



Barnet Borough Partnership

Dementia Strategy

2023 - 2028

YOUR LIFE, YOUR CARE, YOUR CHOICE.



Directorate	Joint Commissioning Unit
Approvers	Adults and Safeguarding Committee Barnet Borough Partnership
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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 has five elements which include Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying Well. See appendix

Foreword

Foreword to be added prior to publication

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.

This strategy will inform the planning, provision, and commissioning of dementia-related services in Barnet. To deliver the associated action plan, we will work across health and social care and with partners across the council, voluntary and community sectors, providers of care and with residents to deliver our plans over the next five years.

A key driver in our approach to meeting the increasing demand for health and social care is reducing and delaying the need for more formal 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.

Early intervention and effective prevention can positively impact an individual's health and well-being. By ensuring that people can access early and timely diagnosis for dementia and have good co-ordination and care planning, people will enjoy an improved quality of life within dementia friendly communities.

Financial pressures alongside increasing numbers of people needing support mean that it is vital to consider models of care and support which will maximise people's independence and well-being and effectively manage demand for statutory services.

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 and the Prime Ministers Challenge on Dementia 2020. It also considers key legislation and guidance, including the Care Act 2014 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.

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

² Prince, M et al. (2014) Dementia UK

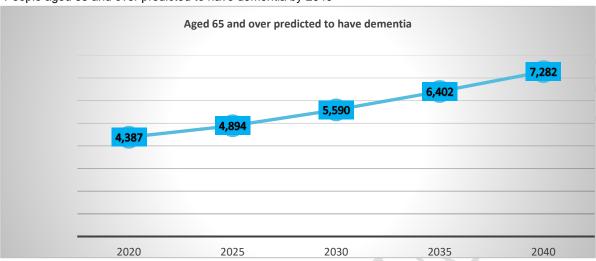
³ https://www.nice.org.uk/

Local context - Dementia Needs Assessment 2022 (see Appendix)

Dementia Projections

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.

People aged 65 and over predicted to have dementia by 2040



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

Diagnosed Dementia Rate

The diagnosed dementia rate indicates what proportion of the number of people estimated to be living with dementia in Barnet, have a formal diagnosis. In Barnet, the estimated diagnosed dementia rate for people aged 65 and over is 65.7%. This is slightly lower than London (66.8%) but hight than the England average (62%).

In Barnet, across London and England-wide, the estimated diagnosis rate has been falling since 2017, which suggests improvements can be made in our identification and diagnostic pathways and processes:

Estimated dementia diagnosis rate (aged 65 and over) for Barnet

100

80

40

20

2017

2018

2019

2020

2021

2022

England

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

Ethnicity Data

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 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.

People with dementia known to adult social care by ethnicity:

Ethnicity	19-20	20-21	21-22
White	602	583	598
Asian/Asian British	84	78	97
Black/Black British	47	44	38
Other Ethnic Groups	39	38	40
Not Stated	21	20	19
Mixed/Multiple ethnic groups	7	6	9
Chinese	6	5	6
Grand Total	806	774	807

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, as well as the voluntary sector in Barnet 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 under each of the main chapters. Some comments are also included below.

We recognise that some of these changes may have already been made, or are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other changes reflect 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.

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

My dad is always happy when he goes to Ann Owen, 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. 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.

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

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. The Well Pathway for Dementia – NHS England Transformation Framework

The Well Pathway for Dementia is a five-year implementation plan which covers five areas: Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying well. Our Strategy aims to align itself with this transformational framework and ensure that all Barnet residents can live well with dementia within the community of their choosing and with the right support and care around them.

Preventing Well

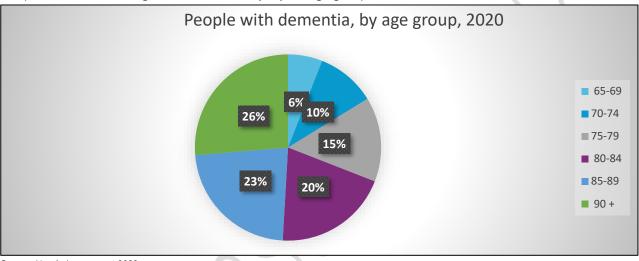
Risk of people developing dementia is minimised

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.

