JSNA 2015 - Dementia

Introduction

What is dementia?

The term dementia is used to describe a syndrome in which there is impairment in cognitive function, including memory, reasoning, and communication skills, which affects the ability of the individual to carry out their activities of daily life without assistance.

Non-cognitive symptoms of dementia may also be present. Non-cognitive symptoms of dementia include hallucinations, delusions, anxiety and agitation.

People with dementia may also develop challenging behaviours. These may include aggression, wandering, hoarding and disruptive vocal activity such as shouting.

Dementia is usually characterized by a progressive decline in function, eventually leading to death.

Underlying causes of dementia

Dementia is caused by diseases or injuries which affect the function of the brain. There are a number of diseases which cause dementia.

The most common cause of dementia is Alzheimer's disease, followed by vascular dementia. Table 1 shows the estimated proportions of people with the different underlying cause of dementia in the UK.

Table 1: Causes of dementia in the UK

Underlying cause	**Proportion of UK dementia cases**
Alzheimer's disease	62%
Vascular dementia	17%
Mixed Alzheimer's and vascular dementia	10%
Parkinson's dementia	5%
Other	9%

Source: Knapp M, Prince M, Albanese E et al (2007). Dementia UK: The full report. London: Alzheimer's Society. The percentages have stayed the same in the 2014 Update.

The impact of dementia

Dementia not only impacts on the person with the condition, but also has an important impact on the family and friends of people with dementia, many of whom act as primary carers. Dementia also has a considerable wider societal and economic impact.

Many people with dementia also suffer from depression and anxiety, with as many as 63% of people with dementia reporting depression or anxiety in a recent survey[1]. (Dementia 2013)

Feelings of isolation are also common amongst people with dementia.

Mild cognitive impairment

Mild cognitive impairment is a syndrome where there is a decline in cognitive function greater than expected for a person's age, but, **unlike in dementia,** there is no notable interference with a person's ability to carry out their normal activities of daily life[2].

People with mild cognitive impairment may remain stable or improve over time. However, the majority will progress to dementia within 5 years.

Late-onset and early-onset (working-age) dementia

Traditionally there has been a distinction between late-onset dementia, which firsts manifests itself in people aged 65 or over, and early-onset dementia which affects younger aged groups. Late-onset dementia is far more common than early-onset dementia, because dementia is primarily a disease of old age. Early-onset dementia is sometimes referred to as working-age dementia. People with working age dementia often have different needs to people with late-onset dementia. People with working age dementia may for example have dependent children, still be in employment or have ageing parents who they need to care for. Getting a diagnosis of dementia can often take a longer time in people of working age, because of a general lack of awareness that dementia can occur in younger age groups.

Risk factors for dementia

Anyone can develop dementia, regardless of gender, ethnicity or lifestyle. There are, however, a number of risk factors for dementia. The most important risk factor for dementia is increasing age, which is non-modifiable.

A number of modifiable risk factors for dementia also exist, which if controlled can lead to a reduction of the risk for dementia. A clear message of 'What's good for your heart is good for your head is needed throughout preventative public health interventions and campaigns to improve public understanding of how people can reduce their risk of developing dementia[3].

[1] Alzheimer's Society. *Dementia 2013: The hidden voice of loneliness*
[2] Gauthier et al. *Mild Cognitive Impairment.* Lancet 2006; 367: 1262–70
[3] Alzheimer's Society. Public Health, prevention and dementia.

People can reduce their risk of developing Alzheimer's disease and vascular dementia by

- Eating a healthy diet
- Regular physical activity
- Managing conditions like type 2 diabetes
- Managing high blood pressure
- Avoiding smoking and excessive drinking

There is also increasing evidence that building up cognitive reserve over life can reduce risk of developing dementia. Educational attainment, complex work, and mental and social stimulation are all important, and give rise to a secondary public health messages encouraging life-long learning – 'use it or lose it'. There is also growing evidence which suggests that mid-life depression is a probable risk factor for later dementia, and its treatment should be encouraged.

National Context

There are currently around 835,000[4] people with dementia in the UK and this is estimated to rise to over 1 million people by 2025 and over 2 million by 2051.[5] Over 40,000 younger people (65 years of age or below) live with the condition. There are also estimated to be 670,000 family and friends acting as primary carers.

Nationally, dementia costs the NHS, local authorities and families an estimated 23 billion pounds.

A recent national survey of people with dementia and their carers found that many people are not living well with dementia. 17% of those surveyed reported not living well with dementia, 55% said they are living quite well with dementia and only 22% said they were living very well with dementia.[6]

The same survey also found that more than 68% of people with dementia had a gap of more than a year between when they first noticed symptoms and when they received a diagnosis[7].

In response to the significant impact of dementia on the UK population the Department of Health published 'Living well with dementia: A National Dementia Strategy' in February 2009. This national dementia strategy provides a framework for high quality dementia care across the UK.

In March 2012 the Prime Minister's Challenge on Dementia was published, with the aim of building on the National Dementia Strategy.

[4] Alzheimer's Society: Dementia 2014: Opportunity for change – England Summary, Alzheimer's Society
[5] Update of 2007 Full Report on Dementia – Alzheimer's Society, 2014
[6] Alzheimer's Society. *Dementia 2013: The hidden voice of loneliness*
[7] Alzheimer's Society. *Dementia 2013: The hidden voice of loneliness*

The Prime Minister's Challenge identified 3 key areas for action

1. Driving improvements in health and care including increasing dementia diagnosis rates.
2. Creating dementia friendly communities that understand how to help.
3. Better dementia research.

NHS Health Check Programme

The national NHS Health Checks programme to assess and improve vascular risk factors for people aged 40-74 now includes content on dementia for people attending the check who are aged 65 or over. The NHS Health Checks highlights the importance of vascular risk factors such as physical inactivity and smoking not only to heart disease, diabetes and stroke but also to dementia. The health checks will also raise awareness of the symptoms and signs of dementia.

Level of Need in Ealing

Population of people aged 65 and over in Ealing, by age group

Table 2: Population of people aged 65 and over in Ealing, by age group

Age group	Number in age group	Proportion of total population
65-69	11,721	3.4%
70-74	8,986	2.6%
75-79	7,655	2.2%
80-84	5,243	1.5%
85-89	3,043	0.9%
90+	1,814	0.5%
65+	38,462	11.2%
Total Ealing population	342,494	

Source: ONS 2013 Mid-year population estimate

Projected number of people with late-onset dementia in Ealing

In the next 10 years (by 2025) the number of people in Ealing with late-onset dementia is projected to rise to 3,729 corresponding to an increase of 34% (Table 3).

