6.2.01 Dementia

Context

800,000 people are currently affected by dementia in the UK and this number is expected to increase to one million by 2012. The cost of the disease to society is estimated at £23 billion per year. However, such headline statistics do little to reveal the true impact of dementia or the unique challenges faced by each individual and their carers, family and friends.

Dementia is the term used to describe a group of symptoms that result from physical and chemical changes in the brain due to the presence of organic disease. The symptoms include a progressive decline in memory, communication skills, cognition and the ability to independently manage the usual activities of daily living. For a significant proportion of individuals their symptoms will progress and they will, at some point, no longer be able to safely live independent lives.

Dementia can affect people at any age but is most common in older people over the age of 65. Early onset dementia, defined as dementia presenting in people under the age of 65, is comparatively uncommon. One in 14 people over the age of 65 and one in 6 people over the age of 80 will have some form of dementia therefore, as the population ages and the numbers of elderly people grows, the number of people in the population with dementia will also grow[1].

There are several different types of dementia, the four most common of which are Alzheimer's Disease, vascular dementia, fronto-temporal dementia and Lewy Body dementia. A number of other, rarer forms of dementia may also present, including the alcohol-related forms of dementia. Since alcohol consumption is increasing in the UK, these conditions may become more common in the future.

Mixed forms of dementia are also seen and Alzheimer's disease and vascular dementia can present together. Vascular dementia is of particular importance because this form of the disease is potentially preventable by addressing lifestyle factors such as smoking and reducing cardiovascular risk[2]. Recent research has suggested that addressing these same issues may also have an impact on Alzheimer's Disease[3].

Dementia is a progressive condition and as the disease progresses, the ability of the individual to live independently become increasingly compromised. For a significant proportion of people with dementia this will mean that increasing levels of social care and support will be required until they eventually reach a point at which some form of long term supported living arrangements, such as admission to a care home, becomes necessary.

Whilst primary care will be the first point of contact in the community, the Memory Assessment and Treatments Services (MATs) have been recommended as the single point of referral for those with a possible diagnosis of dementia in Bradford. MATS provide a specialist diagnostic services ensuing that an accurate and timely diagnosis can be achieved and treatment where possible initiated. Where treatment is not an option, signposting to both follow-up services and support services for the person and their family is delivered.

Hospitalisation is a problem for people with dementia and frequently leads to an increase in the signs and symptoms of the disease. Hospitalisation also results in longer in-patient stays than are seen in people admitted for the same conditions but who do not have dementia. Discharge to a care home becomes more likely and it is also more likely that antipsychotic medication will be required during or following a period of hospitalisation.

Antipsychotics are a class of medications used to manage mental distress mainly in people with bipolar disorder or schizophrenia. In patients with dementia, antipsychotics have been prescribed as a means of managing behaviours that challenge. However, their use for this purpose has been highlighted as potentially damaging to health and plans to reduce their use were included in the NHS Operating Framework 2012[4]. In Bradford and Airedale, work has been going on to address this issue for a number of years, with the first antipsychotics prescribing audit published in 2011[5]. Work is currently focussed on

identifying, developing and implementing alternative approaches to prescription of antipsychotic medication in patients with dementia who exhibit behaviours that challenge.

People with dementia find it hard to feel part of, and participate in, their community. Voluntary and Community sector organisations play a vital role in providing dementia services to people living in the community. In Bradford District, the Alzheimer's Society is the primary provider of services for people with dementia, their carers and the wider family[1]. The services provided include:

- Dementia Advice Service – to ensure all people newly diagnosed with dementia, their carers and their family get access to independent information about dementia and dementia services locally.
- Dementia Support Worker Service – to ensure that people with dementia get continued access to information and support as required through an allocated case worker system.
- Peer Support Services – to provide social activities and practical support in order to provide both enjoyment and the opportunity to develop friendships and gain support from other people in similar situations. Local examples include wellbeing café's, singing groups and discussion groups.

Another major third sector provider of dementia services in Bradford is Meri Yaadain[1], a local initiative focussed on addressing issues related to the disease in Black and Minority Ethnic (BME) communities and, in particular, the District's large South Asian community. Meri Yaadain provide a telephone advice service run as community roadshows and a support group. They also work with schools and also carry out home visits.

