7.5.11 Dementia

Why is this issue important?

Dementia presents a huge challenge to society and will do increasingly in the future. There are approximately 662,373 people aged 65 and over in England with dementia.[1] Dementia costs the UK economy £23 billion a year and this will rise to over £27 billion a year by 2018; the number of people with dementia in the UK doubles every 20 years and will rise to 1.7 million by 2050.[2]

Dementia is a syndrome which results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Individuals may also develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. There are different types of dementia caused by different diseases of the brain, including Alzheimer's disease and vascular dementia. These diseases affect the brain in different ways and produce different symptoms.

Carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life. Dementia is a terminal condition but people can live with it for 7–12 years after diagnosis.[2]

The prevalence of both early onset and late onset dementia increases with age, doubling with every five-year increase across the entire age range from 30 onwards. Overall, 10% of deaths in men over 65 years, and 15% of deaths in women over 65 years are attributable to dementia.[1]

There is evidence that people with dementia have worse clinical outcomes than people with the same conditions without dementia. This contributes towards longer length of stay in general hospitals. Nationally, it is estimated that two thirds of people in care homes have dementia and 40% of these people are not in specialist dementia care homes.[3]

Apart from family members or friends, who provide the vast bulk of care and support, home care is probably the single most important service involved in supporting people with dementia in their own homes. The Commission for Social Care Inspection (CSCI) has found that good-quality, flexible home care services contribute significantly to maintaining people's independence, reducing social isolation, preventing admissions to care homes and hospitals, and supporting carers.[4]

Historically, dementia has been under diagnosed, both locally and nationally. It is estimated that only a third of people with dementia receive a formal diagnosis or have contact with specialist services at any time in their illness. Also, such diagnosis and contact often occur late in the illness and/or in crisis when opportunities for harm prevention and maximisation of quality of life have passed.[4]

Contrary to social misconception, a great deal can be done to help people with dementia.[5] Dementia should be diagnosed early and well so that people with dementia and their carers can receive treatment, care and support to enable them to live as well as possible with dementia.[6]

Key outcomes

- ***Health related quality of life for older people (Public Health Outcomes Framework)***
- ***Estimated diagnosis rate for people with dementia (Public Health and NHS Outcomes Framework)***
- ***Improving experience of healthcare for people with mental illness: Patient experience of community mental health services (NHS Outcomes Framework)***
- ***Enhancing quality of life for people with dementia -estimated diagnosis rate for people with dementia (NHS Outcomes Framework and Public Health Outcomes Framework); a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life (Adult Social Care Outcomes Framework, Placeholder and NHS Outcomes Framework)***

[1] Institute for Public Care. Projecting Older People Population Information System (POPPI). Available at: www.poppi.org.uk (registration required) [Accessed 30th September 2014]
[2] Alzheimer's Society. Facts on Dementia. Available at: http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=535&pageNumber=2 [Accessed 23/05/13]
[3] Commission for Social Care Inspection (CSCI). See me, not just the dementia. 2008
[4] Commission for Social Care Inspection (CSCI). Time to Care? London: TSO. 2006
[5] NICE/SCIE. *Dementia: Supporting people with dementia and their carers in health and social care*. London: TSO. 2006
[6] National Audit Office. Improving services and support for people with dementia. London: TSO. 2007

7.5.11 Dementia

Impact in Brighton & Hove

It is estimated that in 2014 there are 2,849 people aged 65 years or over with dementia in the City, based on applying national prevalence rates to the local population.[1] It is estimated that there are currently 61 people with early onset dementia.[7]

Dementia has been included in the Quality and Outcomes Framework (QOF) measures for GP practices since 2006/07. Since that time the proportion of the GP registered population on local practice dementia registers has increased slightly from 0.3% to 0.5% in 2013/14 (reflecting an increase in actual numbers from 937 to 1,454).[8] This compares to 0.6% in England and in the South of England Commissioning Region. It is also lower than the 12 other Surrey and Sussex Commissioning Groups. QOF data is not adjustable by age, so care should be taken when making comparisons to other CCGs, particularly those in Surrey and Sussex, as Brighton &Hove has a lower proportion of people aged 65 or over.[9]