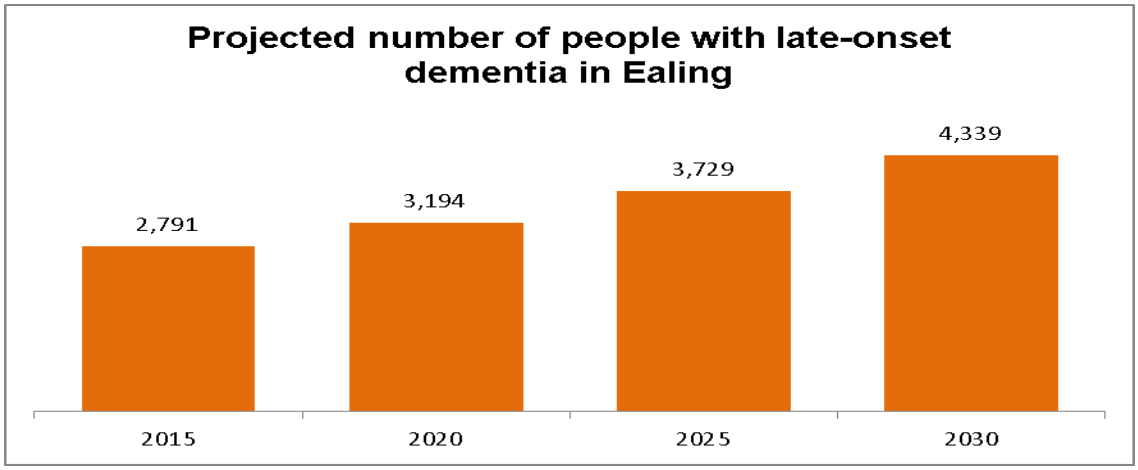
In the next 15 years (by 2030) the number of people in Ealing with late-onset dementia is projected to rise to 4,339, corresponding to an increase of 55%.

Table 3: Projected number of people with late-onset dementia in Ealing

Age group	2015	2020	2025	2030
65-69	155	167	183	212
70-74	245	306	327	363
75-79	457	463	579	627
80-84	670	738	775	976
85-89	639	778	889	950
90+	625	742	977	1,211
Total: 65+	2,791	3,194	3,729	4,339

Source: POPPI, 2014

Figure 1: Projected number of people with late-onset dementia in Ealing



Source: POPPI, 2014

National dementia prevalence rates by age-group

Table 4: National dementia prevalence rates by age-group

Age range	% males with	% females with	% all
65-69	1.5	1.8	1.7
70-74	3.1	3.0	3.0
75-79	5.3	6.6	6.0
80-84	10.3	11.7	11.1
85-89	15.1	20.2	18.3
90-94	22.6	33.0	29.9
95+	28.8	44.2	41.1

Source: 2014 Update of The Full Report: Dementia, 2007 - The Alzheimer's Society

Numbers of males and females with dementia

Of the 2,791 people estimated to have late-onset dementia it is estimated that 1730 are female (62%) and 1061 are male (38%)[8]. The higher number of females with late-onset dementia is a result of the higher numbers of females aged 65 or over in Ealing, particularly in the oldest age groups.

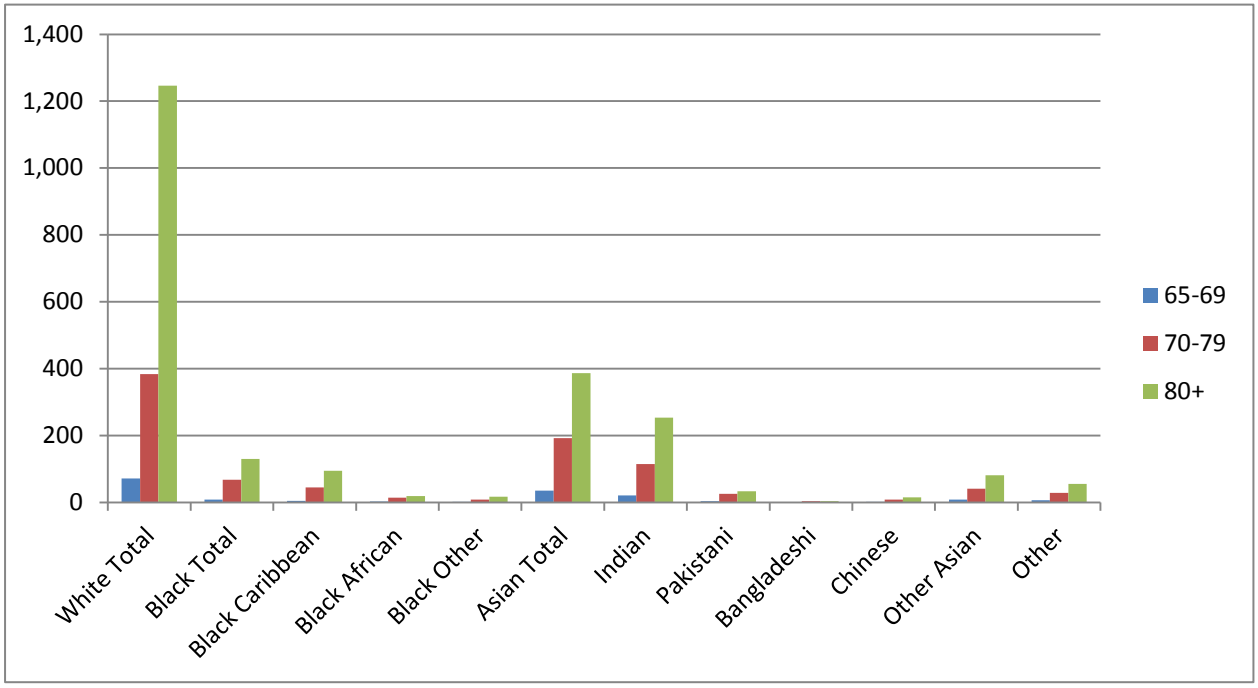
Dementia and ethnicity

In 2011, there were 25,000 people with dementia from black, Asian and minority ethnic groups in England and Wales. This number is expected to double to 50,000 by 2026 and rise to over 172,000 by 2051. This is a nearly a seven-fold increase in 40 years, compared to just over a two-fold increase in the numbers of people with dementia across the whole UK population in the same time period. Despite this, the All Party Parliamentary Group on dementia has found that people from BAME backgrounds are less likely to receive a diagnosis or support. Due to lack of evidence, the prevalence figures for BAME have not been updated in 2014[9].

