

Barnet
Borough
Partnership



Adult
Social Care

The Well Pathway for Dementia – a Barnet Perspective

YOUR LIFE,
YOUR CARE,
YOUR CHOICE.

BARNET
LONDON BOROUGH

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>
<p>"I was given information about reducing my personal risk of getting dementia"</p>	<p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	<p>"I am treated with dignity & respect"</p> <p>"I get treatment and support, which are best for my dementia and my life"</p>	<p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	<p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
<p>STANDARDS:</p> <p>Prevention⁽¹⁾ Risk Reduction⁽⁵⁾ Health Information⁽⁴⁾ Supporting research⁽⁵⁾</p>	<p>STANDARDS:</p> <p>Diagnosis⁽¹⁾⁽⁵⁾ Memory Assessment⁽¹⁾⁽²⁾ Concerns Discussed⁽³⁾ Investigation⁽⁴⁾ Provide Information⁽⁴⁾ Integrated & Advanced Care Planning⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾</p>	<p>STANDARDS:</p> <p>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⁾</p>	<p>STANDARDS:</p> <p>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⁾</p>	<p>STANDARDS:</p> <p>Palliative care and pain⁽¹⁾⁽²⁾ End of Life⁽⁴⁾ Preferred Place of Death⁽⁵⁾</p>
<p>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.</p>				

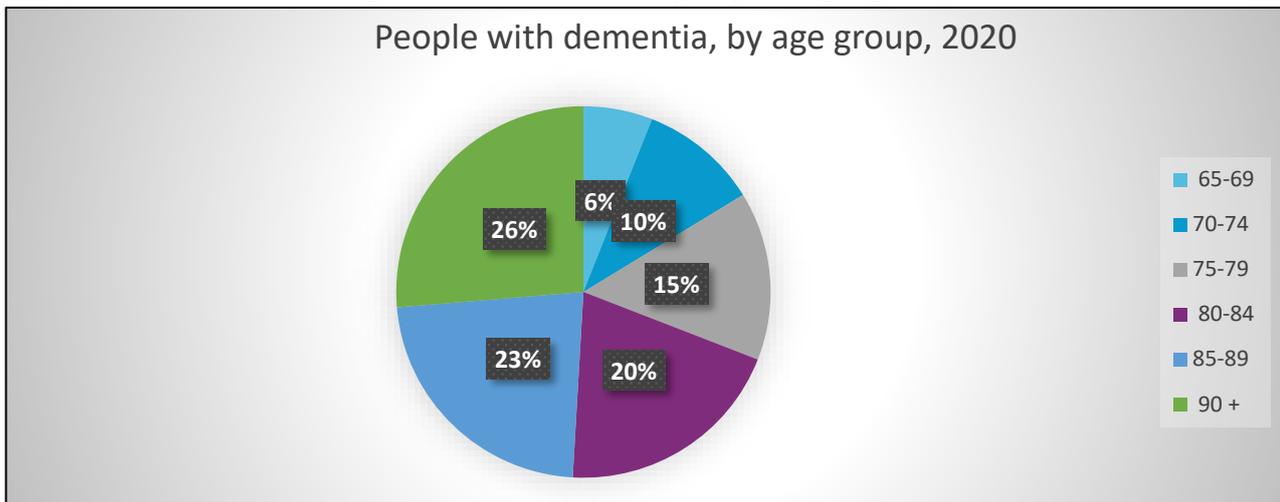
This report will go on to explore each area in more detail, providing relevant data and summarising some of the progress in Barnet.

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.

