



Dementia **in Barnet**

2016





Foreword - Dementia in Barnet

Dementia is one of the defining diseases of our time. For many it is something that is feared more than death yet, as we grow increasingly older and advances in medicine allow many of us to live into our eighties and nineties, more and more people are impacted by it. And it is not just the impact on the individual themselves, the affect of dementia ripples out amongst families, friends, carers and the rest of society. It is essential that we take dementia seriously and look to help and support all those affected by it. We hope, with this report, to add something to the growing body of work that is being done across Barnet by the local authority, the Clinical Commissioning Group, care homes and a myriad of voluntary sector organisations. I would like to thank all of the individuals and organisations who have helped bring this report together and those who are working very hard towards an increasingly dementia friendly Barnet.

Melvin Gamp, Lead Volunteer, Dementia Project

Executive Summary

This report gives an overall view on dementia services in Barnet:

- An estimate number of people with dementia, and how prevalent dementia is likely to be in the next fifteen years
- Current expenditure, and what costs are likely to be in the future
- Patient and carers' experience with dementia services
- Professionals' views
- Patients' views on how to make dementia services work better for everyone

Key findings

- Feedback on patient experience with professionals demonstrates professionals play the key role in contributing to the quality of care a dementia patient and carer may receive.
- Individuals and carers surveyed report that they did not have any information about dementia prior to diagnosis

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- 32% of people with dementia are not known to their GPs or to professionals
- Hospital dementia emergency admission has tripled, from 624 in Quarter 4 2013/14 to 1840 in Quarter 4 2014/15
- The cost of anti-dementia drugs has decreased by 33% in the past three years. Actual expenditure is £245,744 in 2014/15

Recommendations

- To raise awareness of dementia among primary care professionals
- To raise awareness of dementia among ethnic minority communities
- To involve carers in the patient's treatment as an essential part of providing care
- To provide regular follow-up appointments with GPs, and to emergency appointments
- To offer community day services for early-stage dementia

Background of Dementia in Barnet

Current Picture

Diagnosis

Dementia cases had been under-identified by health professionals in Barnet. Identifying patients, with dementia and assessing their needs by a GP or a specialist, is known as a 'diagnosis rate'. Registering their medical detail on the GP records for dementia is called 'dementia register'. In 2014, it was estimated that there were more than 4,000 individuals with dementia in Barnetⁱ, but only 2,425 were identified on the GP records. Since then, Barnet CCG has put an action plan in place to increase the diagnosis rate to 65%. In March 2015, the diagnosis rate stands at 67.7% in Barnet which exceeds the national average of 67%ⁱⁱ. Barnet CCG aims to increase the diagnosis rate to 75% by 2017ⁱⁱⁱ.

Reporting Month	Dementia Register	Diagnosis Rate
March 2015	2959	67.7
February 2015	2823	64.3
January 2015	2750	62.64
December 2014	2569	58.52
November 2014	2538	57.96
October 2014	2425	57.78

Figure 1. Diagnosis rate in Barnet

An integrated care service is provided by Memory Assessment Service and Alzheimer's Society, at point of diagnosis. There is a plan in place to create a Dementia Network Hub for frontline and support services to work together^{iv}.

Hospital Emergency Admission

As reported by the Royal Free London NHS Foundation Trust, the rate of hospital emergency admission for dementia has tripled^v. This reads as 1840 hospital emergency admissions in Quarter 4 in 2014-15, compared to 624 emergency admissions in Quarter 4 in 2013 - 2014^{vi}.

Care at Home and Care Homes

As in December 2015, 24 registered nursing homes, and 65 residential homes have a unit for dementia or elderly mentally impaired (EMI). More than 470 elderly people, with mental impairment (including dementia), live in registered care^{vii}.

Cost

As in March 2015, there are 2,969 individuals in Barnet diagnosed with Dementia^{viii}. If there is no effective support in place, the care package is estimated to cost £24,128 per person annually^{ix}. If everyone with a dementia diagnosis has a care package, this may cost £71.6m per year.

Health inequalities

GP registration for dementia in Barnet shows that there is a variation in the rate of diagnosis and treatment based on the geographical location of where a patient is being treated^x. From our research, evidence suggests that there is also a lack of dementia awareness among ethnic minority groups.