Research into the experiences of people with dementia from BAME communities found that many did not receive a diagnosis of dementia, preventing them from having access to support and treatments that could help them live well with the condition. In addition to this, stigma surrounding the condition meant people with dementia and their families face social isolation, feeling unable to reach out for support. Amongst those who did seek help, there is generally felt to be a lack of culturally-sensitive dementia services.

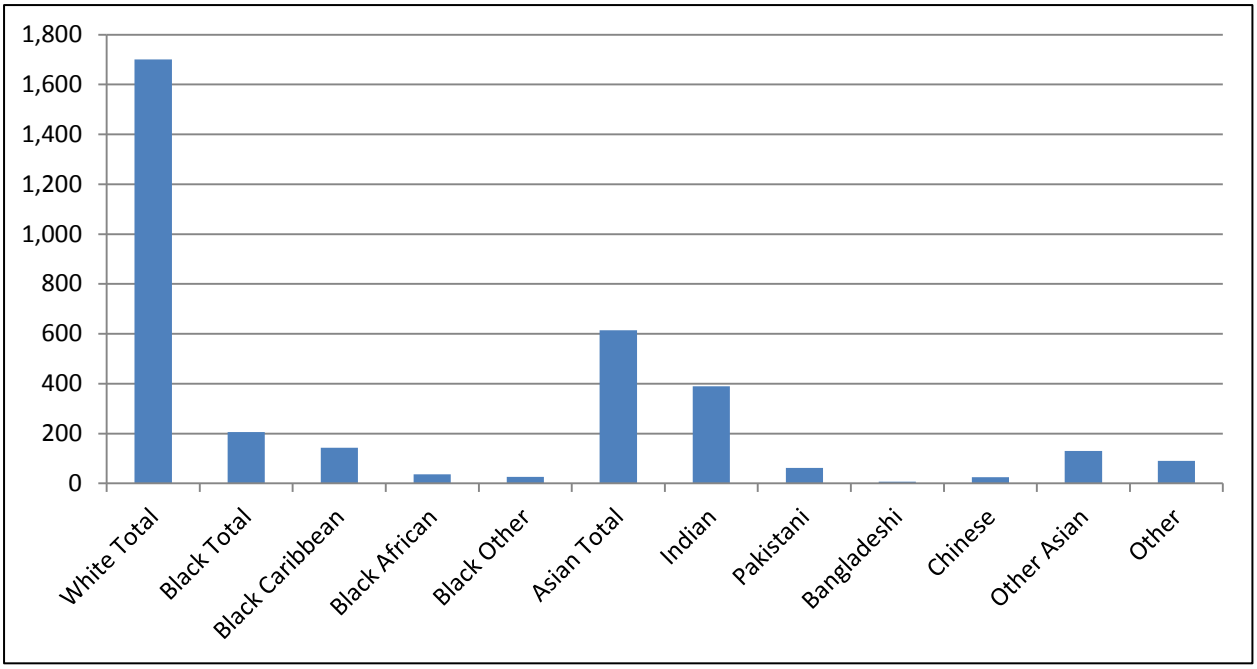
[8] Source: POPPI, 2014
[9] Alzheimer's Society

Figure 2: Estimated dementia prevalence for Ealing BAME population by age cohort



Estimated by applying prevalence rates by age cohort from the Alzheimer's society to ONS population estimates 2015 for Ealing by age cohort

Figure 3: Estimated dementia prevalence for Ealing BAME population, combined estimated total figure for over 65s



Estimated by applying prevalence rates by age cohort from the Alzheimer's society to ONS population estimates 2015 for Ealing combined total age 65+

Another estimate of the ethnic make-up of people with dementia in Ealing comes from data provided by Dementia Concern Ealing, which gives the ethnicity of 750 people with dementia in Ealing.

Although these data are not directly comparable with the ethnicity profile of Ealing's overall over 65 population due to the use of different ethnicity classifications, the proportions in various ethnic groups appear largely similar.

55.3% of people with dementia known to Dementia Concern are in white ethnic groups, compared to 66% of all over 65s,[10] 12.6% of people with dementia are classed as Asian Indian compared to 15.9% of all over 65s, and 9.7% of people with dementia are Black Caribbean compared to 5.9% of all over 65s.

Table 4: Ethnic breakdown of Dementia Concern Ealing clients with dementia (750 people)

Ethnic Group	% of total people with dementia
White British	34.3
White Irish	9.9
White Other	4.8
White Polish	6.3
Any White	55.3
Asian Bangladeshi	0.5
Asian Indian	12.6
Asian Other	2.9
Asian Pakistani	3.9
Sri Lankan	1.7
Black African	0.8
Black Caribbean	9.7
Black Other	0.8
Black Somali	1.2
British	1.5
Chinese	0.3
Mixed Other	0.1
Mixed Wh & Asian	0.5
Mixed Wh & Blk African	0.0
Mixed Wh & Blk Caribbean	0.1
Other	1.1
Not Known	6.9

Source: Dementia Concern Ealing

How well are people living with dementia?

Many people with dementia and their carers are still not living well with the condition, and quality of life remains extremely varied. We all have a role to play in developing dementia friendly communities.

[10] 2013 GLA ethnic group population projections – 2010 round

Nationally.[11]

- 1/3 of people with dementia live on their own in the community.
- However only 23% of people think it is possible for people with dementia to live on their own.
- 24% of over 55s have felt lonely in the last month.
- 38% of people with dementia feel lonely.
- 62% of people with dementia living alone feel lonely.

The right support, at the right time and in the right place, is especially important for people with dementia, to give them choice and control over the decisions that affect them. Some people will just want access to services that should be available to everyone locally, such as transport, leisure, housing and information. Some will need a little more help, for example, maintaining their homes and gardens, their physical health, and peer support networks. As people's conditions progress they will want access to good-quality personal care and intensive support. People will still want to choose how and by whom that care and support is provided, regardless of who is paying for it, and will expect to be treated with dignity and respect at all times.

Estimated severity of dementia for people with late-onset dementia in Ealing

Number of people with mild, moderate or severe dementia

The severity of dementia can be categorised into mild, moderate or severe. Because of the complexity of the condition, this categorisation is not always clear cut. Severity of dementia can be evaluated using tools such as the 30 point mini-mental state examination (MMSE).

Mild dementia (MMSE score 21/30 – 24/30): In this stage people can usually live independently, with a low level of care or supervision.

Moderate dementia (MMSE score 10-20): People with moderate dementia may require significant care and supervision to enable them to carry out their activities of daily living.

Severe dementia (MMSE score <10): Usually severe impairment of daily activities with constant supervision required.

National estimates for the proportion of people with dementia which fit into each category can be applied to the estimated population of people over the age of 65 in Ealing with dementia (table 5).