Explanations put forward for under-diagnosis include the stigma associated with dementia which prevents people from going to their GP about memory loss, as well as dementia being considered by some people, including GPs, as a normal part of ageing.[10] Lack of diagnosis is a key factor that prevents people seeking the treatment they need and gaining support during early stages. [11]

Since 2010/11 the number of anti-dementia drugs prescribed in primary care has doubled from 7,250 to 14,211 in 2012/13. This is likely to be due to changes in prescribing practice as NICE guidance lifted restrictions on limiting these drugs from patients with moderate to severe dementia and extending them to those with early stage dementia. Anti-psychotic prescribing is now relatively low compared to 2009. In 2011/12, 52% of patients were having their medication reviewed at least every 12 weeks.[9]

There were 522 admissions to secondary care where dementia was the primary or secondary condition between 2010/11 and 2012/13. This is likely to be an under estimate as dementia is unlikely to be the primary reason for admission and is not always recorded as the secondary condition.[9] Since October 2012 a dementia CQUIN has been in place to assess patients aged 75 or over admitted for over 72 hours, for a diagnosis of dementia.

Between June 2013 and March 2014, 236 assessments were completed by the Memory Assessment Service (MAS), 180 dementia diagnoses made and 56 carers assessments were also completed.

Patients with dementia should be reviewed within primary care at least every 15 months. In 2011/12 local performance was 76% which was slightly lower performance than for England and the South East Coast Strategic Health Authority (79% and 78% respectively).[12]

Brighton & Hove has 111 registered care homes with 2,326 beds. A recent survey of 43 homes representing 1,239 beds, self- reported 854 residents (69%) with dementia – this is likely to be an underestimate.[9]

The council spent £15.7 million on home care in 2012/13. There are no figures available on the proportion of these clients with dementia but most home carers will be supporting someone with memory loss.[9]

As the cost of care for people with dementia is embedded across the whole of the health and social care system, including acute hospitals, mental health services, residential and nursing homes, it is difficult to determine the precise costs of dementia care.

Where we are doing well

The Heath and Wellbeing Board have identified dementia as a priority for the city and the Joint Health and Wellbeing Strategy includes a section on dementia. A Dementia Joint Strategic Needs Assessment was completed in 2013 and has informed the development of the Brighton & Hove Dementia Joint Strategic Delivery Plan 2014/17.

[7] Institute for Public Care. Projecting Adult Needs and Service Information. Available at: www.pansi.org.uk (Registration required) [Accessed 01.10.2014]
[8] Health and Social Care Information Centre . Quality and Outcomes Framework (QOF) - 2013-14 available at: http://www.hscic.gov.uk/catalogue/PUB15751 [Accessed on 09/12/2014]
[9] Brighton and Hove Clinical Commissioning Group and Brighton & Hove City Council. Dementia Needs Assessment. May 2014.
[10] NHS Brighton and Hove and Brighton & Hove City Council. Annual Report of the Director of Public Health. Brighton & Hove. 2011
[11] Brighton & Hove Joint Dementia Plan. NHS Brighton & Hove, Brighton & Hove City Council. 2012
[12] Health and Social Care Information Centre. Quality and Outcomes Framework (QOF). 2011/12. http://www.hscic.gov.uk/qof [Accessed on 23/05/13]

7.5.11 Dementia

Progress made since the 2012/15 Dementia Plan includes:

- Launch of the Memory Assessment Service, which includes support from Dementia Advisers and Carers' Needs Assessment Workers.
- Secured Department of Health capital funding to make the environment dementia friendly in primary care, acute, community services and care home settings e.g. the refurbished Brunswick Ward at Nevill Hospital has reopened as the Lindridge Nursing Home.
- Reconfiguration of mental health services to create a Living Well with Dementia Team.
- Expansion of the Care Home In-Reach Service to support independent sector care and nursing homes, in particular identifying alternatives to anti-psychotic medication.
- The Alzheimer's Society provides Dementia Café's, Singing for the Brain, the Carer Information and Support Programme, Dementia Support Service, Home Support Respite Service and Carers' Support groups.
- Increased capacity in the Community Rapid Response Service to offer crisis and Short Term Community Support, to enable more people with dementia to be supported at home and avoid hospital admission.
- A dementia champion and specialist dementia nurse posts have been funded at Royal Sussex County Hospital. A dementia pathway has been developed in the hospital to provide a memory screen to 90% of patients over 75 who have been admitted for more than 72 hours. The hospital has also adopted the Butterfly scheme to promote education and a common care approach to patients with dementia. The Emerald Unit specialist dementia ward has opened at Royal Sussex County Hospital.
- A Dementia Friendly Guide has been developed for use by community groups and organisations.
- Specialist resources are being developed to improve the End of Life Care for people with dementia.

