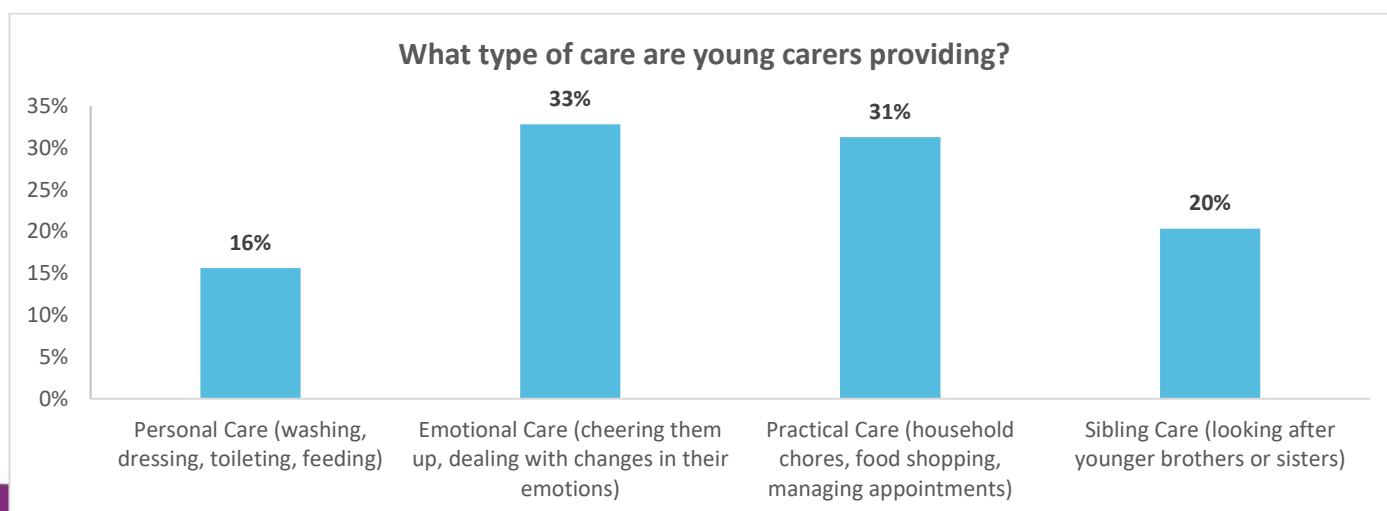
2. Parent carers have emerged as a prominent carers group through recent engagement and co-production discussions (Carers Strategy Survey and Focus Groups)



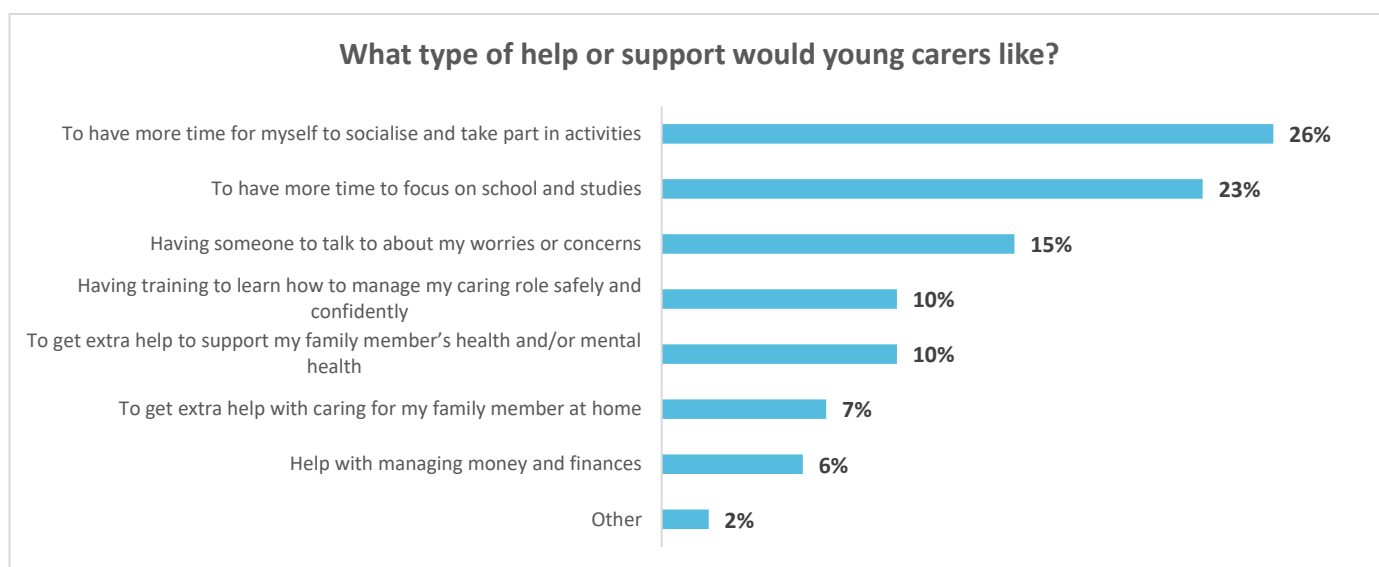
3. Over two thirds of carers reported that caring caused them general feelings of stress (Survey of Adult Carers, conducted biannually by local authorities)