National and local targets

Public Health Outcomes Framework:

- Estimated diagnosis rate for people with dementia
- Health-related quality of life for older people

NHS Outcomes Framework:

- Unplanned hospitalisation for chronic ambulatory care sensitive conditions
- Bereaved carers' views on the quality of care in the last 3 months of life
- Patient experience of community mental health services

Adult Social Care Outcomes Framework:

- Carer-reported Quality of Life
- Permanent admissions to residential and nursing care homes, per 1,000 population
- Proportion of older people (65 and over) who were still at home 91 days after discharge from hospital into re-enablement/rehabilitation services
- Dementia – a measure of the effectiveness of post-diagnosis care in sustaining independence and improving quality of life
- The proportion of carers who report that they have been included or consulted in discussions about the person they care for

Locally:

- The dementia diagnosis rate
- The number of dementia friendly communities established
- The number of Dementia Friends recruited.

Relevant strategies and local documents

- The Care Act 2014
- Dementia Health Needs Assessment for Bradford District 2014
- Improving Care for People with Dementia 2013
- NICE Quality Standard 30: Supporting people to live well with dementia 2013
- Prime Minister's Challenge 2012
- Bradford District Dementia Strategy Action Plan 2010 – 2014
- NICE Quality Standard 1: Dementia 2010
- National Dementia Strategy 2009
- NICE Clinical Guideline 42: Dementia: Supporting people dementia and their carers in health and social care 2006

What do the data tell us?

Bradford District has a young population, with an average age of 34.6 years compared to an average of 39.6 years for England and Wales[1]. However, people in the District are living longer and the population is therefore aging. The number of men and women aged 65 and over currently estimated to be 73,570, making up 14.0% of the District's population, compared to 17.3% for England[6]. Since the risk of dementia increases with age[7], it follows that the number of people with dementia in the District will also increase as the population ages.

The overall prevalence of dementia in the over 65 population in the UK, that is the number of people diagnosed with dementia plus the number with undiagnosed, was thought to be 8.3%[7]. However, this estimate has recently been reduced to 6.5%[8]. Applying this figure to the population aged 65 and over in Bradford District, suggests an overall prevalence of around 5,000 cases in the District[1]. This is a rounded estimate based on known diagnoses plus estimates of undiagnosed cases derived from published research. By comparing the number of diagnosed cases recorded in GP Registers to this estimate of total prevalence for Bradford, a "diagnosis deficit" can be estimated. This suggests that around 2,000 cases of dementia for in the District are currently undiagnosed[1]. Local Clinical Commissioning Groups (CCGs) are working with GP practices in the District to reduce this deficit. The 3000:2000 diagnosed to undiagnosed split is a clear strategic message on which to base service redesign and commissioning.

Estimated prevalence of dementia in Bradford District

Dementia type:	Local estimates of case numbers
Alzheimer's Disease	2500
Vascular dementia	1000
Lewy Body dementia	500
Fronto-temporal dementia	300
Other dementias	700

Source: Dementia Health Needs Assessment 2014, Bradford Metropolitan District Council

The table below shows the projected increase in the numbers of people with dementia across the District to 2020. These estimates suggest that an additional 100 cases will be diagnosed every year, placing a significant resource and financial burden on diagnostic and care services.

Projected increase in the number of people with dementia in Bradford District

Age:	2012	2014	2016	2018	2020
65-69 yrs	260	286	304	287	289
70-74 yrs	444	453	467	553	591
75-79 yrs	836	853	840	815	844
80-84 yrs	1,266	1,287	1,334	1,391	1,401
85-89 yrs	1,371	1,294	1,367	1,428	1,506
90+ yrs	1,047	1,136	1,253	1,312	1,429
TOTAL	**5,169**	**5,309**	**5,564**	**5,785**	**6,059**

Source: Dementia Health Needs Assessment 2014, Bradford Metropolitan District Council

The incidence of dementia varies between men and women according to their age group. In the UK, the overall prevalence of dementia is higher in older women than in older men, but it is not clear whether this is due to a true difference in presentation between men and women or differential survival, with fewer men surviving to the ages when dementia is most common, or to the longer survival of women compared to men once they have developed dementia. The gap widens in favour of women in the over 85s.

Bradford District has a rich ethnic diversity, with high numbers of people from BME communities, particular the South Asian community. The number of people of South Asian origin is also set to rise significantly to the year 2031[1]. The increased incidence and risk of cardiovascular disease and diabetes in South Asian and Black African people places them at an increased risk of developing vascular dementia. Clearly, there is potential for primary and secondary prevention of vascular dementia amongst the BME community.

