How Dementia affects older people in Norfolk

Joint strategic needs assessment
SUMMARY

NHS NORFOLK

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KADHIM ALABADY, GIFT OCHIBA, JEREMY BONE, JONATHAN WILLIAMS AND LINDA HILLMAN

EXECUTIVE SUMMARY

Assessment of Dementia need in Norfolk; an epidemiological approach

Introduction

There have been major health and social care publications recently on the subject of Dementia. This document presents information currently available that we have found, relevant for Norfolk in 2010, including, where possible Great Yarmouth and Waveney.

Discussing, collecting and presenting information accurately require specialist knowledge, collaboration and time. Service development is similar, under the pressures of increasing service need. Hence this document, as part of the Norfolk Joint Strategic Needs Assessment (JSNA) should be constantly updated as data and evidence change, as do service needs. The authors wish the current analyses to be shared although work is ongoing and successive versions of this document, or projects arising from it, will be the way forward to assist commissioners in understanding the epidemiological aspects. Where possible, data across NHS Great Yarmouth and Waveney are included.

A major report published by the Alzheimer's Society in 2007, *'Dementia UK'*, brought to attention the scale and impact of dementia within Britain.

It identified 700 000 people with dementia including

- 15 000 younger people known to be affected, this being likely to be a major underestimate because the way that data relied on referrals to services.
- 11 500 people with dementia from black and minority ethnic groups

The report further highlighted that

- There would be over a million people with dementia by 2025
- Two thirds of sufferers are women
- The proportion of older adults with dementia doubles for every five year age group, affecting one third of people over 95
- 60 000 deaths per year are directly attributable to dementia; delaying the onset of dementia by five years would reduce deaths directly attributable to it by 30 000 per year.
- The financial cost in 2007 was over £17 billion per year
- Family carers of people with dementia save the UK over £6 billion per year
- 64% of people living in care homes have a form of dementia
- Two thirds of people with dementia live in the community while one third live in a care home.

The Alzheimer's Society asked that dementia be made a national health and social care priority, that there should be more publicly funded dementia research, and improvement in dementia care skills , development of community based support, better carer support, discussion on who pays and development of comprehensive integrated care models.

In 2009, a National Dementia Strategy was published. Appendix 1 shows the care pathway, key themes and the objectives. On 30th June 2010, A Quality Standard for Dementia was published by the National Institute for Health and Clinical Excellence (NICE).

This needs assessment for Norfolk is an epidemiological approach based on the framework used by NHS Commissioning Support for London, '*Dementia - needs assessment, Appendix 1'.* A variety of indicators and other evidence is presented describing the current and future picture in Norfolk and will help us to agree further local work to be taken forward collectively through the JSNA processes.

Current data predicts increases in the numbers of people being identified with dementia in the future. Due to the aging population, this will be pronounced in districts with older populations and will also depend on changing ethnic mix of successive aging cohorts and local and personal socioeconomic circumstances for residents.

NHS Norfolk (2010) is estimated to have 11789 dementia sufferers, rising to 15590 by 2020. In NHS Great Yarmouth and Waveney, 3470 current sufferers will rise to 4603 by 2020 according to the projections used.

SUMMARY OF NORFOLK DEMENTIA NEEDS ASSESSMENT

1.0 What is dementia?

- It is a progressive neurological condition; symptoms become more severe over time. Loss of memory is common but communication difficulties, mood and personality changes occur also.

- Of the several forms of dementia, Alzheimer's disease is the most common followed by cerebrovascular disease, Lewy body disease and combinations of these ('mixed dementia'). There is an increased incidence of Alzheimer's in people with Down syndrome and fronto-temporal degenerative disease is a common cause in younger adults.

- Dementia can affect people of any age, but is most common in older people. One in 20 people over 65 and one in five people over 80 has a form of dementia.

- Due to the rapidly increasing proportion of older people in our population, due to other illness being managed and people living longer, dementia is an increasingly important public health issue.