1,840 hospital emergency admissions

Estimated cost of a care package is £24,000



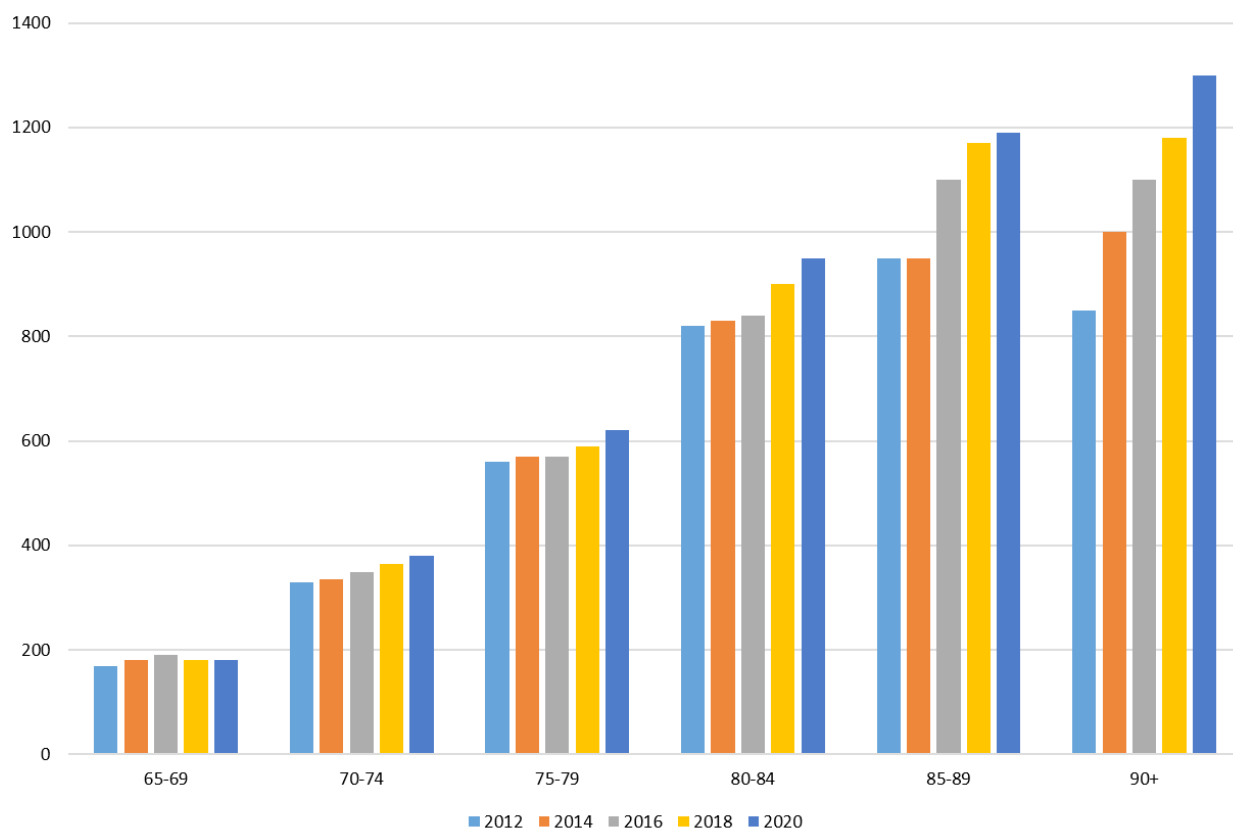
9 out of 10 people with dementia in Barnet are over 75

Prevalence of Dementia in Barnet

Dementia is one of the biggest challenges for health and social care in Barnet. Barnet has one of the largest proportions of elderly residents in London. Approximately 8% of people aged 65 years (and around 25% of people aged over 85) in Barnet have some form of dementia. In Barnet, 9 out of 10 people with dementia are over 75^{xi}. As indicated earlier, currently this means that around 4,000 people with dementia in the borough, with around just over half having been diagnosed with the illness. If people with dementia do not have a diagnosis, they are less likely to have access to support and services.

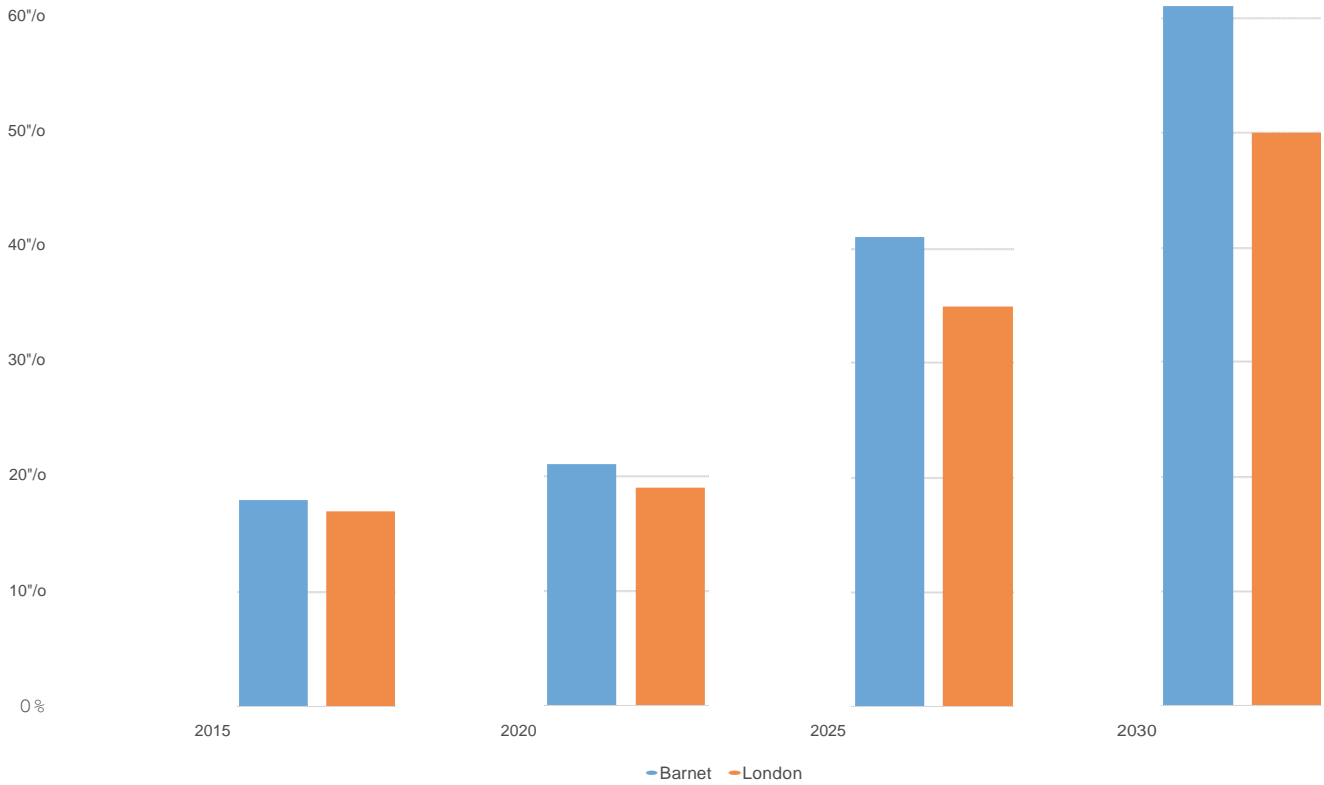
In Barnet Health and Wellbeing Report, the number of people aged 65 years and over in Barnet is projected to increase by 20% by 2020. The projected total number of people with dementia within Barnet is forecast to increase by 24% over the next 8 years compared to 19% across London. Due to the increasing life expectancy in men, the largest increase in dementia (28%) is expected to be in men aged 75 and over^{xii}.