Local inequalities

Dementia affects men and women in all social and ethnic groups. There is limited local evidence available on whether dementia has a differential impact on equality groups. Nationally, dementia is more common in women with two thirds of people with dementia being women.[3] This is largely due to longer female life expectancy. Research suggests early onset dementia is more common in men.[9]

Although there is no good quality data available on the prevalence of dementia in different ethnic groups, it is likely to be more prevalent amongst Asian and Black Caribbean elders. This is because some of the risk factors for dementia (high blood pressure, diabetes, stroke and heart disease) are more common in these communities. Nationally it is estimated dementia will increase seven-fold by 2051 in BME groups as these populations age.[13]

Nationally, it is known that people with Downs syndrome are at greatly increased risk of developing dementia with a lower age of onset than the general population. This is of increasing importance as the life expectancy of people with Downs syndrome is increasing. Rates of dementia are also higher in people with learning disabilities other than Downs syndrome.[14] There are currently 13 individuals on the Community Learning Disability Team's dementia care pathway, aged between 45 and 80 years, seven of them have Down's Syndrome.[9]

Lesbian, Gay and Bisexual people with dementia are more likely to require Adult Social Care support, as they are more likely to live on their own and less likely to have children or see family members. They may also fear prejudice and discrimination from support groups and residential care staff, which may put them off seeking help with their dementia.[15]

Based on national research it is likely that at least 71% of people with dementia have a carer. In

[13] All Party Parliamentary Group on Dementia. Alzheimer's Society. Dementia Does Not Discriminate. July 2013.

[14] http://www.alzheimers.org.uk/site/scripts/documents_info.php?documentID=103

[15] Musingarimi, P (2008). Social Care issues affecting Older Gay, Lesbian and Bisexual People in the UK. A policy brief. London ILC. Cited in Don't Look Back? (2010) Equality and Human Rights Commission, Manchester.

Brighton & Hove this equates to over 2,300 carers or 10% of all carers in the city.[16]

Research findings indicate that abusive behaviour by family carers towards people with dementia is common, with a third reporting important levels of abuse and half some abusive behaviour.[17] A YouGov survey commissioned in 2008 found that 19% of carers of people with Alzheimer's sometimes or often feel threatened by the person they care for.[18]

Brighton & Hove is included in the Pan Sussex Integrated End of Life Dementia Pathway. This aims to improve the end of life care for people with dementia, and enable more to die in their preferred place of death; increase advance care planning for people with dementia; and increase practitioners' knowledge and skills about end of life dementia care.

Other inequalities experienced by some people with dementia include people in the early stages not being referred for diagnosis by GPs. There is also a lack of affordable local authority funded specialist dementia beds in the city, so that 150-200 people are placed in accommodation outside the city (some people will have chosen this to live nearer relatives). People with severe dementia have less choice of care homes and people who can't afford to pay for their own respite have to wait longer to access it. Those without their own transport can face long journeys travelling to and from day centres.[9]

Predicted future need

By 2030, it is projected that the number of people aged 65 years or over with dementia will increase to 3,892 (Table 1).[1]

The number of people with early onset dementia is projected to increase by 21% (to 69) by 2020.[7]

However, these figures do not take into account the current under-diagnosis of dementia. If levels of diagnosis improve, the proportional increases could be much greater (The Memory Assessment Service has been set a target of increasing the dementia diagnosis rate from 54% to 67% by 2015). Nor do they take account of the anticipated decrease in dementia due to the reduced number of people at risk of cardio-vascular disease, though this is likely to be offset by the increase in obesity.