Key findings of the HNA relating to dementia and ethnicity include:

- The majority of BME groups live primarily in the City area, and are less likely to live in urban areas
- Community based activity in the Third Sector is structured around five generalized ethnic groups, White, South Asian, African/Caribbean, Central Eastern European and Irish
- People from the South Asian are relatively underrepresented amongst hospital admissions
- Poor quality of ethnicity coding limits the applicability and robustness of local data
- Services should be culturally appropriate and staff culturally competent
- Cultural attitudes to elders may be important in generating referrals for diagnosis and treatment
- Cultural attitudes and norms in respect of dementia and mental illness may be preventing people from BME communities from accessing dementia services
- South Asian families may be more reluctant to put elders into care

As people get older, their probability of being diagnosed with multiple diseases (comorbidities) rises concomitantly. A recent large UK study[9] found that the prevalence of people with more than one disease increases substantially with age and is present in most people aged 65 years and over, the age at which dementia is most prevalent. Frailty, a recognizable state of increased vulnerability to adverse health outcomes resulting from aging-associated decline in reserve and function across multiple physiological systems, is a key element of this.

The management of comorbidity is an important element of any holistic care package for a person with dementia. There is some evidence that certain comorbidities may be underdiagnosed in people with

dementia, in particular depression which is a growing problem among older people[1]. It is important to understand that in every case, dementia will affect how their other long term conditions are managed.

Integration of care services to address the health and social care needs of people with dementia and their carers is therefore a key area for service development.

We know that across Bradford District, at least 63% of all residents in care homes have dementia[1]; this is more than 2000 people, making up 40% of total number of people with dementia in the District. We also know that, although Alzheimer's Disease is the most common form of dementia, amongst our care home population, vascular dementia is the most common form of the disease diagnosed.

The evidence base underpinning alternatives to antipsychotic prescribing in dementia, both pharmacological and non-pharmacological, has evolved in recent years and there is a growing body of research that highlights approaches that can be used as alternatives to antipsychotic medication in both care homes and in the home environment[10]. The key elements of effective approaches are provided in the Dementia Health Needs Assessment[1].

The first audit of antipsychotic prescribing showed that an estimated 16.5% of people with dementia in Bradford District were prescribed antipsychotic medication in 2011[4], lower than the national estimate. The 2012 audit[11] showed that this figure had fallen to 10.8%, a reduction of 5.7% in the year and equating to an overall reduction of 34%. Work on reducing the use of antipsychotics is continuing and overseen by an Antipsychotic Working Group for the District.

The course of dementia is characterised by a progressive worsening of symptoms to the point of death. Life expectancy of those diagnosed between the ages of 60 and 69 is just 6.7 years. For those diagnosed at age 90 and over, it is 1.9 years. The World Health Organisation[12] states that, for people with dementia, "*The last stage is one of nearly total dependence and inactivity. Memory disturbances are very serious and the physical side of the disease becomes more obvious*." Evidence shows that, compared to other patients in need of end of life care, patients with dementia are less likely to be referred to palliative care services, are prescribed fewer palliative care medications and are infrequently referred to hospice care[1]. Work to address these inequalities is being taken forward following the Dementia HNA and will become part of the Dementia Action Plan for Bradford District.

What do our stakeholders tell us?

The Dementia HNA included a piece of qualitative research s designed to capture the insights and opinions of key stakeholders so that their insight and knowledge could be captured to inform the conclusions and recommendations of the needs assessment.

In total 49 people were interviewed, including elected members, service providers and commissioners. Focus groups were held with local people with dementia and their carers. The data collected were analysed using standard qualitative techniques; the following themes were identified:

- Goodwill across the District
- School of Dementia Studies
- Funding
- Post-diagnosis care
- Keeping patients at home
- Importance of the Third Sector
- Need to reduce stigma
- Need to spread information

Future needs and gaps in provision

As progress is made and people with undiagnosed dementia are identified and offered diagnosis and support, it is essential to be aware that successful identification of the undiagnosed cases will ultimately determine the impact on services in respect of demand and capacity. A sound understanding of the present and projected age profiles of the local population, its ethnic composition and the patterns of socioeconomic deprivation across the District are central to the strategic planning of services for people with dementia, their carers and their family.

The number of older people in the population is rising, and as the numbers of elderly people in the local population grows, so will the number of people with dementia. Given that people, including those with dementia, are living longer than ever before, it is clear that there will be a growing pool of need in relation to dementia in the District. It is equally clear that local services must develop in order to meet this need and ensure the best quality of life and of care for people with dementia in Bradford.