Figure 1. Projected number of people in Barnet with Dementia by age group: Source: POPPI

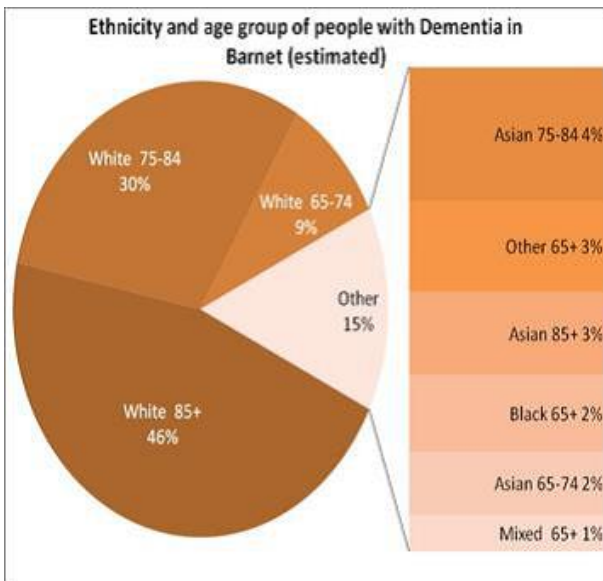


In Barnet approximately 80% of the population aged 65 and over are White. The largest ethnic minority group is Asian/ Asian British (13% of the 65+ population). Barnet will see an increase in the ethnic diversity of their older populations and thus a greater proportion of people with dementia will be from Black and Minority ethnic groups in the future^{xiii}.

Figure 2. Projected percentage increases from 2010 in number of people aged 65+ with dementia
Source: Department of Health's POPPI system 2010 estimates and projections



Ethnicity and age group of people with dementia in Barnet (estimated)



9% of people with dementia in Barnet are from Asian communities

Cost of Dementia in Barnet

The annual estimated cost in Barnet may go up to £87.8 million per year^{xiv}. Expenditure on Dementia users overall has increased, although spend per head appears to have dropped since 2007/2008. As per Barnet Joint Needs Assessment, “this is partly explained by new cheaper homecare contracts, but lower average costs in other service types particularly nursing care, may be explained by later admission dates, and facilitated by greater support out in the community”^{xv}.

To demonstrate dementia expenditure, Jewish Care, a social care charity that provides dementia services, reports that their dementia spend is nearly £13.50m per year. This is equal to 30% of their annual turnover of £45m of overall care services they provide. Their dementia day services alone cost £500,000 per year, for which they subsidise more than 80% of the service.

Assessment and Diagnosis

It is estimated that 53% of adults who have dementia are diagnosed in primary care in Barnet, which is the 5th highest of all the London boroughs^{xvi}.

The proportion of dementia patients on the primary care dementia register is higher in Barnet (0.6%) compared to any other London borough. In 2009/10, 2,038 people within Barnet were registered on GP records for dementia. These figures are likely to be grossly understated due to a lack of recording and diagnosis – in London only 37% of people with dementia are recorded on registers – but they do help illustrate both the upward trend in recent years in people presenting at GPs with dementia, as well as the particularly high incidence of dementia on Barnet registers compared to the London average. Of those on the register in Barnet at the end of 2009/10, 90% had had their care reviewed, by their GP, in the past 15 months^{xvii}.

Hospital Admission and Discharge

The rate of dementia hospital admission (per 100,000 people) in Barnet (53) is lower compared to the London (75) and England (80) averages^{xviii}. In Barnet and Chase Farm and the Royal Free hospitals (period April-March 2012/13), people with dementia stay longer in hospital than similar patients without dementia; someone with dementia is also more likely to be readmitted after a spell in hospital than similar patients without dementia, and people with dementia are more likely to die in hospital than similar patients without^{xix}.

Rate of hospital admission Per 100,000 people

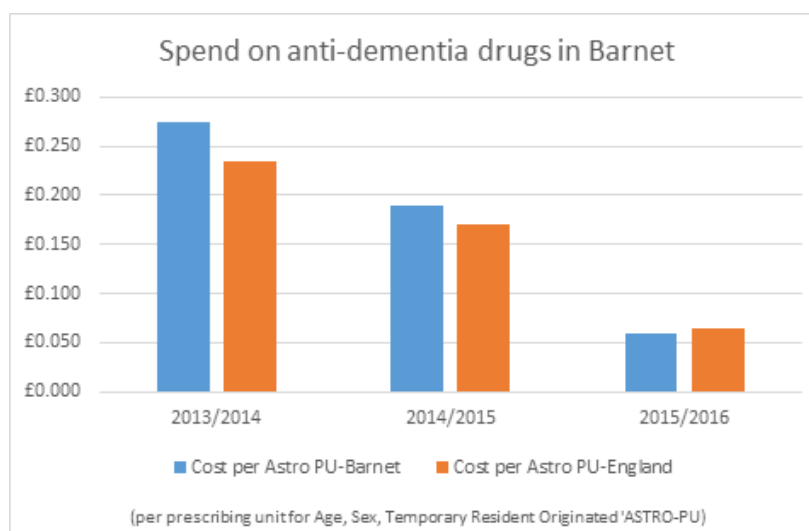
Barnet	53
London	75
England	80



Dementia Medication

A report, by NHS England, on primary care prescribing for anti-dementia drugs shows that there are different types of medication, with varying degrees of effectiveness, pending the type of dementia that is being treated^{xx}. The rate of prescribing medication used for dementia per person on the primary care dementia register in Barnet is in the mid-range for London^{xxi}.

