7.26 Dementia

Contributors: Arabjan Iqbal, Stasha Jan, Mary Knower

The term 'dementia' describes a set of symptoms which include loss of memory, mood changes, and problems with communication and reasoning. These symptoms occur when the brain is damaged by certain diseases, including Alzheimer's disease and damage caused by a series of small strokes.

The Prime Ministers' Challenge on Dementia 2020[1] sets out the vision to provide high quality care for people with dementia from diagnosis to the end of their life. This is done through raising public awareness of dementia through dementia friends and dementia friendly communities and the G8 dementia summit showcasing research and development both nationally and internationally.

Dementia is progressive[2], which means the symptoms will gradually get worse. How fast dementia progresses will depend on the individual person and what type of dementia they have. Each person is unique and will experience dementia in an individual way. It is often the case that the person's family and friends are more concerned about the symptoms than the person may be themselves. Early symptoms of dementia[3] may include the following:

- Loss of memory − this particularly affects short-term memory, for example forgetting what happened earlier in the day, not being able to recall conversations, being repetitive or forgetting the way home from the shops. Long-term memory is usually still quite good.
- Mood changes − people with dementia may be withdrawn, sad, frightened or angry about what is happening to them.
- Communication problems − including problems finding the right words for things, for example describing the function of an item instead of naming it.

In the later stages of dementia[4] the person affected will have problems carrying out everyday tasks and will become increasingly dependent on other people.

Recorded dementia prevalence is relatively low in Barking and Dagenham according to the Quality Outcomes Framework, though the total of dementia cases as a proportion of the total population is affected by the fact that the area has a relatively youthful population. In 2014/15 the overall prevalence rate of dementia (the percent crude rate, unadjusted for age structure) recorded by GP practices in Barking and Dagenham CCG was 0.36% (i.e. 36 cases per 10,000 population) compared with 0.74% for England as a whole.

The variation in prevalence rates between practices was considerable, from 0.07% to 1.6%[5], though genuine differences exist because practices vary in responsibilities for frail populations (e.g. patients in nursing homes). It is likely that dementia

[1] https://www.gov.uk/government/publications/prime-ministers-challenge-on-dementia-2020
[2] http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200363
[3] http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200341
[4] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=101
[5] http://www.hscic.gov.uk/qof

prevalence is under recorded, meaning that individuals and their families may not receiving the help they need, though this is a general problem not restricted to the local area.

The dementia diagnosis rate for Barking and Dagenham within the dementia prevalence cohort is better than the national average, standing at 67.6% compared to 66.6% across England as a whole (June 2016). A total of 920 (aged 65+) patients registered compares to 1,362 expected within the dementia prevalence cohort[6]. As a further indicator of primary care, for those patients who are recorded as having dementia, 83.9% have had their care reviewed in the previous 12 months, similar to the England level of 84%[7]. There are continous strives being made across the partnership to better record dementia diagnosis records and therefore provide a more holistic picture of diagnosis rates.

What causes dementia?

There are several diseases and conditions that can result in dementia. These include:

- Alzheimer 's disease[8] – this is the most common cause of dementia. During the course of the disease the chemistry and structure of the brain change, leading to the death of brain cells. Problems of short-term memory are usually the first noticeable sign.
- Vascular dementia[9] − if the oxygen supply to the brain fails due to vascular disease, brain cells are likely to die and this can cause the symptoms of vascular dementia. These symptoms can occur either suddenly, following a stroke, or over time through a series of small strokes.
- Dementia with Lewy bodies[10] − This form of dementia gets its name from tiny abnormal structures that develop inside nerve cells. Their presence in the brain leads to the degeneration of brain tissue. Symptoms can include disorientation and hallucinations, as well as problems with planning, reasoning and problem solving. Memory may be affected to a lesser degree. This form of dementia shares some characteristics with Parkinson's disease.
- Fronto-temporal dementia (including Pick's disease)[11] − In fronto-temporal dementia, damage is usually focused in the front part of the brain. At first, personality and behaviour changes are the most obvious signs.

