DEMENTIA AND ALZHEIMER’S DISEASE

What’s the issue?

“Dementia is a common condition that affects about 800,000 people in the UK. The risk of developing dementia increases with age, and usually occurs in people aged 65+ years. Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of the brain and its abilities. This includes problems with memory loss, thinking speed, mental agility, language, understanding and judgement. People with dementia can become apathetic or uninterested in their usual activities, and have problems controlling their emotions. They may also find social situations challenging, lose interest in socialising, and aspects of their personality may change. They may lose empathy (understanding and compassion), may have hallucinations (see or hear things that other people do not), or may make false claims or statements. As dementia affects a person’s mental abilities, they may find planning and organising difficult. Maintaining their independence may also become a problem. A person with dementia will therefore usually need help from friends or relatives, including help with decision making. Most types of dementia can’t be cured, but if it is detected early there are ways you can slow it down and maintain mental function” [324].

With the ageing population, the numbers of people with dementia will increase. It is predicted that the numbers of people aged 65+ years with dementia in England will increase from an estimated 679,000 in 2015 to 1,073,500 by 2030, an increase of 58% [309].

Nationally, Alzheimer’s disease has the sixth highest disability adjusted life years (DALY – see page Error! Bookmark not defined.) and thus has a substantial impact on the quality of people’s lives [81] as well as substantially affecting the lives of carers.

What’s our situation?

For 2015/16, the percentage diagnosed with dementia (on the GP disease registers) was second lowest out of seven comparator areas at 0.68% for Hull (range 0.79% to 0.89% for other six comparators and 0.60% for Leicester) [93]. There was no association between the diagnosed prevalence and deprivation. A total of 2,002 patients were on the dementia disease register in Hull (having increased from 1,529 from 2013/14). Based on modelling (October 2016), it is estimated that there are 2,740 practice patients with dementia. If the model is reasonably correct, then it suggests around 700 people in Hull have undiagnosed dementia. The diagnosis rate is estimated to be around 63% for Hull compared to 59% in England for 2014/15 [82, 94]. The same model estimates that around 2,611 people living in Hull aged 65+ years have dementia (excluding East Riding of Yorkshire residents registered with Hull GPs and Hull patients aged under 65 years), but this is projected to increase to 3,704 by 2030 [75].

During the three year period 2008/09 to 2010/11, there were 266,244 daycase and inpatient clinician episodes of which 306 (0.1%) had a primary diagnosis of dementia [94].

There were 496 dementia deaths (479 aged 75+ years) over the three year period 2012-14 giving a directly standardised mortality rate of 76.6 per 100,000 population having increased from a rate of 89.2 per 100,000 population for 2011-13 (with 441 deaths) [325]. There was a strong association between mortality and deprivation with mortality rates much higher in the more deprived fifth of areas of Hull (129 deaths per 100,000 population) compared to the least deprived fifth of areas of Hull (48 deaths per 100,000 population) [93, 325]. Given a lack of an association between deprivation and prevalence on the GP disease registers, this could mean that there is inequity present and/or a higher prevalence of undiagnosed dementia among those living in the most deprived areas. Although there are nursing homes in the more deprived areas of Hull, and this could partly explain the differences in the mortality rates among the most and least deprived areas.

For more detailed information, see the JSNA Toolkit: Mental Health and Learning Disability, and Older People reports.
What are the strategic needs?
Many of the disabling effects of dementia can be combated using the social model of disability, and Hull is seeking to become a Dementia Friendly City by providing advice and training to people providing universal services, such as bank and shop staff so that people with dementia can use local services independently, increasing their wellbeing and reducing their reliance on carers and on paid support. Making them feel empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. There are four broad work streams: (i) stimulate demand and awareness; (ii) invest in early detection; (iii) access to treatment; and (iv) support to carers.

There is a need to work with partners to ensure that there is a shared understanding of people’s needs and that services are integrated, high quality and accessible in ways that offer people appropriate choices such as care organised around care hubs. There is a need to work together to promote self-care, reablement or mutual support in community settings so this is viewed as the norm and reduce reliance on residential or home care. The most vulnerable citizens should be identified so their specific needs are addressed in the way they wish. The new Care Act 2014 focuses around meeting needs and promoting wellbeing rather than simply the provision of services and on preventing, reducing or delaying the development of need, so individual needs should be assessed holistically within the context of their support network and each individual’s circumstances considered to provide the most appropriate care, help and support for that individual. These individual needs will need to consider the caring arrangements, and how carers need to be supported in their role, and that their health needs do not suffer.

People (supported by their carers where necessary) should be encouraged to attend their NHS Health Check if they are eligible, and people already diagnosed with dementia should attend their annual reviews (generally within primary care) so that they get the best on-going treatment for their condition.

References