According to Barnet CCG, total expenditure in 2013/14 is £342,132 compared to 2014/15 is £245,744^{xxii}.

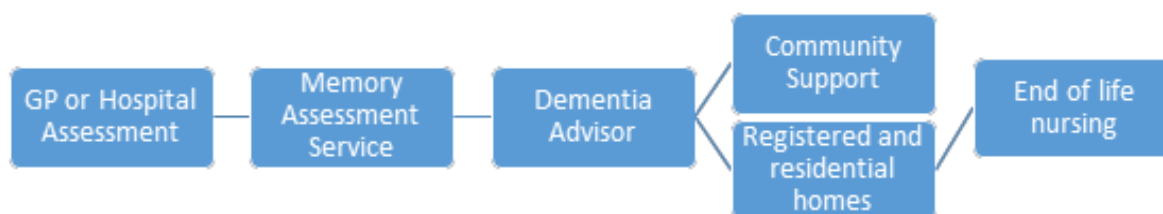


Dementia Services

There are two types of services in Barnet:

Diagnostic services:

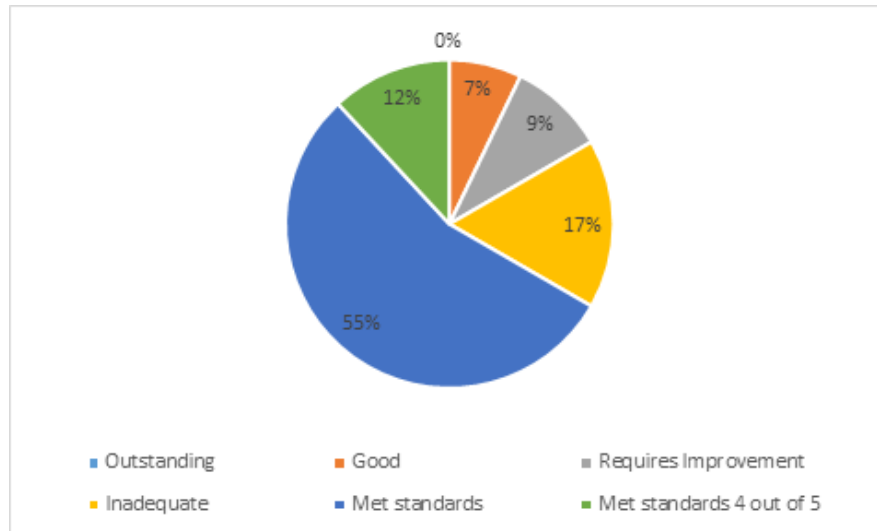
Primary Care (GPs) and Secondary Care (Memory Assessment) services work together along with the voluntary sector (Alzheimer's Society), to support patients at the point of diagnosis. See Referral Pathway figure for illustration.



Post-diagnostic services:

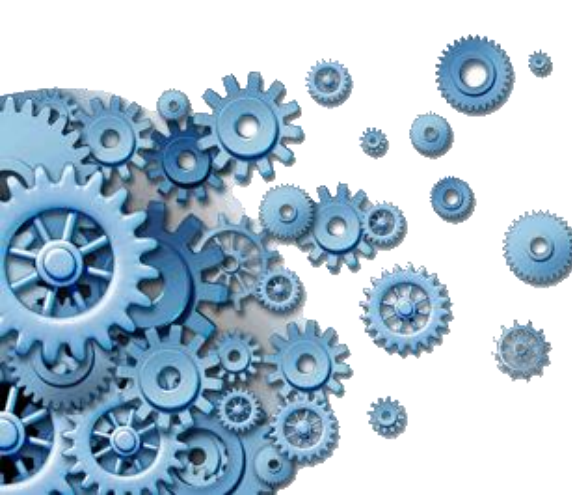
This includes day centres, support groups, social activities, care homes, end-of-life service, and carer's support. There are 41 care homes registered with the CQC, which provide an EMI service (elderly mentally impaired). Around 26% of the registered care homes are rated as 'Inadequate' or 'Requires Improvement'^{xxiii}.

Figure 5. CQC Rating for 41 Care Homes with EMI Service in Barnet



Geographical areas

It would appear that residents in all geographical areas are at risk of dementia, although GP registrations suggest that those in the South cluster are at greater risk than in other areas, particularly those in the West of the borough. Hospital admission rates suggest that patients in the South are treated more effectively to stay out of hospital, potentially because of early identification and treatment via primary care. However, these figures might be distorted by recording issues surrounding dementia at both GP and hospital level^{xxiv}.



Current challenges in Barnet

According to the Alzheimer's Society's London Dementia Manifesto^{xxv}, the current challenges in London are the following:

- 1. Postcode lottery of dementia care and support; borough support ranges significantly.**
- 2. The majority of the 25,000 people from black and ethnic minority backgrounds who have dementia in the UK are living in London. Awareness of dementia and how to treat it is often not very high in such communities, meaning that significant work can be done to provide access to relevant support. See Findings and Recommendations for an example from Barnet.**
- 3. Older people in London are far more isolated than other areas of the country.**
- 4. People with dementia occupy a quarter of all London's hospital beds. By providing an early diagnosis, as well as creating a dementia-friendly community and ensuring that support, information and advice is readily available, then this number could dramatically decrease.**

The Alzheimer's Society^{xxvi} are calling on all local councils and communities to support people (and their families/cares) with Dementia in the following ways:

- 1. Get a timely diagnosis and appropriate post-diagnosis support.**
- 2. Receive the best quality care and support.**
- 3. Feel part of a Dementia-friendly community and have choice and control over their own lives.**

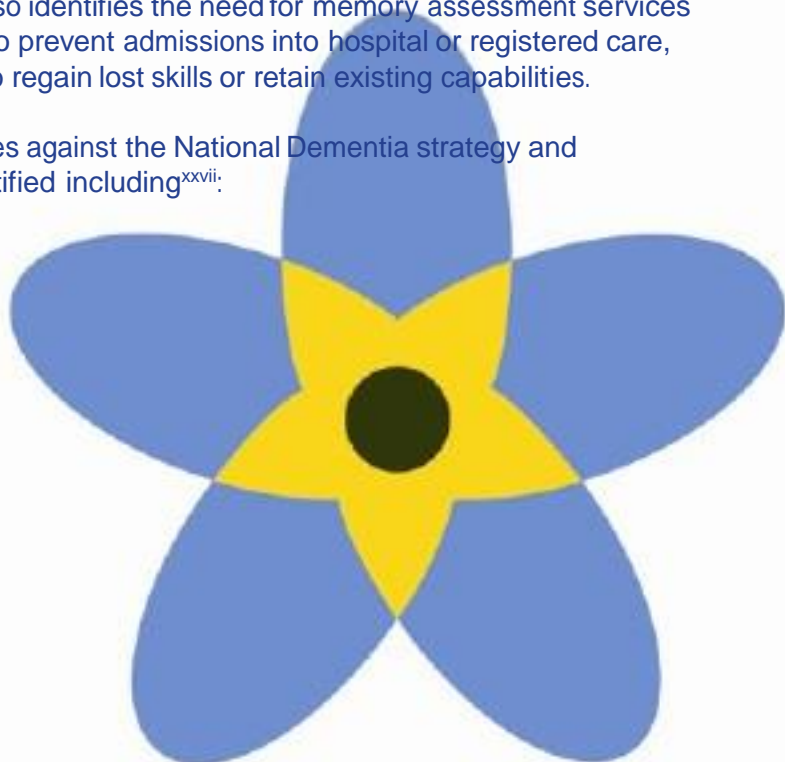
The Barnet, Enfield and Haringey Mental Health Trust's 2013-2018 Clinical Strategy sets out a strategic vision which includes:

- 1. Enhancing dementia assessment and treatment services, in order to meet the demands of the increased older population, by providing timely and accurate assessment, with subsequent treatment and support**
- 2. Integration of community and mental health services for older people to provide more seamless care, and better outcomes for mental and physical health problems**
- 3. Working with residential and nursing homes to reduce unnecessary admissions to hospital**
- 4. Working with commissioners, social services and other partners to develop new models of care for older people, including working with local acute hospitals in improving care**

However, in Barnet Joint Strategic Needs Assessment (2011-15), it is noted that two-thirds of people with dementia live out in the community, so the strategy also identifies the need for memory assessment services for early diagnosis, dementia home treatment teams to prevent admissions into hospital or registered care, and personalised services to help enable individuals to regain lost skills or retain existing capabilities.

Barnet's Dementia Action plan has mapped out services against the National Dementia strategy and identified gaps. A number of priorities have been identified including^{xxvii}:

- 1. Improving public and professional awareness**
- 2. Provision of good quality information**
- 3. Good quality early diagnosis and intervention**



Findings and Recommendations

There are some limitations to this research. A limited number of respondents participated in our survey, which is a very small number on which we cannot make quantified conclusions about findings and recommendations. This may create some bias in representing our data in statistical figures. The questions were read out to people and they discussed them in pairs then feedback was noted down. It was difficult to have more written survey responses to rate satisfaction with services. In view of the group response, this part was not felt to be practical to assess. This could be due to the fact that individuals were more comfortable to respond to our questions in focus groups and discussions. Extensive feedback and qualitative data were also collected

through these events including a case study, on all of which the following findings are based. It is important to note that these findings are likely to reflect the experiences and opinions of those who took part in the discussions, and do not necessarily represent the experience of all service users and their carers.

Research Methodology

A number of focus groups, interviews, and a case study held to demonstrate how the patients experience care on the ground. We carried out the following exercises as part of the research, totalling 170 participants, and dementia care staff:

- A focus group held with Sangam Asian Women's Association, as part of their health seminars, 120 Asian women attended.
- A group discussion facilitated at Dementia Café, Finchley Memorial, 35 people attended including carers and those with dementia.
- A survey/focus group run by Advocacy in Barnet at the Barnet Carers' Centre, 12 people (carers and patients) attended.
- A case study from a dementia carer.
- A survey carried out with Jewish Care's Service Manager for Creative Arts, Disability & Dementia and the lead social work manager for Jewish Care's Community Support and Social Work specialised Dementia Team

The number of participants includes carers, patients, and members of the public took part in this research; 12 responded to a survey, and 156 participated in events and focus groups. A sizeable number of participants were Asian female respondents, which might not be a true representation of Barnet population, but we aimed to seek the views of ethnic minority groups, which otherwise, could be under represented. Feedback demonstrates common themes, categorised as areas that are working, and areas that are not working, followed by a case study highlighting a carer's experience.

Findings

Awareness of symptoms (were you aware of symptoms?)

Some participants said yes but others said no that not until problems became pronounced. Some became aware only after six months and following their own research; usually followed on from examples of severe forgetfulness and in some cases accusations towards the carer.

Assessments were carried out by GP or Memory Clinic (Springwell), and in one case a home visit. Some had their assessment in hospital following an admission for another problem and nurse/doctor recommended an assessment.

Participants generally felt there was adequate time to ask questions, and some thought the questions odd or irrelevant.