[11] Alzheimer's Society. Dementia 2013

Table 5: Estimated severity of dementia for people with late-onset dementia in Ealing

Severity of dementia	Number of people (% of total)
Mild	1535 (55%)
Moderate	893 (32%)
Severe	363 (13%)
Total*	2791

Source: Dementia UK 2007: Dementia: The Full Report (updated 2014)
**POPPI Estimate for 2015*

Estimated number of people with late-onset dementia living in their own homes or in care homes

An estimate of the number of people in Ealing living in care homes and in their own homes can be obtained by applying national estimates of residence type to Ealing's population with dementia[12].

Using this method it is estimated that 1,758 people (63%) with late onset dementia in Ealing live in their own homes and 1,033 live in care homes (37%). There is however significant uncertainty about the accuracy of this estimate.

Of 750 people with dementia living in their own homes in Ealing, who are known to Dementia Concern, 35% are living alone.

Gap between modelled and recorded prevalence of late-onset dementia

Patients with a recorded diagnosis of dementia on GP registers can be compared to the estimated dementia prevalence amongst people registered with Ealing GPs[13].

In 2013/14 1,276 patients were recorded as having late-onset dementia on GP registers in Ealing[14]. This corresponded to 46.6% of the modelled prevalence of dementia amongst the population registered with Ealing GPs. This percentage can be referred to as the diagnosis rate for dementia.

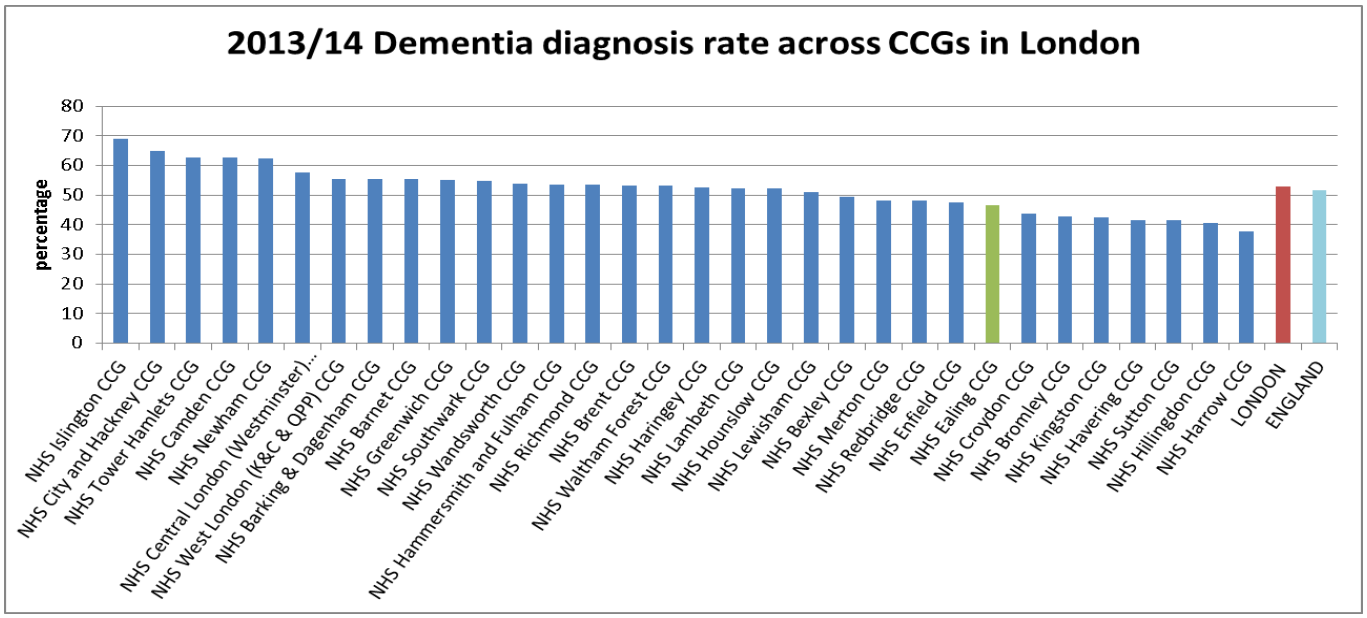
Figure 2 shows how this diagnosis rate of 46.6% in the area now covered by Ealing Clinical Commissioning Group compares to clinical commissioning groups across London. The average diagnosis rate for London in 2013/14 was 53.0% and for England 51.8%.

Figure 2: Dementia Diagnosis Rates across Clinical Commissioning Groups

[12] Estimates taken from: Dementia UK 2007: Dementia: The Full Report.

[13] Note that the number of people projected to have dementia amongst Ealing's GP registered population is higher than amongst Ealing's resident population, because GP registered population also includes people living outside Ealing.

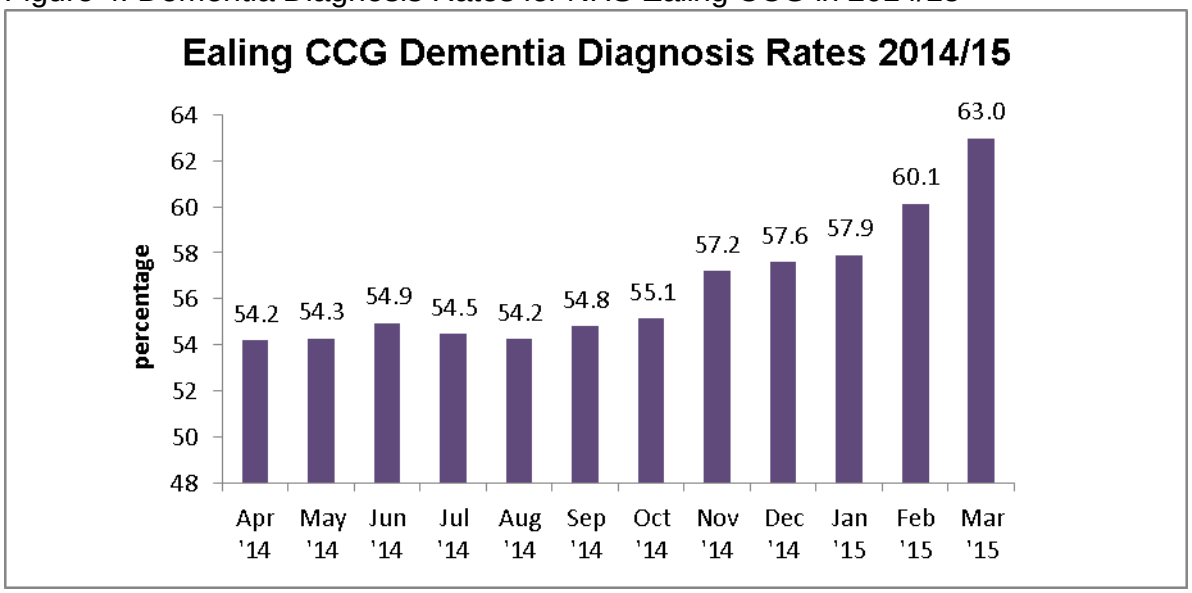
[14] Source: NHS Indicators, 2015



Source: NHS England Dementia prevalence calculator (Primary Care Web Tool), 2015

Figure 3 below shows the improvement in dementia diagnostic rates in Ealing over 2014/15. In March 2015 there were 2,012 people on dementia registers in Ealing GP practices[15] and an estimated additional 1,183 people with dementia who are currently undiagnosed (diagnosis rate of 63%).