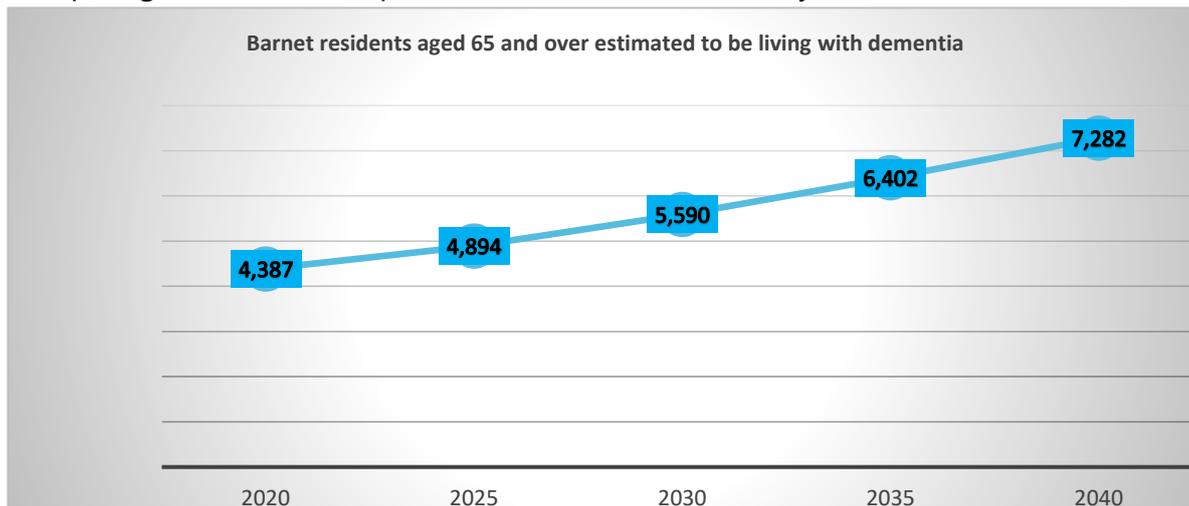
2. Diagnosing Well

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

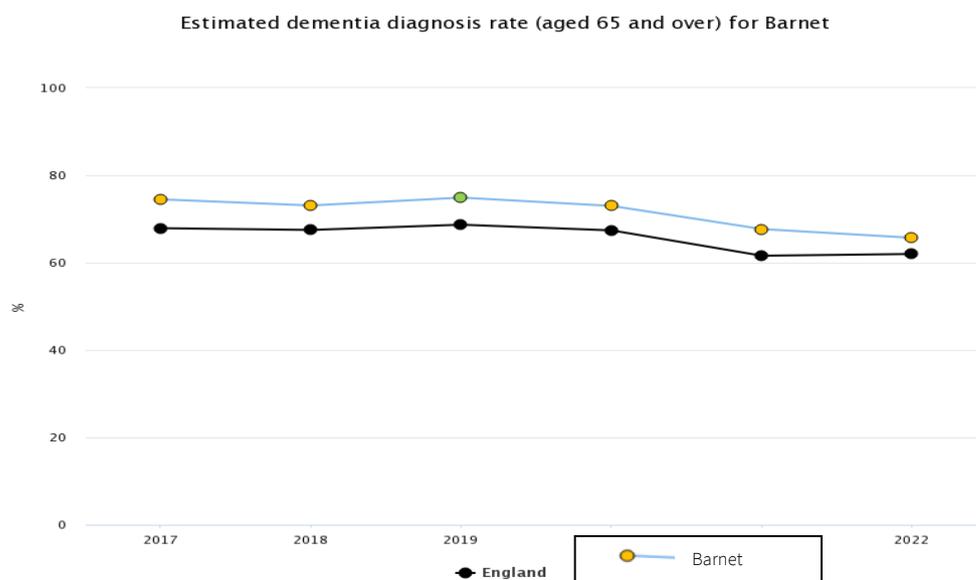


Source: POPPI (based on ONS data). Available at: <http://www.poppi.org.uk/>

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:



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

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 \(modern-dementia.org.uk\)](https://www.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