The Assessment process

Participants indicate that information given was usually written although there was some verbal as well. Most found it useful. They indicated that information is needed to be in a more user-friendly language.

Some thought materials were written with compassion and professionalism.

Most felt they were involved in the assessment and they were as well as those who went to Springwell were very pleased with the treatment received.

Follow-up care after assessment

Concerns were expressed because the referral system now is that the Springwell Memory Clinic is only available for the first 8 weeks and then care reverts to the GP which most thought was not a good prospect.

What is working?

Communication with professionals (GPs and Memory Clinic)

- Generally, professionals show compassion, care, and respect towards the patient's needs.

Experience with the assessment process

- Patients report that they are given sufficient time to have their questions answered or raise any concerns related to their health, management of medication, or coping mechanisms.

Access to support and services

- GPs are one of the first point of contact, which makes it easier for individuals to access help in the community
- Patients and carers report that they are able to access support and services mainly via the following channels (in no particular order):
 - Individual's search for information
 - Day centres
 - Voluntary-sector organisations
 - Support services funded by trusts and local businesses
 - Social workers
 - Private services (support from a private dementia specialist or psychiatrist)

Prescribing

- Online prescribing is available as an option to obtain the medication required.

What is not working?

Dementia awareness among health professionals

- Some GPs are unable to identify patients with dementia.
- Concerns raised about their GP's competency to monitor their medication effectively.
- One patient reports that they had an incorrect diagnosis by their GP.

Dementia awareness among the general public

- Lack of information on dementia among ethnic minority groups, who are less likely to access support and services, and more likely to experience isolation.
- Some patients report that they had no access to a dementia specialist or psychiatrist, which implies that they do not necessarily have the knowledge that this service is available through their GP.

Quality of information available on dementia

- Some information provided on dementia is too clinical and difficult to understand.
- Some information provided on dementia, in other languages, is inaccurate.

Access to community-based services

- Limited access to GP's emergency appointments.
- Varying experience of a long wait from the time of referral to diagnosis, up to seven months.
- Difficulties making GP appointments online compared to phone booking.
- Lack of specialist follow-up after discharge from the Springwell Centre (Memory Clinic).
- Most agreed that GPs gave no information out about dementia either written or verbal.
- People with dementia in the early stages are unable to access Day Centre Services due to the introduction of means testing for funding. This group of users would benefit more from Day Centres than those in the later stages.

Access to secondary or tertiary-care services

- Sometimes, it is experienced that the transport system has delays with less staff to assist patients attend their hospital appointments.
- Dementia placements in care homes have limited availability

A Case Study: Joe and Lidia

Joe is aged 78 years old, and Lidia is 52.

In 2009 Joe was diagnosed with Parkinson's disease.

In 2010 Lidia stopped working to care for her husband. At the same time, she was diagnosed with fibromyalgia, with episodes of fatigue, sensitivity to pain and lack of sleep.

In 2012 Joe showed signs of deteriorating memory. For a year, Lidia made attempts with Joe's GP, to refer him to a specialist regarding his memory problems. GP responded that 'patient is 'just' forgetful'. As his memory got worse, Joe's driving presented a risk of harm to himself or others. Lidia contacted Joe's Parkinson's consultant, in order to forward latest report to DVLA to revoke her husband's driving licence.

In 2013 Joe was diagnosed with Dementia. Before the

assessment, there was no confirmation of hospital appointments in writing or communication from the memory clinic. On the day of the assessment, in mid-January, hospital transport was unreliable and delayed. Lidia says that Joe and she had to use public transport and private cab, which was very difficult to use due to Joe's mobility needs. At the appointment, Joe was fragile and frail. There was no access to toilet facility on the ground floor at the memory clinic, and it was difficult for him to use the toilet. Joe was prescribed dementia patches. He had an allergic reaction on several occasions. Lidia was unable to contact his consultant. There was no follow-up. Joe had to stop using the dementia patches.

In 2014 Lidia registered as a carer with Barnet Assist. Joe had a fall in November, and again in December, and was taken to hospital.

From 2015 to the present day. As Joe becomes increasingly forgetful and frail, his GP continues to remind Joe to attend the surgery for his appointments and blood tests. Lidia requested the GP receptionist for a visit from the district nurse. Her request was declined. Currently, Joe and Lidia are unable to find another GP locally close, and are still exploring other options to find an accessible and dementia understanding GP. Joe has been recently seeing a consultant at the Royal Free, for his Parkinson's and dementia. Joe has shown some improvement as his condition is progressing. Lidia highlights that contact with other agencies (DWP, dentist) has also been good and helpful; a gesture of kindness that was appreciated by Joe and Lidia.



Analysis

Clinical picture

- Clinical access to support: it is a commendable effort to increase access to support by identifying patients with dementia either at primary care or hospital level. This is reflected in the increasing level of primary care rate of diagnosis from 55% to 67.7% as in March 2015, and also possibly through the hospital assessment if a person is identified upon an emergency admission. The new Barnet target is set to identify 75% of people with dementia by 2017. The increasing rate of identifying patients might also be demonstrated in individuals' feedback to our survey; more than 40% are satisfied with the assessment and referral process, compared to 25% who are not^{xxviii}.
- Medication cost: since 2012, the spend, on anti-dementia drugs, has been falling down steadily, per prescription. However, the overall spend remains slightly higher than the national average, except in 2015. While drug cost is falling down, the expenditure is expected to rise. This may be due to the fact that Barnet has a larger population of patients with dementia, and a higher rate of identifying individuals with dementia compared to England average.
- Emergency admission: the number of emergency admissions, reported by the Royal Free London Trust, covers other areas besides Barnet. It is, therefore, difficult to distinguish the number of admission for Barnet only. However, as the rate of identifying patients with dementia is increasing in Barnet, a portion of these admissions are relevant to Barnet. However, since the admission rate has increased to nearly three times higher in Quarter 4 in 2014/15 compared to Quarter 4 in 2013/14 the same period, this can be due to several factors. General emergency admission can be attributed to the lack of awareness of how to manage one's condition effectively, lack of awareness of alternative community services, or lack of services itself. As this case is more specific to dementia, and per patients and carers' feedback, it is more relevant to note that the factors are related to the lack of awareness among individuals and communities, either they do not know what dementia is, or if they do, they do not necessarily know what community services are available to support them further. An increasing emergency admission could be a result of the lack of information and advice.