Other diseases that may also lead to dementia, including progressive supranuclear palsy, Korsakoff's syndrome, Binswanger's disease, HIV/AIDS, and Creutzfeldt−Jakob disease (CJD). Some people with multiple sclerosis, motor neurone disease, Parkinson's disease and Huntington's disease may also develop dementia as a result of disease progression[12].

---

[6] https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/
[7] http://www.gpcontract.co.uk/browse/07L/Dementia/14
[8] http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=7
[9] http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=95
[10] http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=70
[11] http://www.alzheimers.org.uk/site/scripts/services_info.php?serviceID=54
[12] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=135

There are a number of theories about what causes dementia, including suggestions of environmental exposure to certain elements such as aluminium. So far none of these have been proven.

Mild cognitive impairment

Some individuals may have noticed problems with their memory, but a doctor may feel that the symptoms[13] are not severe enough to warrant a diagnosis of Alzheimer's disease or another type of dementia, particularly if a person is still managing well. When this occurs, some doctors will use the term 'mild cognitive impairment' (MCI). Recent research has shown that individuals with MCI have an increased risk of developing dementia. The conversion rate from MCI to Alzheimer's is 10-20 per cent each year, so a diagnosis of MCI does not always mean that the person will go on to develop dementia.

Prevalence of dementia

Nationally, approximately one in five people over the age of 80 are predicted to suffer from dementia. In addition, it is likely that there will be an increase in the younger age group possibly associated with long term heavy drinking and drug use. Primarily dementia is an age related condition, and because people are on the whole living longer, the number of people with dementia is projected to increase. This increase will be greatest in residents aged over 90 years (Table 7.26.1). Most of these are likely to be women as women generally live longer than men.

Table 7.26.1: Dementia prevalence in Barking and Dagenham projected to 2030[14]

	2012 Dementia rates		2014	2015	2020	2025	2030
Age range	**% males**	**% females**					
65-69	1.5	1.0	72	73	75	89	107
70-74	3.1	2.4	114	114	139	145	172
75-79	5.1	6.5	220	213	207	253	270
80-85	10.2	13.3	362	338	338	335	419
85-89	16.7	22.2	406	406	383	383	400
90+	27.9	30.7	329	329	388	416	474
Total number with dementia aged 65+			**1,502**	**1,473**	**1,530**	**1,620**	**1,842**

Source: Figures from POPPI – Projecting Older People Population Information system (POPPI). www.poppi.org.uk

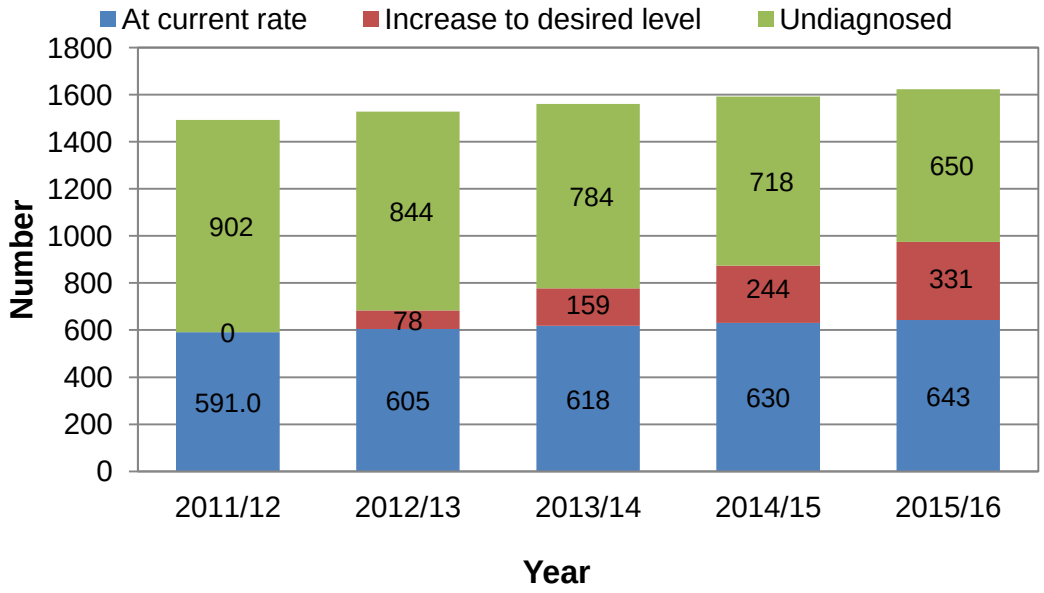
[13] http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200341
[14] The prevalence rates have been applied to ONS population projections of the 65 and over population to give estimated numbers of people predicted to 2030