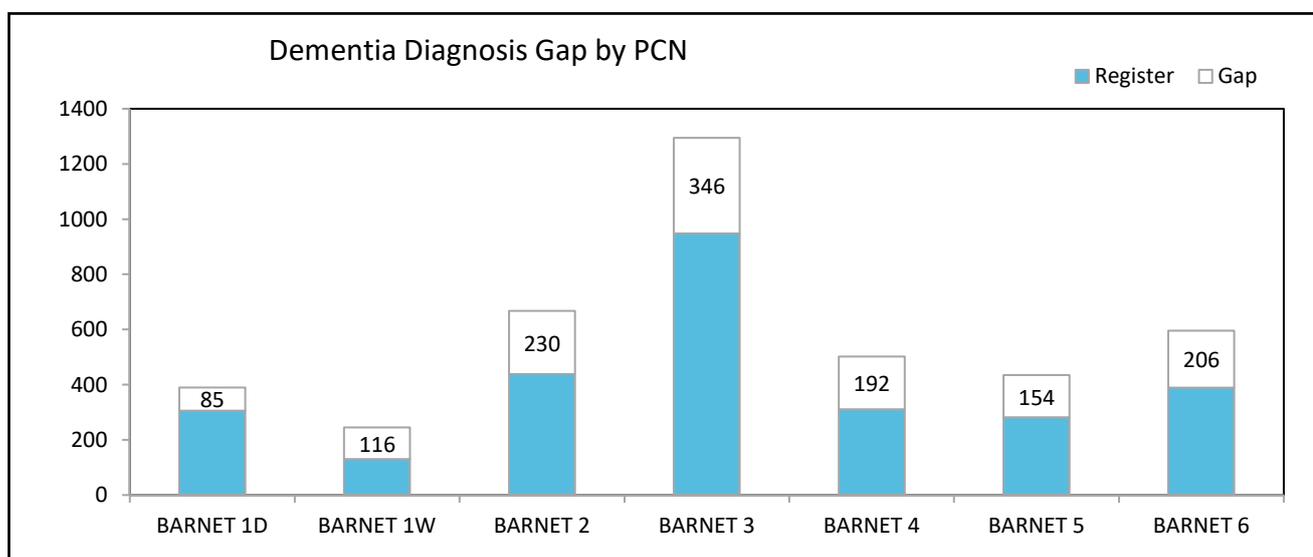
Source: Memory assessment service 2022

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

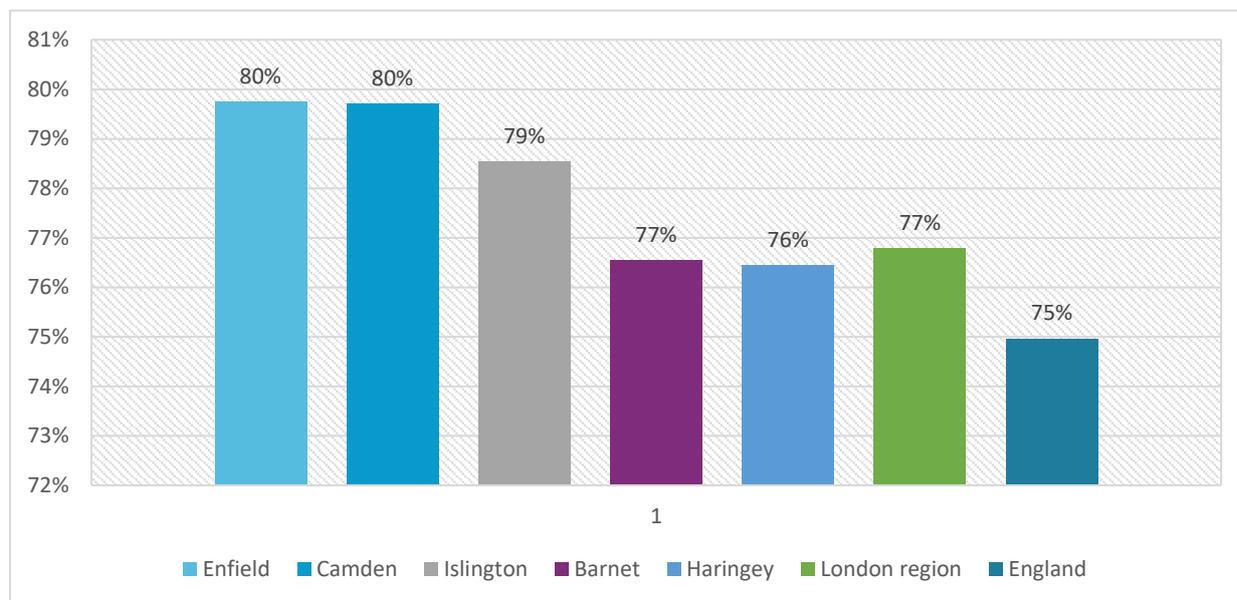
Annual care plan reviews with the GP

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/institute-of-epidemiology-and-health-care)

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.

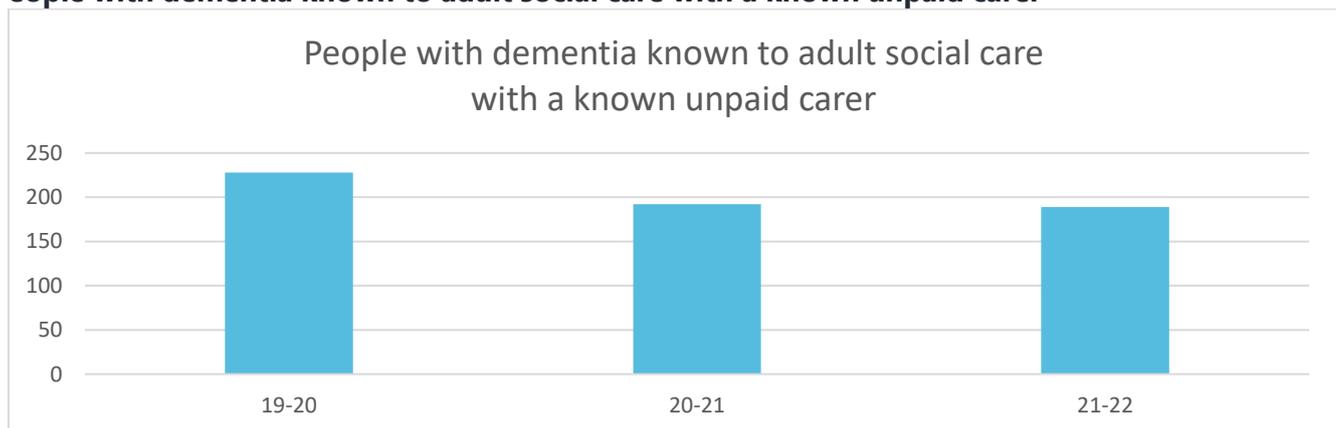
- AgeUK Barnet also runs a **Dementia café** that serves both people living with dementia and their carers. The cafe is an informal social point at which people living with dementia and their carers can come together, share views, obtain mutual support, gather information, and participate in arts and 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://www.phe.org.uk/dementia-profile)