Community picture

- Community awareness: individuals, carers and communities repeatedly feedback that prior to diagnosis, they did not have information about dementia. Some individuals, from ethnic minority groups, report that dementia is not something to talk about with friends and family. This may make it more difficult on professionals to identify patients who are more vulnerable and harder to reach.
- Patient access to information: although Barnet is investing in identifying more individuals with dementia in GP practice at primary care level, patients and carers report that they tend to seek information about the condition through different community groups rather than clinical or professional channels. The source of information is more commonly used is non-clinical channels either getting in contact with local groups, voluntary organisations, day services, social workers, or self-search which may include the internet or family and friends.

Individuals' experience

- Confidence in primary care professionals about dementia awareness: individuals tend to have different experience with GPs. Generally, individuals tend not to have confidence in their GPs to identify someone with dementia, or to be able to monitor the use of anti-dementia drugs effectively. Patients' concerns about GP treatment and care may be due to the insufficient time a GP may have to communicate effectively with their patient, and ensuring that a patient feels that they understand their condition, care and treatment.
- Experience with professionals: it is generally mixed with positive and negative views. Some patients appreciate the support they receive from their social worker, the Springwell Centre, and a number of day centres; this both includes taking the time to talk and to listen to the patient's emotional and practical needs. Other patients would like to receive more personable support. Feedback received generally emphasises the importance of professionals reassuring patients on how to manage dementia, and what to expect on the longer term.
- Experience with facilities and services: individuals report that there is a shortage in good-quality care services, including limited availability in care homes, long wait to access services, limited number of day services, and some services are not suitable for patients who are elderly and with dementia needs. Individuals report to want to have access to ground-floor toilets, responsive hospital transport services, simplified access to make booking online for routine and emergency GP appointments, and access to good-quality day services.

Recommendations

The Health and Wellbeing Board has developed a Barnet Dementia Manifesto (October 2015). It aims to provide a local pathway offering a more integrated and flexible community-based service for both people with dementia (PWD) and their carers. Our recommendations, from a patient's experience, may complement the manifesto, as follows:

Experience focus: enhancing patient and carer's experience

- Regular communication is on the top list of patients and carers' needs, where they consistently expect sympathy and reassurance from professionals. Patients and carers appreciate to learn that the condition is manageable and support opportunities are available to maximise the quality of life. Regular communication from frontline and primary care staff and GPs with whom patients are more likely to get in contact with is essential for enhancing the patient and carer's experience with care.
- Commissioning day services that provide good-quality social activities for both patients and carers, is paramount to the patient's quality of life. This is specifically to support the patient's independence for a longer period through the means of evidence-based social, cognitive, and physical activities when appropriate.
- Providing respite support for carers is increasingly crucial to enrich the quality of life and the wellbeing of both patients and carers. Some carers tend to be elderly who care for their partners or their parents, and they may have health conditions that would require medical attention and long-term management of their own care. Respite care would support carers in their role, and give them also the care they may need.
- Providing information on financial support and resources, in partnership with the voluntary sector, through the use of 'social prescribing services' in GP practices or appropriate community centres.

Community focus: working collaboratively to respond to dementia as individuals, professionals and communities

- Raising awareness of dementia, specifically through communication channels that individuals and families already use and request for. Working in partnership with local and community groups is more likely to reach out to vulnerable groups who are at a higher risk including Asian and Black communities. This may include developing a culturally-sensitive approach to activities for raising awareness in a language and environment that are user-friendly.
- Promoting a healthy lifestyle can make a difference. There is evidence that taking on healthy habits and diet may prevent or delay the onset of dementia. Individuals value social and daily-life activities which may contribute significantly to the quality of their lives, which should be more widely publicised among communities. This includes:
 - Carrying out cognitive or mental exercises, for example, playing puzzles or word games, or learning a new language^{xxix}
 - Singing or taking part in musical groups, and attending a Dementia café regularly
 - Reducing alcohol consumption^{xxx}
 - Eating Mediterranean food; a diet, that is rich with fruits and vegetables^{xxxi}
- Involving carers in patient's treatment is increasingly becoming paramount to effective care. Communicating with carers is more likely to reduce missed medical appointments, to reduce emergency admission, and to enhance a patient's experience.

Clinical focus: supporting GPs and increasing access

- The use of dementia guides at primary care level should be encouraged. There is a number of comprehensive guides produced by various NHS and/or CCG organisations that could support GPs in managing and prescribing for dementia.
- The monitoring of GP performance for dementia should include patient experience on how they are being treated, and followed-up regularly. GPs should be encouraged to actively seek the feedback of patients and carers to improve primary care services.
- Access to good-quality community services should be available, easy and quick. This includes a shorter waiting time for a follow-up appointment with GPs, more options with day activities and centres, and assigning a key worker to work closely with the patient and their carer.

Research focus: assessing the impact of drugs and community support

- Further research on impact assessment is needed. This is to assess the impact of spending on drugs and care packages, and of spending on community support services, and how they impact the quality of a patient's life and their families.