4. Young carers are providing care for a wide range of things (Carers Strategy Young Carers Survey)



5. Young carers need support with a range of things including time to themselves and time to focus on school (Carers Strategy Young Carers Survey)



Engagement & Co-production



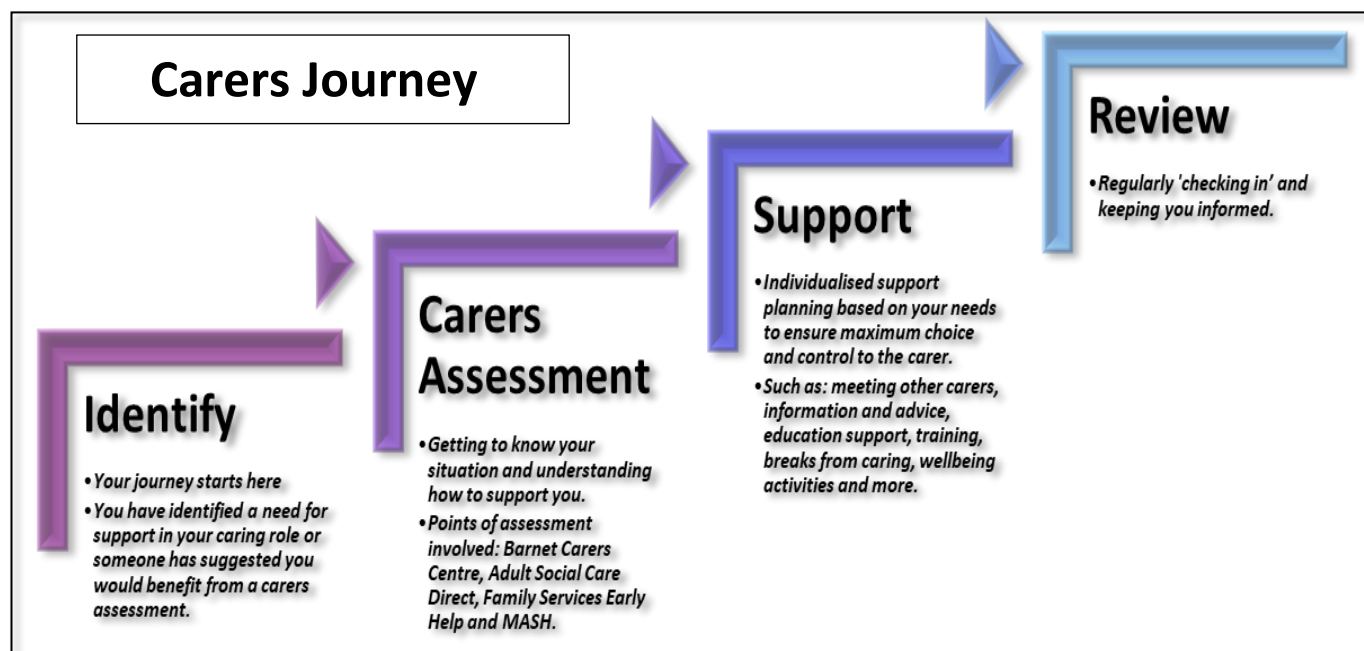
The engagement and co-production activity has been helpful in collecting a varied range of feedback and recommendations directly from carers. We recognise that some of this feedback may relate to pathways that already exist, changes that have been made, or changes that are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other feedback reflects gaps in our local system that we will aim to address through this strategy and its associated action plan.