Figure 4: Dementia Diagnosis Rates for NHS Ealing CCG in 2014/15



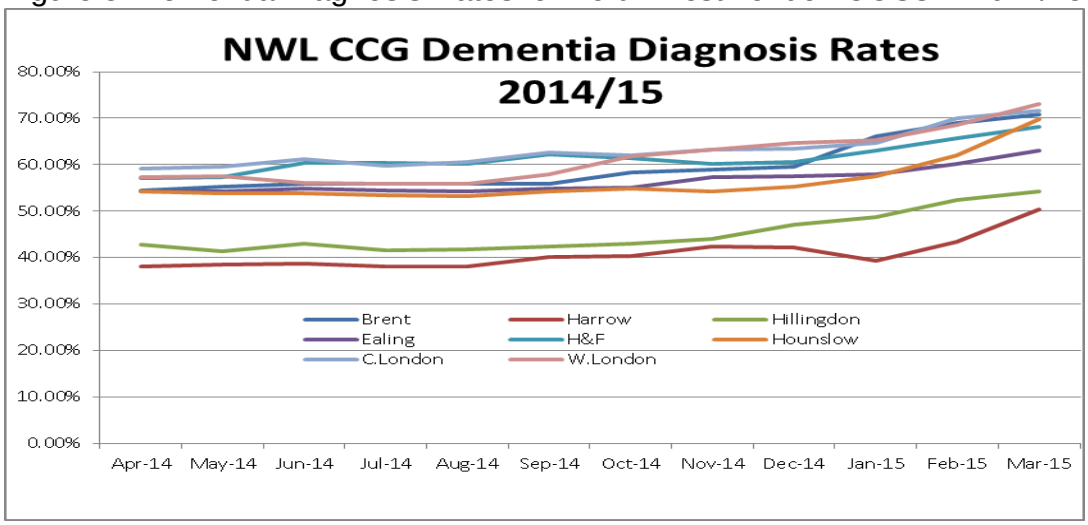
Source: NHS England Dementia prevalence calculator (Primary Care Web Tool), 2015

NHSE set a diagnostic ambition of 67% of people with dementia to be diagnosed and on GP QOF Vase register by April 2015. Current London rate is 65.79% Ealing achieved 63%

[15] QOF Recorded Dementia Diagnoses – April 2014 to March 2015

in March 2015, up from 54% in April 2014. A further increase of 4% will be required to achieve 67% by March 2016.

Figure 5: Dementia Diagnosis Rates for North West London CCGs in 2014/15



Source: NHS England Dementia prevalence calculator (Primary Care Web Tool), 2015

Prevalence of working-age dementia (early-onset dementia) in Ealing

In working age or early-onset dementia, symptoms start below the age of 65. Working-age dementia is much less common than late-onset dementia, accounting for less than 2% of all cases of dementia nationally.

2013 data from local memory clinic services suggests that there are more than 300 Ealing residents with working age dementia.

This number is much higher than estimates generated by applying national prevalence rates of early onset dementia to Ealing's population structure suggest that in 2015, which estimate there are only 76 people in Ealing with early-onset dementia[16]. This disparity between the estimated number of working age dementia cases and local data needs further investigation.

Evidence of what works?

Summary of evidence-based good practice for dementia

NICE has produced comprehensive evidence and consensus-based guidance on good practice in health and social care for dementia.[17]

A number of the key recommendations from the NICE guidance are summarised here.

1. Prevention, diagnosis and assessment

[16] Source: PANSI, 2014
[17] NICE and SCIE: *Quick reference guide for Dementia* (revised 2011)

In middle-aged and older people, vascular risk factors for dementia should be reviewed and treated.

General population screening for dementia is NOT recommended

People with suspected dementia should be screened for physical causes of memory problems and referred to specialised memory assessment services as appropriate.

Memory assessment services (provided by a memory assessment clinic or community mental health teams) should be the single point of referral for people with possible dementia.

A diagnosis of dementia should only be made after a comprehensive assessment including:

- History taking
- Cognitive and mental state examination
- Physical examination
- Medication review
- Brain imaging (MRI preferred)

People who are assessed for possible dementia should be asked whether they wish to know the diagnosis and with whom it should be shared.

Following a diagnosis of dementia, verbal and written information should be given on:

- Course and prognosis
- Local care and support services
- Treatments
- Sources of financial and legal advice and advocacy
- Medico-legal issues including driving

2. Promoting independence and maintaining function

Health and social care staff should aim to promote and maintain the independence, including
mobility, of people with dementia. Essential components of good care include

- Consistent and stable staffing
- Retaining a familiar environment
- Minimising relocations
- Flexibility to accommodate fluctuating abilities
- ADL advice and skill training from an occupational therapist
- Advice about independent toileting skills
- Environmental modifications to aid independence
- Physical exercise, with assessment and advice from a physiotherapist when needed.
-

3. Interventions for cognitive symptoms and maintenance of function

Pharmacological

The three acetylcholinesterase (AChE) inhibitors donepezil, galantamine and rivastigmine are recommended as options for managing mild to moderate Alzheimer's disease.

- Treatment should be initiated by specialist services.
- Treatment should be reviewed by an appropriate specialist team, unless there are locally agreed protocols for shared care (with primary care).

Non-pharmacological treatments

People with mild-to-moderate dementia should be offered the opportunity to participate in a structured group cognitive stimulation programme.

4. Interventions for non-cognitive symptoms and behaviour that challenges

People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, should be offered an assessment and treatment at an early opportunity.

Anti-psychotic medication should be considered only if there is severe distress or an immediate risk of harm to the person with dementia or others.

5. Palliative and end of life care

A palliative care approach should be adopted from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing.

6. Support for carers

Health and social care managers should ensure that the rights of carers to an assessment of needs.