Conclusion

There is an observation that government effort is focussed on increasing diagnosis of dementia, so people can access services and feel less isolated. The patient's experience is that they tend not to have any knowledge of dementia prior to diagnosis. Once they are able to access services, their expectation is that treatment should come from a place of sympathy, understanding and information on how to manage a

long-term condition for the rest of their lives. Carers' contribution is becoming more vital to have an effective care experience for patients, and clinicians. There is also an opportunity to promote and to adopt a healthier lifestyle including healthy diet and seeking support in community cohesion. In order to fully build resilience in the fight against dementia, collaborative efforts between health authorities, professionals, carers and communities are increasingly more needed.

Acknowledgements

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Age UK Barnet

Alzheimer's Society

Barnet Carers

Barnet CCG

Barnet Council

Barnet, Enfield and Haringey Mental Health Trust

Jewish Care

Memory Clinic, Springwell

Royal Free London Foundation Trust

Sangam Centre

Lidia and Joe

Melvin Gamp

All participants and members of the public

Community Barnet staff, members and volunteers



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References

ⁱ Barnet CCG Dementia Update, April 2015. Accessed on 4 November 2015.

<http://www.barnetccg.nhs.uk/Downloads/boardpapers/20150430/Paper%2021.0%20Dementia%20Update.pdf>

ⁱⁱ see note 1

ⁱⁱⁱ Barnet CCG & London Borough of Barnet, Older Adults Partnership Board, a Presentation of Barnet Dementia Manifesto, 15 October 2015.

^{iv} See note 1

^v This includes hospitals managed by the Royal Free London Foundation Trust, based in and outside Barnet

^{vi} NHS England, Dementia Assessment and Referral. Accessed on 10 July 2015. <http://www.england.nhs.uk/statistics/statistical-work-areas/dementia>

^{vii} Data obtained from Integrated Quality in Care Homes, Barnet Council, received on 18 December 2015.

^{viii} Barnet CCG Dementia Update, April 2015. Accessed on 4 November 2015.

<http://www.barnetccg.nhs.uk/Downloads/boardpapers/20150430/Paper%2021.0%20Dementia%20Update.pdf>

^{ix} Barnet Health and Wellbeing Report, Dementia Manifesto for London, January 2015

<http://barnet.moderngov.co.uk/documents/s20682/Dementia%20Manifesto%20January%20HWBB%20FINAL%20v1.0150115%202.pdf>

^x Barnet Joint Strategic Needs Assessment 2011-15

^{xi} London Borough of Barnet (2014), JSNA Refresh 2013/14 Dementia Barnet. Accessed on 4 November 2015

<http://barnet.moderngov.co.uk/documents/s11686/Appendix%20E%20Draft%20Dementia%20JSNA.pdf>

^{xii} See note 9

^{xiii} London Borough of Barnet (2014), JSNA Refresh 2013/14 Dementia Barnet. Accessed on 4 November 2015

<http://barnet.moderngov.co.uk/documents/s11686/Appendix%20E%20Draft%20Dementia%20JSNA.pdf>

^{xiv} Barnet: Mental Disorder Treatment Needs Assessment, Dr Jonathan Campion, September 2014

^{xv} London Borough of Barnet, (2011), Joint Strategic Needs Assessment: Barnet 2011-15. Accessed on 4 November 2015

http://www.barnetccg.nhs.uk/Downloads/Document%20Library/JSNA_2011_-_Release_version.pdf

^{xvi} see note 12

^{xvii} See note 12 and 13

^{xviii} See note 12

^{xix} Care Quality Commission, Care Update, 2013. Accessed on 4 November 2015. http://www.cqc.org.uk/sites/default/files/documents/cqc_care_update_issue_2.pdf

^{xx} Dementia Revealed, What Primary Care Needs to Know, a Primer for General Practice, July 2014. Dr Elizabeth Barrett, Shires Health Care, Hardwick CCG, and Professor Alistair Burns, NHS England

<http://www.england.nhs.uk/wp-content/uploads/2014/09/dementia-revealed-toolkit.pdf>

^{xxi} Barnet: Mental Disorder Treatment Needs Assessment, Dr Jonathan Campion, September 2014

^{xxii} Data obtained from Barnet CCG's Pharmaceutical Lead, received on 26 November 2015

^{xxiii} CQC rating was checked for 41 care homes in Barnet. The number of care homes might be different from the time this information has been obtained.

Information accessed on 4 August 2015. Some CQC reports for some care homes may follow the old rating system as inspections were done prior to the new rating measures.

^{xxiv} London Borough of Barnet, (2011), Joint Strategic Needs Assessment: Barnet 2011-15. Accessed on 4 November 2015

http://www.barnetccg.nhs.uk/Downloads/Document%20Library/JSNA_2011_-_Release_version.pdf

^{xxv} Alzheimer's Society (2014), the Dementia Manifesto for London.23/04/2015

http://www.alzheimers.org.uk/site/scripts/download_info.php?fileID=2100

^{xxvi} See note 21

^{xxvii} London Borough of Barnet (2014), JSNA Refresh 2013/14 Dementia Barnet. Accessed on 4 November 2015

<http://barnet.moderngov.co.uk/documents/s11686/Appendix%20E%20Draft%20Dementia%20JSNA.pdf>

^{xxviii} For more information on Barnet performance, please visit <https://engage.dh.gov.uk/dementiachallenge/dementia-map/>

^{xxix} Speech and language therapy provision for people with dementia, Royal College of Speech and Language Therapists, Position Paper 2014,

http://www.rcslt.org/members/publications/publications2/dementia_position_paper2014

^{xxx} Learning second language 'slows brain ageing', NHS Choices. Accessed on 26 November 2015, <http://www.nhs.uk/news/2014/06June/Pages/Learning-second-language-slows-brain-ageing.aspx>

^{xxxi} Science behind the headlines: How to reduce your risk and other popular topics, Alzheimer's Society. Accessed on 26 November 2015

https://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=2211&pageNumber=2