During the engagement and co-production activity, carers advised us that:

- They feel there is a lack of awareness of the role Carers play in supporting the cared for person, by the Health and Social Care system and the wider community.
- They are only identified when they have reached crisis, which means it is too late for preventative support.

- They need more support with transport costs and entitlements such as free bus passes and access to discounted goods, products, and services to enable them to continue supporting themselves and the cared for person.
- They value a choice of activities that enable them to have regular breaks from their caring responsibilities to support balancing their caring roles with their own personal lives and interests.
- They would benefit from training sessions about the disabilities / conditions of the cared for person and the various Health and Social Care pathways that can be used to access support.
- They have struggled during the pandemic - often not being informed when there is a change to the care and support of the cared for person (e.g., plan for the reopening of day opportunities).
- They need regular respite, and they do not know what respite is available and how to access it.
- There is an issue around “inconsistent care” with different paid carers turning up to carry out care, which can be distressing for the cared-for person.
- Young Carers often take on huge amounts of responsibility and need support to balance competing responsibilities and demands. Priorities for young people included pursuing their education and to have time dedicated to their mental health and wellbeing support as well as time for themselves and socialising.
- Timely, accessible, and appropriate support is required to enable sustained improvement in mental health and wellbeing. Many of the young carers we spoke to mentioned difficulties around accessing effective mental health and wellbeing support, specifically citing waiting times or accessibility.
- Young carers raised concerns around the demands of their education, and a sense that not all teaching staff were aware of how their caring responsibilities impact the abilities of young carers to participate and achieve in the same ways as their fellow pupils.
- Young Carers spoke of a need for increased understanding on the part of teaching and pastoral staff around their attainment and school performance relative to their caring responsibilities.
- Some young carers were concerned about finances and young carers were not always aware of the financial support available.

4. Existing Offer and Services



Family Services, Adult Social Care and Health are committed to working together to ensure that carers and young carers are identified, offered assessments, and supported based on a whole family approach, whichever service they are identified through. This is in order to ensure that carers and young carers receive the support that they need in their caring role.

We actively promote carers using local resources and support networks in the community. For those needing more targeted support, we support them to access statutory support services where this is needed.

Carers Assessments are currently completed by a social care professional employed by the local authority, or by an appropriately trained professional working for Barnet Carers Centre. Associated care and support planning, where decisions are required around access to social care funding, are handed over to the local authority.

GPs are actively encouraged to identify carers when they access primary care services and record this on their care record. GPs are able to signpost to carer support and make onward referrals as needed, as well as making reasonable adjustments to ensure that carers are able to support their cared for in accessing the healthcare services that they need.

Support that is available to carers within the borough includes:

- Information and advice
- Respite vouchers (for use in residential or nursing homes)
- Training – including modules on practical support like safe Moving and Handling, supporting those living with dementia, or a mental health diagnosis.