According to Alzheimer's society, whilst not all older people have dementia, the most significant risk factor for dementia is ageing, as supported by the following Barnet data. The chart shows how this population is broken down by 5-year age group. Older age groups account for larger proportions of the dementia population in Barnet.

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



Source: Needs Assessment 2022

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 factors⁴. The Lancet Commissions on Dementia Prevention, Intervention and Care identified that 35% of dementia was attributable to a combination of the following risk factors⁵:

- 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.

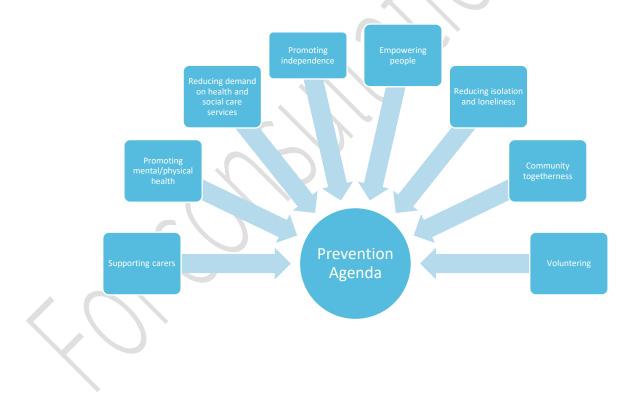
⁴ Lancet Neurology (2014)

⁵ The Lancet (2017) 390

- Preventative factors include educational and occupational attainment and social isolation.
- 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.

What is already happening 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 VCS providers deliver sessions on ⁶preventing well.



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⁶ Age UK Barnet | Activities and events

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.

Diagnosing Well

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

Why is this important?

A timely diagnosis enables people with dementia, their carers, and healthcare staff to plan accordingly and work together to improve health and care outcomes. Early diagnosis of dementia is a government priority, and the National Dementia Strategy 2009 describes the value of early diagnosis and intervention. 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 end up having a dementia diagnosis.

What is already happening in Barnet?

Barnet's Memory Assessment Service (MAS) is commissioned by NCL ICB and provided by Barnet Enfield and Haringey Mental Health Trust (BEHMHT). Since 2013, the service has been providing:

- Early holistic assessment for people with memory problems
- A multi-disciplinary service, that follows National Institute for Health and Care Excellence⁷ (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.

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.

⁷ https://www.nice.org.uk/guidance

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

Whilst referrals to the memory clinic increased in 2021-2022, there were fewer people with a diagnosis in comparison to 2018-2019. This could be due to several reasons, such as inappropriate referrals, remote diagnosis during the pandemic may have made a diagnosis difficult, or people not attending appointments. We need to increase our diagnosis levels so that people can get the support they need earlier in their journey to maximise their independence for as long as possible.

With the current integrated dementia pathway, all referrals to the MAS are for diagnostic purposes. Additional support available from the service includes cognitive stimulation therapy for twelve weeks post-diagnosis for those with mild to moderate dementia and support for the carer via the START (StrAtegies for Relatives) programme. This programme has been proven to reduce depression and anxiety for families of people living with dementia.

The MAS provides 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. The GP is then responsible for ongoing personalised care and support, which should be reviewed yearly.

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, although referrals to MAS are always welcomed. 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.

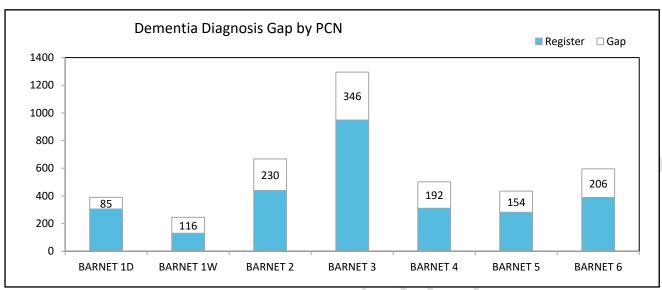
Whilst most people are likely to have access to appropriate support and care, there is more we can do to identify undiagnosed people.

⁸ START-Intervention-Summary.pdf (modem-dementia.org.uk) pg 2

The graph below shows the gap in diagnosis against prevalence data, within each Primary Care Network.