Table 1: Number of people aged 65 or over predicted to have dementia by age, 2014 and 2020 projection

	2014	2030
65-69 years	143	189
70-74 years	222	302
75-79 years	392	507
80-84 years	647	909
85-89 years	728	889
90 plus	717	1,097
Total 65 +	**2,849**	**3,892**

Source: Institute for Public Care. Projecting Older People Population Information System. www.poppi.org.uk

What we don't know

The Dementia JSNA found gaps in information in the following areas: the number of people with a dementia diagnosis living in care homes or receiving home care; how many people with dementia receive personal budgets or direct payments, how many people are self-funding their dementia care; the extent of dementia by ethnic group or protected characteristic groups, apart from gender; the number of people with dementia being admitted to acute hospitals.

Key evidence and policy

The Prime Minister's Challenge on Dementia was published in 2012. This made key commitments for driving improvements in health and care; developing dementia friendly communities that understand how to help and better research. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/146773/dh_133176.pdf

A National Dementia Strategy was published in 2009 and updated in 2010. It identified four

[16] Brighton & Hove Multi-Agency Commissioning and Development Strategy for Carers Refresh 2012-2013
[17] Cooper C et al. Abuse of people with dementia by family carers: representative cross sectional survey. BMJ 2009;338:b155
[18] YouGov. YouGov / Channel Four Survey Results. 2008. http://iis.yougov.co.uk/extranets/ygarchives/content/pdf/C4%20results%20alzheimers.pdf [Accessed on 26/08/2012]

priority areas to improve the quality and outcomes of care for people with dementia and their carers:

- Good quality early diagnosis and intervention for all
- Improved quality of care in general hospitals
- Living well with dementia in care homes
- Reduced use of antipsychotic medication

https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/168220/dh_094051.pdf

Other key documents include:

Quality standard for supporting people to live well with dementia – NICE April 2013
https://www.nice.org.uk/guidance/qs30/resources/guidance-quality-standard-for-supporting-people-to-live-well-with-dementia-pdf

The NICE-SCIE guideline on supporting people with dementia and their carers in health and social care. National Collaborating Centre for Mental Health. 2006. Modified October 2012
http://www.scie.org.uk/publications/misc/dementia/

A report into prevalence. Dementia UK. 2007
http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2

Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy. Department of Health. 2010
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/135771/dh_119828.pdf.pdf

Living well with dementia: A national dementia strategy - good practice compendium. DH. 2011
https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/147541/dh_123475.pdf.pdf

Brighton & Hove Clinical Commissioning Group and Brighton & Hove City Council. Dementia Needs Assessment. May 2014.
http://www.bhconnected.org.uk/sites/bhconnected/files/JSNA%20dementia%202014.pdf

Recommended future local priorities

The Brighton & Hove Dementia Joint Strategic Delivery Plan 2014-17 sets out the key action areas for development, based on the JSNA findings:

- Develop a single point of dementia information for public, professionals and carers.
- Workforce dementia training, including care home, homecare workers, sheltered housing, extra care housing, homeless services, learning disability services, community and voluntary workers.
- Good quality early diagnosis and support before and after diagnosis.
- Develop advice, support and capacity building in primary care.
- Ensure joined up integrated care for people with dementia and their carers.
- Create a Dementia Action Alliance to develop a Dementia Friendly Community.
- Ensure mainstream services are dementia friendly.
- Encourage uptake of direct payments and personal health care budgets by people with dementia and their carers.
- Continue to improve: number of carers receiving assessments, access to respite, training, awareness and support.
- Explore how to involve wider community in sheltered and extra care housing.
- Consider how to increase dementia friendly design of homeless accommodation.
- Explore ways of increasing dementia awareness of Estate Agents and Landlords.
- Promote telecare and telehealth to staff.
- Continue to develop and implement the End of Life Care in dementia pathway.

Key links to other sections

- Ageing well
- Mental health
- Adults with learning disabilities

Further information

NHS Brighton & Hove, Brighton & Hove City Council. Brighton & Hove Dementia Joint Strategic Delivery Plan 2014-17.

Last updated

October 2014