Diagnosis

Within the local population the dementia diagnosis across all ages is 67.1 which is higher when compared to the rate across England at 65.1%. As mentioned above, the dementia diagnosis rate for Barking and Dagenham stands at 64% compared to 61% across England as a whole. A total of 1,453 patients registered compares to 1,926[15] estimated, with 107 patients in care homes and 1,346 living in the community.

The Dementia Partnership's Dementia Prevalence Calculator[16] maps the future expected prevalence of dementia including undiagnosed dementia. The yellow bars below (fig. 7.26.1) show the additional reported cases with diagnosis working up to 60% in 2015/16.

Figure 7.26.1: Dementia Prevalence Trajectory with improved diagnosis 2011-2016



Emergency hospital admissions of people with dementia

In recent years there have been a number of national reports highlighting the plight of people with dementia in acute general hospital settings. Increasingly the health and social care system is looking to ways to improve preventative interventions and thus reducing the need for people with dementia requiring emergency admissions to hospital for physical conditions.

Year to date data (January 2016) for emergency admissions shows that out of 644 dementia related cases 6 had a primary diagnosis of dementia, Table 7.26.2. The remainder had varying primary diagnosis on admission to hospital with dementia as the secondary diagnosis. Urinary tract infection made up 13% of the emergency admissions related to dementia.

[15] https://www.england.nhs.uk/mentalhealth/dementia/monthly-workbook/
[16] http://dementiapartnerships.com/diagnosis/dementia-prevalence-calculator/

Table 7.26.2 Emergency admissions for BD CCG patients across all providers.

Dementia Diagnosis	Main reason for admission	2015/16 (Whole year)
Dementia as primary diagnosis	Dementia	8
Dementia as primary diagnosis total		**8**
Dementia as secondary diagnosis	Asthma	2
	Cellulitis	9
	Complications of Diabetes	10
	Convulsions and epilepsy	8
	Dehydration and gastroenteritis	6
	Exacerbation of COPD	22
	Fractured Neck or Femur	37
	Heart Failure	4
	Pneumonia	72
	Urinary Tract Infection	100
	Other reasons (not long term condition)	515
Dementia as secondary diagnosis total		**785**

Source: NEL Commissioning Support Unit

In October 2015 the prevalence of dementia in England was estimated to be around 740 per 100,000 population[17] with the number of diagnoses representing around 61% of the individuals in England currently estimated to have dementia. Therefore the actual prevalence of dementia (including those who have not been diagnosed yet) would around 1,215 per 100,000 population based on March 2015 NHS dementia prevalence estimates.

Admissions to acute general hospital

People with dementia, along with the general population, are prone to develop physical conditions as part of living and the aging process. However people with dementia can have more complex needs than those of the general population because of the condition, which can potentially result in difficulty with assessment or treatment prolonging the individual's recovery period. If the complex needs of such individuals remain unaddressed, then a likely outcome is that emergency hospital care is required. Table 7.26.2 shows the number of emergency admissions[18] based on short term stay for individuals with dementia in England, 2012-2014. Table 7.26.2 shows End of Life Care for dementia patients.