The cost of caring for people with dementia across in Bradford District can be expected to rise concomitantly with this growing need; there is therefore a pressing need for robust forward planning, both to design effective and efficient services for the future and to make fiscal allowances for the resources required.

Summary of priorities

The priorities of Bradford District's Dementia Strategy Action Plan are as follows:

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

The action plan was updated for 2012-13 to include three additional local priorities:

- Improving public and professional awareness
- Community support
- Carers

The Dementia Health Needs Assessment has defined four key overarching priorities for dementia care in Bradford District. These are:

- Supporting people to remain in their own homes for as long as possible
- A greater strategic focus on people in care homes in the District
- Prevention: 1 in 3 cases of dementia are potentially preventable through healthy lifestyles
- High quality palliative care for people with dementia

The Dementia Action Plan for Bradford District is being updated to ensure that the recommendations of the Dementia Health Needs Assessment and the wide variety of other work happening across the District are coordinated and integrated so that good progress is made against both national and local targets.

References

[1] Dementia Health Needs Assessment for Bradford District 2014, Bradford Metropolitan District Council. http://www.observatory.bradford.nhs.uk/Docs/default.aspx?RootFolder=%2fDocs%2fDocuments%2fHealth%20Needs%20Assessments%2fDementia%20Health%20Needs%20Assessment&FolderCTID=0x0120000BE4C7E6BA82594C85481C460BADA62E&View=%7bA50A16B9-7E2F-4499-99B5-0A925A2D55D2%7d

[2] Norton S., Matthews F. E., Barnes D. E., Yaffe K., & Brayne C. (2014) Potential for primary prevention of Alzheimer's disease: an analysis of population-based data. The Lancet: Neurology 13(8):788–794. https://kclpure.kcl.ac.uk/portal/files/13136570/ADPAR_v4_1_TLNrevisedclean.pdf

[3] Prince M., Albanese E., Guerchet M., Prina M. (2014) World Alzheimer Report 2014: Dementia and Risk Reduction. Alzheimer's Disease International, London. http://www.alz.co.uk/research/WorldAlzheimerReport2014.pdf

[4] The Operating Framework for the NHS in England 2012/13 (2011), Department of Health. https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/216590/dh_131428.pdf

[5] Bradford and Airedale Audit of Antipsychotic Prescribing 2011, NHS Bradford and Airedale.

[6] Office for National Statistics (2014) *Annual Mid-Year Population Estimates for the UK, mid-2013*. Office for National Statistics. http://www.ons.gov.uk/ons/publications/re-reference-tables.html?edition=tcm%3A77-322718

[7] Dementia UK: A report into the prevalence and cost of dementia (2007) Personal Social Services Research Unit, London School of Economics and the Institute of Psychiatry, King's College, London for the Alzheimer's Society. http://www.alzheimers.org.uk/site/scripts/download.php?fileID=2

[8] Matthews F.E., Arthur A., Barnes L.E.,Bond J., Jagger C., Robinson l., Brayne C. (2013) A two-decade comparison of prevalence of dementia in individuals aged 65 years and older from three geographical areas of England: results of the Cognitive Function and Ageing Study I and II. The Lancet 382(9902): 1405–1412. http://ac.els-cdn.com/S0140673613615706/1-s2.0-S0140673613615706-main.pdf?_tid=4a9dbf18-8395-11e4-8d44-00000aacb35f&acdnat=1418563975_9891b478dddbc62ebfece017eaea3170

[9] Barnett K., Mercer S.W., Norbury M., Watt G., Wyke S., Guthrie B. (2012) *Epidemiology of multimorbidity and implications for health care, research and medical education: a cross-sectional study.* The Lancet 380(9836):37–43. http://ac.els-cdn.com/S0140673612602402/1-s2.0-S0140673612602402-main.pdf?_tid=17f9c55a-8397-11e4-9352-00000aacb360&acdnat=1418564749_d2b71b81eec86dd7e50ee9ea591d152a

[10] Evidence Briefing on Non-Pharmacological Interventions for Dementia in Care Home Settings (2013) Centre for Reviews and Dissemination, National Institute of Health Research.

[11] Bradford and Airedale Audit of Antipsychotic Prescribing 2012, NHS Bradford and Airedale.

[12] Dementia – A Public Health Priority (2012) World Health Organisation. http://apps.who.int/iris/bitstream/10665/75263/1/9789241564458_eng.pdf?ua=1