- Service Provision to address the needs identified in the Assessment – delivered by a provider arranged by the local authority or funded via a Direct payment (these are cash payments, which can be used to purchase support, which you have been assessed as needing to support you in your caring role)
- Peer support and carer forums
- Counselling for carers
- Mental Health support (through Barnet, Enfield & Haringey Mental Health Trust) Working with key partners to provide whole family support where needed (e.g., health and Family Services)

Support offered through the commissioned lead provider, Barnet Carers Centre, includes: -

- Activities
- Information and advice
- Engagement with, and support within, schools
- Leisure pass scheme
- Wellbeing support
- Counselling for carers
- Carer specific training
- Referrals to local agencies and services
- Mentoring
- Educational support to young carers

In addition to the above, other statutory and voluntary sector organisations working across the borough also offer support to carers both formally and informally.

5. Delivering Change

The implementation of this strategy will be planned in consideration of good practice principles, to ensure the associated action plan is accessible, co-produced, timely and tailored to deliver meaningful outcomes to carers of all ages.

An important strand of our action plan will be addressing challenges relating to under-representation or disproportionality, following further interrogation of demographic data - notably census data that has recently become available.

To deliver the action plan we will work across the council and its partners from social care, health, education, housing, and the voluntary and community sector. We will also develop relationships across the wider council and community, including employment and business sectors as part of this approach, and will continue to put Carers at the heart of this process through their direct involvement in the Carers Partnership Board =, which will be set up as a priority action arising from this strategy. The Board will be multi-disciplinary, multi-organisation and include representation from carers of all ages in Barnet.

Priorities

We have coproduced the following four priorities to guide our action planning:

1. Proactive identification of carers and young carers.
2. Individualised support so that carers and young carers can get the support they need and are entitled to.
3. Involving carers to shape future services and support offer.
4. Raising the profile of carers and young carers.

Outcomes

The outcomes we will achieve through this strategy include:

1. Carers and young carers are identified at the start of their caring journey, and this enables them to access the support they need.
2. Carers are supported to fulfil their education, training, and employment potential, and have their own time for positive and recreational activities.
3. Young Carers are prevented from having to undertake inappropriate caring and provided with the support they need to learn, develop, thrive, and enjoy a positive childhood.
4. Carers are fully aware of resources available to them to help them in their caring role.
5. Carers are supported to access, financial information, and advice and as a result feel financially secure and not financially disadvantaged due to their caring role.
6. Carers see an improvement in their mental health and wellbeing.
7. Young carers feel supported in schools to enable a positive school experience.
8. The way we work across the system is informed by insight from carers' lived experience and valuable contribution.
9. Carers can actively participate in the care and support planning of the person they care for and are able to advocate for themselves and their loved ones when needed.

Review

We have captured feedback from carers about changes to services that they feel are needed and included them directly in this strategy. We recognise that some of this feedback may relate to pathways that already exist, changes that have been made, or changes that are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other feedback reflects gaps in our local system that we will aim to address through this strategy and its associated action plan.

The dedicated action plan will be implemented to deliver on the priorities and outcomes outlined in this strategy over a two-year period. Oversight will be via a multi-disciplinary, multi-organisation Carers Partnership Board. There will be workstreams established, as needed, that will report into the Board. Progress towards the Action Plan will be monitored by the Board and reported to the Barnet Borough Partnership Board, the Health and Wellbeing Board and other boards/committees as requested.

Through the two-year Action Plan, the Board will identify interventions and expect to evidence:

- An increase in the number of new carers who are identified at an early stage in their caring role, with a notable improvement in identifying under-represented groups.
- Carers report a positive experience of working in partnership with Health and Social Care for their benefit and the benefit of the cared for person.
- An increase in the number of Carers who report they are aware of and are able to access appropriate information, advice, and guidance in relation to their caring role via the national and local Carers surveys.

6. Further reading

Adult Social Care Reform White Paper	https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper
Barnet Joint Strategic Needs Assessment (JSNA) information	Joint Strategic Needs Assessment Barnet Open Data
Census 2021 Barnet information	Census Maps - Census 2021 data interactive, ONS
Barnet Council Labour Party Manifesto	Manifesto - Barnet Labour Party - Barnet Labour Party
Personal Social Services Survey of Adult Carers in England, 2021-22	Personal Social Services Survey of Adult Carers in England, 2021-22 - GOV.UK (www.gov.uk)