Dementia Diagnosis Gap by Primary Care Networks (PCN)

Source: NHS Digital, 2020/21



We want GPs to continue supporting their patients to get a diagnosis because 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.

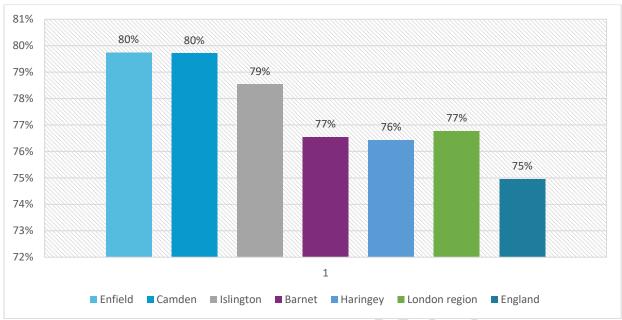
Annual care plan reviews

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 a face-to-face review in the preceding 12 months. Barnet had a lower rate of patients whose care plan had been reviewed by GPs in the last 12 months than Enfield, Camden and Islington, similar to London and slightly higher than Haringey and England.

Dementia care plan has been reviewed in the last 12 months, North Central London



Source: <u>Dementia Profile - OHID (phe.org.uk)</u>

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

- A clear dementia pathway, so people know precisely 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, including regular yearly reviews, should be part of the process.
- Local information and advice appropriate at all stages of dementia.
- A better-coordinated memory assessment service that engages the support of the person living with dementia and families should be the norm. 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 of referral.

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. Supporting people living with dementia is costly 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 billion⁹.
- This is set to rise sharply over the next two decades to £ 94.1 billion in 2040.
- The most significant proportion of this cost, 45%, is social care, which totals £ 15.7 billion.
- 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)

What is already happening in Barnet?

Adult Social Care, Health services, the Memory Assessment Service, GPs, AgeUK, as 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.

Primary Care

- The Aging-Well Multi-Disciplinary Team is commissioned to work with patients across all of Barnet. This 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' have been trialled in two GP surgeries in PCN2 Oakleigh Rd North Clinic and Brunswick Park Medical Centre.

⁹ What are the costs of dementia care in the UK? | Alzheimer's Society (alzheimers.org.uk)

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. Given the positive outcomes achieved, it should be explored whether this approach is mirrored across Barnet in future.

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 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 ratio of inpatient service use to recorded diagnosis is lower than both London's 52.8% and England 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 years 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 significant (Dementia Profile - OHID (phe.org.uk).

Further emergency admissions could be avoided if patient's underlying causes are managed well, and individuals are well supported.

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.
- 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.
- 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%.

Quality rating of residential care and nursing home beds (aged 65 years and over), 2020

Area	Value		Lower CI	Upper Cl
England	74.1		74.0	74.3
Neighbours average	76.7*	H	76.1	77.4
Harrow	97.8	Н	96.6	98.6
Richmond upon Thames	95.9	H	94.0	97.2
Kingston upon Thames	91.6	H	89.7	93.3
Merton	89.6	H	87.0	91.7
Redbridge	88.7	H	86.3	90.7
Wandsworth	86.0	H	83.9	87.8
Barnet	83.9	Н	82.2	85.5
Bromley	82.1	H	79.7	84.3
Croydon	77.3	H	75.3	79.1
Hounslow	74.2		70.4	77.7
Brent	71.9	—	68.5	75.1
Enfield	71.6	H	69.1	74.1
Sutton	70.3	H	67.3	73.2
Hillingdon	63.0	H	60.2	65.7
Ealing	55.2	H	52.2	58.1
Bexley	47.5	H-1	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%:

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 for people living with dementia and their carers.
- More funding for community organisations to keep offering support
- Care agencies that have dementia-trained staff so that carers can feel safe leaving their family members.

Living Well

People with dementia can live normally in safe and 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 2020/21¹⁰ 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 lives of people living with dementia in Barnet and their role in maintaining the health and well-being of the person they care for.

In October 2022, Barnet was successfully recognised as working towards being a Dementia Friendly Community by Alzheimer's Society. Our associated dementia training programme will continue to be rolled out within communities, cultural centres, faith groups, voluntary organisations, businesses, and residents and will help promote awareness locally.