[17] Quality Outcomes Framework 2014/15 HSCIC [online] available from: http://www.hscic.gov.uk/catalogue/PUB18887

[18] Public Health England: Dementia Profile -http://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia

Table 7.26.2 Emergency Admissions for dementia patients

	2012/13	2013/14	change	High/Lower than London	London	England
Dementia: DSR of emergency admissions (aged 20+), per 100,000	1019.00	972.52	-4.6%	Similar	937.16	779.34
Dementia: DSR of emergency admissions (aged 65+), per 100,000	3927.35	3769.91	-4.0%	Similar	3684.51	3046.37
Dementia: Short stay emergency admissions (aged 20+)	21.31	21.54	1.1%	Significantly Lower	27.27	25.47
Dementia: Short stay emergency admissions (aged 65+)	20.71	21.54	4.0%	Significantly Lower	26.67	25.37

Table 7.26.3 End of life care for dementia patients[17]

	2012	2013	change	High/Lower than London	London	England
Deaths in Usual Place of Residence: People with dementia aged 65+	54.11	47.71	-11.8%	Lower	54.06	66.59
Place of death - care home: People with dementia aged 65+	48.65	44.16	-9.2%	Similar	43.98	58.62
Place of death - hospital: People with dementia aged 65+	44.59	52.60	17.9%	Significantly Higher	44.40	32.60
Place of death - home: People with dementia aged 65+	4.73	3.25	-31.4%	Significantly Lower	9.70	7.35

The Better Care Fund

It is crucial that everyone works together to improve the lives of people with dementia in Barking and Dagenham. The partnership between health and social care is of particular importance and as such, the local authority and the CCG have agreed that support to people with dementia should be one of the key themes of the Better Care Fund (BCF). The BCF locally brings together £21m of investment to get services working together more closely, particularly to help prevent people having unnecessary stays in hospital.

In particular, the BCF plan sets out that we will:

- Improve the support available to people with dementia , recognising early information and advice enables reductions in rates of avoidable admissions to hospitals and care homes;
- Identify additional services required for people with dementia and supporting commissioning activities to develop these services;
- Meet the requirements of the Care Act;
- Improve the experience of carers and service users by ensuring that their needs and priorities are reflected in provision.

- The Better Care Fund is playing a pivotal role in 2016/17 to path find an effective pre and post diagnosis support model for dementia patients and carers in the borough through a dementia advisor model. The Dementia Advisors will help to deliver the plan set out in the Borough's Better Care Fund. In particular, the provision of information, advice and signposting to the support and services available to service users and carers reduces the level of care and support needed within more acute settings for carers and those that they care for. Examples of such sources of information have been that several dementia friendly awareness sessions were run in June and July 2015, with 81 dementia friends trained as a result and a dementia journey play was delivered by a local dementia charity to support the Council's Anniversary event – with around 100 people attending.
  This has a positive impact on both the health and wellbeing of people with early dementia. Investment in the service is part designed to evidence impact on quality of care for patients in order to demonstrate the need and value of further investment at different points along a patient's dementia journey.

Key messages

Data at local and regional level is not available yet but at National level:

- Dementia diagnosis rates have increased from 46% to 64% in 2015/16.
- There has been a 4% decrease in the number of emergency admissions during 2012 and 2013
- In relation to End of Life Care there has been a 17% increase in the number of people dying in hospital between 2012 and 2013
- The number of people with dementia dying in their own homes has also decreased
- by 31.4% and both hospital and home End of Life pathway indicators perform poorly compared to regional and national data and are moving in the wrong direction
- Urinary tract infection made up 13% of the emergency admissions related to dementia.

Dementia needs assessment

In 2014 a Dementia Needs Assessment was commissioned and the results reported to the Health and Wellbeing Board[19]. The study was commissioned to:

- Understand the prevalence of dementia in Barking and Dagenham and patterns of future need.
- Consult with key stakeholders including carers to obtain a wide range of views on current services and unmet needs.
- Produce an agreed set of recommendations and supporting actions that can be used to improve the state of dementia care in the borough.