Care plans for carers should include tailored interventions, such as:

- individual or group psychoeducation
- peer-support groups
- telephone and internet information and support
- training courses about dementia, and dementia-care problem solving.

Psychological therapy (including cognitive behavioural therapy) should be offered to carers who experience psychological distress.

Carers of people with dementia should have access to a comprehensive range of respite services.

7. End of Life-Care

Adopt a palliative care approach from diagnosis until death to support the quality of life of people with dementia and to enable them to die with dignity and in the place of their choosing.

Ensure people with dementia have the same access to palliative care services as others.

8. Co-ordination of care

Health and social care managers should coordinate and integrate the work of agencies involved in the care of people with dementia.

9. Staff training

Health and social care managers should ensure all staff working with older people in the health, social care and voluntary sectors have access to dementia-care training.

NICE quality standards for dementia care

NICE has also published two documents which identify key quality standards for dementia care. The first document (**NICE QS1)**, published in 2010 gives 10 key quality standards for dementia care as follows:

1. People with dementia receive care from staff appropriately trained in dementia care.

2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.

3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.

4. People with dementia have an assessment and an on-going personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.

5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of :
   - advance statements and advance decisions to refuse treatment
   - Lasting Power of Attorney
   - Preferred Priorities of Care.

6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.

7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors.

8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.

9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

The second quality standards document, published in 2013 gives 10 key quality standards for supporting people to live well with dementia as follows **(NICE QS30)**

1. People worried about possible dementia in themselves or someone they know can discuss their concerns, and the options of seeking a diagnosis, with someone with knowledge and expertise.

2. People with dementia, with the involvement of their carers, have choice and control in decisions affecting their care and support.

3. People with dementia participate, with the involvement of their carers, in a review of their needs and preferences when their circumstances change

4. People with dementia are enabled, with the involvement of their carers, to take part in leisure activities during their day based on individual interest and choice.

5. People with dementia are enabled, with the involvement of their carers, to maintain and develop relationships.

6. People with dementia are enabled, with the involvement of their carers, to access services that help maintain their physical and mental health and wellbeing.

7. People with dementia live in housing that meets their specific needs.

8. People with dementia have opportunities, with the involvement of their carers, to participate in and influence the design, planning, evaluation and delivery of services.

9. People with dementia are enabled, with the involvement of their carers, to access independent advocacy services.

10. People with dementia are enabled, with the involvement of their carers, to maintain and develop their involvement in and contribution to their community.

Supplementary evidence review

In order to supplement information summarised in the NICE guidance above, a number of rapid literature searches were performed to look for key evidence in the following areas of dementia care that had been highlighted as key local considerations by stakeholders.

- The benefits of early diagnosis
- Effectiveness of memory clinics
- Ethnicity related barriers to dementia care

1. Early diagnosis

The World Alzheimer Report 2011- The benefits of early diagnosis and intervention[18], provides a comprehensive review of the benefits of early diagnosis for dementia.

This review found:

- A lack of quantitative studies looking at clinical/quality of life benefits of early diagnosis
- Evidence for benefits of early diagnosis is therefore based on expert opinion and experience
- Benefits of early diagnosis cited by experts include:
    - better general medical care
    - better understanding of symptoms, less resulting anxiety and better quality of life
    - more advanced directives
    - fewer unmet needs for dementia-specific care
    - fewer accidents
    - better clinical outcomes
    - lower health care and societal costs.

2. The effectiveness of memory clinics for dementia care

A narrative (non-systematic) overview of evidence for the effectiveness of memory clinics published in 2009 reported that:[19]

- For diagnostic assessment:
    - Randomized trials have reported improved quality of life outcomes for people with dementia and their carers who are diagnosed and assessed in memory clinics compared to those experiencing usual care.
- For on-going treatment for dementia:
    - There is a lack of randomised studies looking at the effectiveness of memory clinics for on-going treatment.

3. Ethnicity related barriers to dementia care.

A systematic review of studies, which included studies from the UK, looked at ethnicity related barriers to accessing dementia care and reported:[20]

[18] The World Alzheimer Report 2011- *The benefits of early diagnosis and intervention*

[19] Melis et al 2009: *Are memory clinics effective? The odds are in favour of their benefit, but conclusive evidence is not yet available*. J R Soc Med 2009: **102:** 456–457.

- Barriers to accessing care in BME groups included:
  - Personal beliefs about the causes of dementia
  - Shame and stigma
  - Negative experiences of healthcare services.
- Increased knowledge about dementia and recognition that dementia is an illness encouraged people in BME groups to seek help for dementia

Current Interventions and Assets

Hospital admissions for dementia

People with dementia are substantial users of hospital care. In 2001 the National Service Framework for Older People found that older people (over 65 years of age) are the core patient group in acute hospitals, accounting for 60%of hospital bed days in the UK (Department of Health, 2001). Of this 60%, research found that up to 40% have dementia (Holmes and House, 2000), meaning that people with dementia over 65 years are using up to one quarter of hospital beds at any one time[21].

Local hospital episodes data shows that in 2013/14, 1479 people in Ealing were admitted to general hospital who had a recorded primary or secondary diagnosis of dementia[22]. Of these, 1372 (93%) were admitted through accident and emergency.

The total cost of these admissions given by the payment by results tariff was £4,820,885. The true cost of hospital admissions for people for dementia is, however, likely to be considerably more, firstly because there was no data on cost available for 4.5% of the recorded dementia admissions and secondly because the number of dementia admissions is likely to be an underestimate due to a lack in complete recording of dementia diagnoses.

The mean length of stay for people with dementia admitted to hospital was 15.8 days. 356 admissions were of 21 days or more (24% of total).

Table 6: Age of patients with diagnosis of dementia admitted to hospital with a mean length of hospital stay in days

Age group	Number of admissions	Mean length of hospital stay (days)
35-64	47	28.6
65-74	209	15.6
75-84	554	15.2
85-94	613	15.2
95+	56	12.8

[20] Mukadam et al 2011. *A systematic review of ethnicity and pathways to care in dementia.* Int J Geriatr Psychiatry 2011; 26: 12–20.
[21] Counting the Cost Report – Alzheimer's Society, 2009
[22] Local SUS data: Diagnostic codes for dementia (F00 – F03, G30, G31.0)

Source: Local SUS data, 2013/14

Table 6 above shows that the majority of admissions for Ealing residents with dementia were for more than 15 days. 3 patients in the age group under 65 had a length of hospital stay beyond 200 days (with one of them staying over 400 days), hence the high mean length of stay for that age group.