What is already happening in Barnet?

Working with partners in the public and voluntary sector, Barnet has developed local dementia services focusing on improving information and advice and supporting people mainly in the early stages of the

¹⁰ https://www.gov.uk/government/collections/family-resources-survey--2

condition. Several changes have been made at different stages of the pathway to ensure a more joined-up approach between health and social care and to prepare for the challenges ahead. This has been achieved through the following:

- o Improved access to memory assessment and building capacity and support in the community.
- o Working with primary care to improve the Dementia Diagnosis rate.
- o Utilising the Better Care Fund in its 2022–23 framework which builds on initiatives initiated during the pandemic. Thereby strengthening the integration of commissioning and delivery of services providing person-centred care by enabling people to stay well, safe, and independent at home for longer and providing the proper care at the right time.
- o As part of this, we are developing capacity and plans for intermediate care covering admissions avoidance and hospital discharge across health and social care.

Dementia-Friendly Barnet (See appendix)

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.¹

The Dementia Friendly Barnet Partnership is formed of over 60 local organisations with a joint leadership where the CEO of Barnet Carers, the CEO of Age UK Barnet, and the founder of Dementia Prevention 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 partnership has successfully applied to Alzheimer's Society to gain recognition as a borough working towards becoming dementia friendly.

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

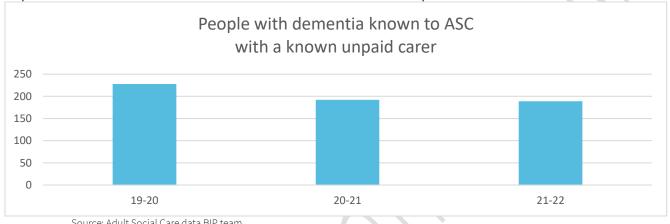
- AgeUK Barnet is currently commissioned to deliver the living well service to provide day
 opportunities for people with mild to moderate dementia across two sites in the borough, one at
 the Ann Owen Centre in East Finchley and the other in Hendon. It offers a range of cognitive,
 physical, and social 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 independent in their homes.

As per the graph below, the number of carers 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. As a result, we need to improve the way we are capturing our carers for those with dementia known to adult social care.

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 Strategy 2023-2028. (see appendix)

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.

Dying Well

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

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 Ryder¹¹ discovered that the top priorities for people at the end of their lives were:

- o Being in a familiar surrounding
- o Having dignity and privacy
- o Surrounded by loved ones and
- o 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.

What is already happening in Barnet?

We must ensure that people have the right support to choose where they die, whether at home, at the hospital, in a hospice or at 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 AgeUK 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: <u>Dementia Profile - OHID (phe.org.uk)</u>

 $^{^{\}rm 11}$ Sue Ryder, A time and place: what people want at the end-of-life 2013

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

- Enough information available about the level of GP support around pain management and palliative 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.

5. 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) (Joint Strategic Needs Assessment 2015 to 2020)

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%).

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, 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 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.

6. 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 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 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 these changes may have already been made, or are planned, which indicates that we need to review communication, awareness, and accessibility. Whereas other changes reflect gaps in our local system that we will aim to address. This will all be taken into account in the development of the action plan to implement this strategy.

The action plan will focus on priorities for the next five years and will be overseen by the Joint Commissioning Team.

Priorities

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

- 1. Improved information and advice (Before diagnosis, at diagnosis, and post-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 post-diagnosis)

Outcomes

Outcomes as identified by the Well Pathway for Dementia – NHS England Transformation Framework:

"I was given information about reducing my personal risk of getting dementia" "I was diagnosed in a timely way"

"I am able to make decisions and know what to do to help myself and who else can help" "I am treated with dignity & respect"

"I get treatment and support, which are best for my dementia and my life"

"I know that those around me and looking after me are supported"

"I feel included as part of society"

"I am confident my end of life wishes will be respected"

"I can expect a good death"

Performance Framework

Monitoring and evaluation of this strategy

As requested, we will report the action and progress against this strategy to the Health and Wellbeing Board, the Barnet Borough Partnership and other boards/committees as required.

7. Appendices

To be added.

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Joint Commissioning Team

Thanks for your input in pulling this strategy together

Jo Kamanu February 2023