Key findings in terms of the situation and needs of the current and predicted future population with dementia in Barking and Dagenham were:

- In 2013, an estimated 1537 people in Barking and Dagenham had dementia. Of these, 669 were diagnosed with dementia and recorded on GP registers (figures from August 2013).
- Overall, it is expected that the number of people with dementia in Barking and Dagenham will rise by approximately 10% over the coming decade; however, this increase is much steeper in the 90+ age group, with the number of people with dementia in this age group increasing by nearly 50% in this time.
- Barking and Dagenham's poor general health and high levels of risk factors for vascular dementia, such as heart disease, diabetes and smoking rates, may result in a more rapid increase in dementia prevalence than is predicted in the figures above.
- Diagnosis rates of dementia have improved in the borough (currently standing at an estimated 43%-46%) but further work is needed to reach the 60% target. Since the dementia needs assessment they have reached 64%.
- Combined with the expected prevalence increase, if diagnosis rates are successfully increased to this level by 2023, over 1,000 people in the borough will be diagnosed with dementia (compared to a current 669), increasing service demand.
- It is important to take into account the specific needs of people with dementia who live on their own, as more than a third of people aged 65+ in Barking and Dagenham currently live alone.
- The ethnic diversity of the dementia population in Barking and Dagenham is expected to increase substantially over the coming years, services and awareness raising programmes will need to adapt to the different needs of these groups.

[19] http://moderngov.barking-dagenham.gov.uk/documents/s82579/Dementia%20Needs%20Assessment%20Report.pdf
http://moderngov.barking-dagenham.gov.uk/documents/s82583/Dementia%20Needs%20Assessment%20-%20Appendix%201.pdf
(Accessed 26 September 2014)

Support services available for people with dementia and their carers

- Memory Café managed by NELFT Memory Service
- Memory Service part of the NELFT Older Adults Mental Health Service
- Dementia Advisor roles provided by both Alzheimer's Society and Carers of B&D
- GPs and Practice Nurses
- District Nurses and Community Matrons for patients needing Integrated Case Management
- Pharmacies providing advice and guidance around medicine management

Update on work to date

A dementia care pathway has been developed in partnership with GPs and the Older Adult Mental health Service, which is now being used as the template for good practice and standardisation of dementia care for patients across the borough.

Diagnosis and assessment

• Implementing the Dementia Friendly Communities Programme (Alzheimer's Society Guidance), the delivery was scoped in 2015/16 and pilot commissioned for delivery in 2016/17

• Outline and promote a dementia pathway dementia diagnosis, a dementia pathway developed in partnership with CCG and NELFT, and launched in 2015/16

• Review GP contact with older people - a number of schemes have been delivered in 2015/16 to improve patient recall, review and care planning in primary care. Included Everyone Counts, Dementia and Admissions Avoidance enhanced services, and a local service which aligned GP practices to nursing homes

• Address under-recording of dementia in primary care primary, the care engagement programme delivered in 2015/16 included education sessions during GP PTI, Practice Managers forum, Practice Locality meetings, and raising awareness with 40 GP Practices by the Barking and Dagenham Clinical Lead for dementia.

Early stages of dementia

• Ensure that decisions and advanced planning related to end of life are raised with people with dementia There is an on going programme of GP engagement around EOLC planning for patients and carers in 2015/16 and rolling on into 2016/17, includes an EOLC Facilitator delivered by NELFT.

Skills and capacity

• Review training and skills programmes

• Consider increasing the capacity of hospital specialist liaison teams, admiral nurses and the memory service

Recommendations for Commissioners

As a consequence of the recommendations made in the needs assessment a Dementia Action Plan has been approved by the Health and Wellbeing Board. The main recommendations are:

Personalisation and market development

- Enabling people to stay in their own home rather than placing them in a care home
- Reviewing support for people who do not meet the critical or substantial need threshold
- Conducting further work to promote take-up of personal budgets

Support for carers

- Offering a range of more appropriate respite and support options

Middle and later stages of dementia

- In residential homes consider handover from family carers, support to avoid hospital admissions, rehabilitation and levels of stimulation

Living well with dementia

- Ensure life history and reminiscence techniques are core skills for professional staff
- Consider how activities and day trips can be increased by working with partners

Integration and joined-up working

- Ensure voluntary and community organisations are integrated into services and planning
- Consider how the crisis/rapid response services support people with dementia

Dementia Advisor Provision

- Facilitate the post of a dementia advisor in partnership with the Alzheimer's Society for a period of six months, with a view to a longer term commission dependant on the outcomes of the initial pilot.