The main causes of admission in people with dementia in Ealing are shown in the table below. Urinary tract infection, followed by pneumonia and falls, fractures or wounds were the three leading causes of admission. Many of these admissions are likely to be preventable, for example by early detection and treatment of urinary tract and respiratory infections or through falls prevention interventions. Dementia was given as the primary reason for diagnosis in only 6.6% of admissions.

Table 7: Primary cause for cause for admissions to hospital in Ealing residents with dementia

Primary diagnosis	Number of hospital admissions for people with dementia	Proportion of hospital admissions for people with dementia
Urinary tract infection	172	11.6%
Pneumonia or lower respiratory tract infection	238	16.1%
Falls, fractures or wounds.	168	11.4%
Any dementia primary diagnosis	98	6.6%

Source: Local SUS data: 2013/14

Dementia and learning disability

People with learning disabilities have an increased likelihood of developing dementia at an early age, and this is most pronounced for people with Down syndrome, who may develop dementia in their 30s[23].

The Community Learning Disability Team has its own 'Memory Clinic', which currently assesses and supports 24 adults with learning disabilities who are either diagnosed with dementia, show possible early signs of relative decline, or are known to be at higher risk of developing dementia. 7 of these 24 people have a confirmed diagnosis of dementia.

Not all Ealing residents with learning disability are known to the community learning disability team, so there are likely to be further unidentified people living in Ealing with both learning disability and dementia.

[23] Royal College of Psychiatrists and The British Psychological Society (2009). Dementia and People with Learning Disabilities: Guidance on the assessment, diagnosis, treatment and support of people with learning disabilities who develop dementia.

London Borough of Ealing's annual spend on care home placements and home care for older people

As of June 2015, there are 476 Ealing's residents with dementia in residential placements. The average annual cost per person is £19,472 with a weekly cost of £374. The projected cost of residential care for 2015/16 is £9,268,626.

Specialist services for people with dementia and their carers in Ealing

The Limes

Location of service: 10 Merrick Road, Southall, UB2 4AU

Description of service: The Limes unit is a bedded unit that provides rehabilitation and recovery services for adults with complex mental health needs, including those with dementia.
The Limes has a total of 20 beds.

Level of service use: In 2014/15, 2 of 9 females and 4 of 9 males in The Limes had a primary diagnosis of dementia. There were 3 admissions of the patients with dementia in the same year.

Provider of service: West London Mental Health Trust

Jubilee Ward

Location of service: St Bernard's Hospital, Uxbridge Road, Southall UB1 3EU.

Description of service: Specialist in-patient ward providing acute care and treatment for older people (male and female) with primary mental health needs including dementia.

Level of service use: There are 18 in-patient beds on Jubilee Ward, with people with dementia accounting for around 25% of total bed occupancy. There were 6 admissions of patients with dementia in 2014/15.

Provider of service: West London Mental Health Trust

London Borough of Ealing Day Centres for people with dementia

Location of services: 2 sites. Sycamore Lodge, Acton. Elm Lodge, Greenford.

Description of service: Day opportunities (day care) for people with dementia.

Level of service use: Sycamore Lodge: 30 places per day (62 users of service in total). Elm Lodge: 30 places per day (79 users of service in total).

In 2014/15 there were 543 admissions of people with diagnosed dementia at Elm Lodge, whilst Sycamore Lodge had 766 admissions during the same period.

From the total of 1309 admissions of people with diagnosed dementia, 61% (797) were female and 39% (512) were male. 37 of the total number were aged between 36 and 64.

London Borough of Ealing day services closed in May 15 (memory service).

Provider of service: West London Mental Health Trust

Ealing Liaison Psychiatric Service

Location of service: Ealing General Hospital

Description of service: 24/7 service open to people presenting with urgent mental health needs, including delirium or dementia at Accident and Emergency (A&E) or the Urgent Care Centre (UCC), as well as whilst an in-patient at Ealing General Hospital.

People with diagnosed or suspected dementia or cognitive impairment have access to consultant-led assessment and treatment when they are admitted to the hospital or A&E for symptoms caused by their dementia or by unrelated medical problems. Access is within 24 hours for ward referrals or within 1 hour for referrals from A&E.

Level of service use: 216 referrals in 2014/2015 for people with a pre-existing or new primary diagnosis of dementia (average of 18 referrals per month).

There is also likely to be a further cohort of patients who are seen by the team with dementia or cognitive impairment, when dementia is not recorded as a primary diagnosis.

Provider of service: West London Mental Health Trust

Services provided by Dementia Concern Ealing and Alzheimer's Society

Dementia Concern Ealing

Description of services: Dementia Concern currently delivers the following services to people with dementia and their carers living in the community in Ealing.

Dementia Concern Ealing currently provides services for 675 people with dementia in Ealing

1. Assessment service
    - Assessing or reassessing the person with dementia and his or her carer, enabling them to gain access to a wide variety of services – provided by Dementia Concern or externally
    - Reviews, screening and monitoring service
2. Advice & Information (One-to-one)
3. Welfare Benefits Advice and Support Service
4. Client representation service
5. Hospital Customer representation service
6. Emotional Support
7. Weekend Day Care (25 spaces per day at both Elm Lodge and Sycamore Lodge)
8. Community Support Work - Monitoring and support for people with dementia living alone with high levels of need
9. Call and Care- Short breaks for carers and support for people with dementia in their own homes.
10. Working Age Dementia Day Care service
11. Information, support & social activities (from the Hobbayne Centre)
12. Carers' information Evenings
13. Carers' Voice Newsletter
14. Dementia Café – Ealing Town Hall
15. Former Carers' Support Group
16. Christmas Lunch

Alzheimer's Society

Description of services: The Alzheimer's Society provides the following services to people with dementia and their carers in Ealing.

1. Dementia support worker

2. Monthly Memory Lane Café at Greenford Community Centre, 170 Oldfield Lane South, Greenford UB6 9JS.
    - This is a place to meet friendly and supportive people affected by dementia and spend time sharing information and experiences.

3. The Carer Information and Support Programme (CrISP).

- A series of workshops for people caring for a family member or friend with dementia.
- First programme for Ealing residents currently being delivered to 11 carers.

Social care and continuing care for people with dementia

A full description of all other health and social care services used by people with dementia and their carers is beyond the scope of this needs assessment. However, information on a selected number of key services is described here.

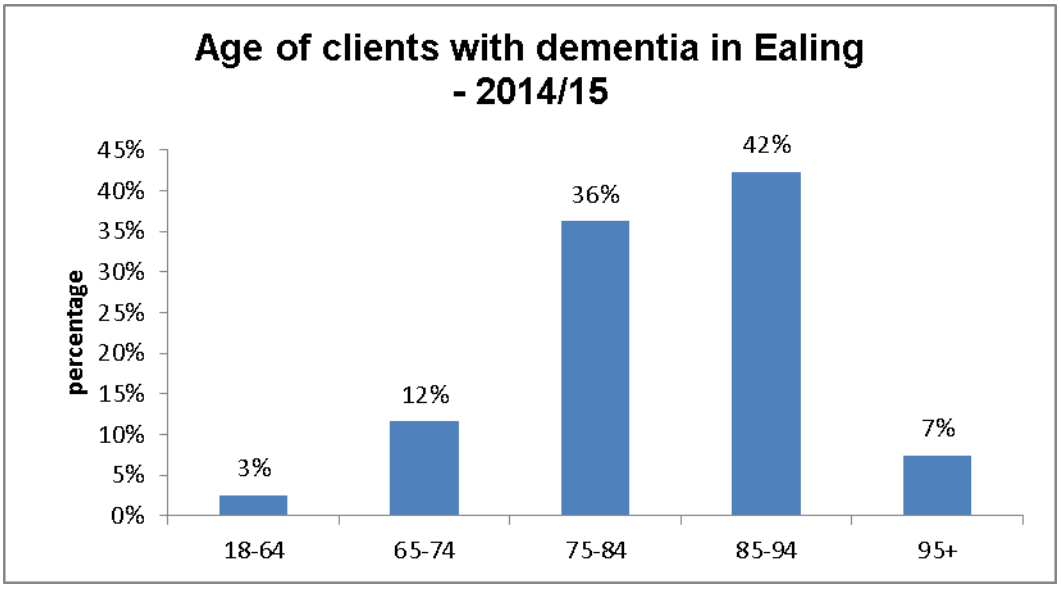
Social care

In 2014/15 London Borough of Ealing Adult Social Care team made an assessment of 2183 clients, of these 119 were recorded as having dementia (5%). This is likely to be a significant under-estimate of the number of people with dementia, due to limitations in the recording of this data.

In the same year, there were 473 Ealing Adult Social Services clients whose primary support reason was dementia and a further 552 who had a different primary support reason, but they had a recorded health condition of dementia.

In 2014/15 there were 26 clients with recorded dementia who were aged under 65. The highest number of clients with dementia were aged 85-94 (433 people), followed by 75-84 age group (371 people) (Figure 5).

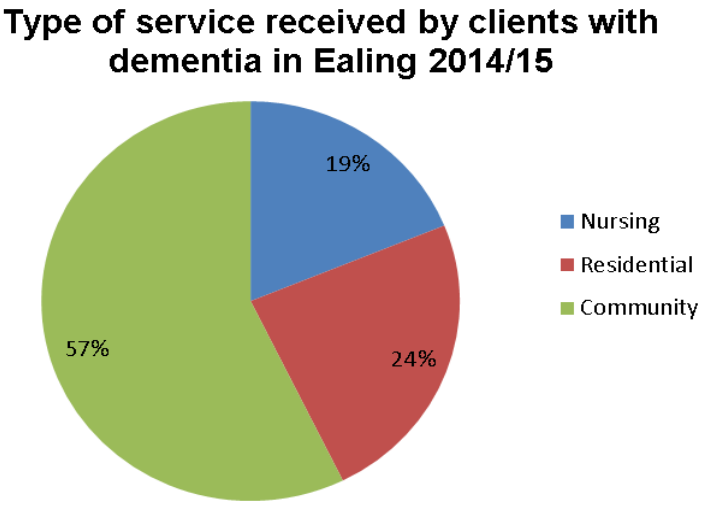
Figure 6: Age of Ealing Adult Social Services clients with recorded dementia



Source: Ealing Adult Social Services

From the total number of 1025, 193 (19%) received nursing support, 245 (24%) residential and 587 (57%) community support in 2014/15 (Figure 6). 645 of clients were female (63%) and 380 male (37%).

Figure 7: Type of service received by clients with dementia



Home care (domiciliary) for people with dementia

The London Borough of Ealing provided home care for 384 customers with dementia in 2014/15. 10 of these customers were aged under 65. This is likely to be a significant under-estimate of the number of people with dementia receiving home care, due to limitations in the recording of this data.

Care home provision for people with dementia

Data from London Borough of Ealing's Adult Social Care team, reports that in 2014, 245 of 713 Ealing residents in residential homes (34%) and 193 of 455 residents in nursing homes (42%) had a diagnosis of dementia recorded on their information system. Again, this is likely to be a significant under-estimate of the number of people with dementia in care homes.

Ealing Dementia Action Alliance

The Ealing Dementia Action Alliance is made up of organisations working across the borough to make the lives of people living with dementia and their carers better. By taking positive action to make a difference to the lives of those affected locally.

Progress since last JSNA chapter and gaps

There has been good progress on a number of recommendations made in the JSNA 2012 dementia chapter some of which are mentioned below

Completed actions

- London Borough of Ealing have commissioned specialist domiciliary services to provide tailored support for people with dementia with complex needs

Ongoing actions

- There has been an increase in the number of people presenting to primary care with symptoms of dementia. Ongoing work needs to be done to ensure that this continues through awareness campaigns
- Local commissioners and providers have been working to improve ways of reducing acute admissions to hospital by improving pathway design and training for staff.
- The voluntary sector have been working to provide information and support to people with dementia and their carers
- Commissioners and providers have been working on improving shared protocols between primary and secondary care
- Local providers have been working on improving service activity data monitoring. There is an ongoing need to improve data cleansing and coding
- People have been trained to be dementia friends and dementia champion events have been held in the borough. Training is to be rolled out more widely once more champions are trained

New gap

- More work needs to be done to improve care home capacity to deal with challenging behaviour

Recommendations for commissioners

- To increase the number of care homes in the borough able to look after people with challenging behaviour and complex needs
- To develop alternative models of respite care other than bedded respite care for people with dementia, such as domiciliary care
- To improve post diagnostic support for people with dementia and their carers including better, more accessible and timely information, crisis response and support, support for carers
- To continue to improve towards improving diagnosis rates, pathways and recording of data for people with dementia
- To locally raise public and professional awareness on the signs and symptoms of dementia and the links to vascular risk factors
- To raise awareness and access to dementia services amongst people with learning disabilities

- To continue to increase awareness and access to dementia services amongst South Asian and BME groups by exploring imaginative and innovative approaches via existing community groups and activities
- To continue to work towards making Ealing a dementia friendly community together with the wider community including commercial businesses, service industries, leisure facilities. To ensure that public facing staff especially those in the local authority and NHS receive appropriate dementia awareness training.
- To locally work to destigmatize and promote positive attitudes towards dementia and improve the lives of people living and affected by dementia as part of any national campaigns