- Understanding how the disease progresses can be useful in helping someone with dementia anticipate and plan for change

2.0 Norfolk Profile:

- Norfolk continues to have a relatively elderly age profile, with around a fifth of the population aged 65 and over (21.48%) and one in ten aged 75 and over (10.13%)

- People aged 65-74 and aged 75 and over would increase by 56 and 94% respectively by 2031

- North Norfolk has the largest proportion of older people (hence numbers in relation to its population size) with 28.5 % aged 65 years and over compared to other districts and Norfolk as a whole (21.48% aged 65 years and over). However in terms of actual numbers of people aged 65 years and over, King's Lynn and West Norfolk comes top in Norfolk.

- Females in all Norfolk districts except Great Yarmouth and males in all districts except Great Yarmouth and Norwich have an average life expectancy that is greater than the English average.

- Mental health problems are experienced by over a third of older people in the UK. Dementia is second most common after depression and anxiety, which themselves are more common among older people than any other age group.

- There are no data presented in this report on the local prevalence of Down Syndrome; until a local study is carried out, it should be assumed to be close to the average for England.

- The Index of Multiple Deprivation, a national measure to compare deprivation between different areas, uses indicators for health deprivation & disability to contribute only 13.5% over all. The effects of the other components, such as poverty, housing etc need to be addressed if inequality in the impact of dementia is to be addressed. This requires a multi sectoral approach.

3.0 Dementia Epidemiology:

- It is not known why some people get dementia and others don't. But direct risks identified in the literature include age, gender, genetics or family history, aluminium and/or zinc toxins, head injury and Down's syndrome.

- Strokes may be related to dementia, and the risk factors for stroke are [1] **h**igh blood pressure, high cholesterol, diabetes, smoking, obesity, lack of exercise and/or irregular heart beat, such as atrial fibrillation.

- There is an estimated number of over thirteen thousand[2] people in Norfolk with dementia. This will rise significantly to over twenty four thousand by 2030.

- Approximately 2.1% of people aged 65 years or over will develop dementia eventually and in 2010, 3823 and 589 new cases are expected in Norfolk (95% CI, 2675 to 5584) and Waveney (95% CI, 414 to 857), respectively.

- King's Lynn and West Norfolk district is projected to have the largest number of new cases for both males and females aged 65 and over between 2010 and 2030 because there are more people aged 65 years and over but in relation to its population size, North Norfolk has the largest proportions of older people. The lowest numbers and increases are expected in Norwich.

- Age at onset of dementia has been shown to have a significant effect on survival times; whereas the median survival time is 4.5 years, those

[1] Tegos TJ, Kalodiki E, Daskalopoulou SS, et al. Stroke: epidemiology, clinical picture, and risk factors (part I of III). Angiology. 2000; 51: 793-808.
[2] *POPPI, 2010*

diagnosed in their sixties have a mean survival time of 10.7 years whereas of those diagnosed in their nineties; the median survival time is 3.8 years.

- There is evidence that increased mortality rates are a result of late diagnosis or diagnoses at a time of crisis (when the individual is at a critical interval of need) and this reinforces the need to increase awareness training amongst professionals and the public as set out in the National Dementia Strategy and in NHS Norfolk's Bold and Ambitious.

- Gender and disability prior to dementia onset are said to affect survival times. In relation to gender, this is borne out by data for Norfolk, although there is variation between the districts.

- Of all the people who died in Norfolk or Waveney between 2006 and 2008, with dementia recorded as the primary cause, for NHS Norfolk, 92.8% of NHS Norfolk residents and 95% of Great Yarmouth and Waveney residents had been born in England.

4.0 Dementia in Primary care:

- Data from the Quality and Outcomes Framework (QOF) disease registers record no increase in dementia recording between 2007/08 to 2008/09 for NHS Norfolk or NHS Great Yarmouth and Waveney.

- Dementia recording (reported through QOF) is slightly higher for both NHS Norfolk (0.5%) and Great Yarmouth and Waveney (0.6) when compared to East of England SHA (0.4%) and England (0.4%)

- The ratio of GP recorded dementia cases to the prevalence estimated through applying the National model to the Norfolk population was 33%, which was slightly below the average for England, which is 38%, GP databases are likely to record the most severely affected.

- Modelling predicts 11,157 people with late-onset dementia within NHS Norfolk in 2009/10, 4,028 males and 7,130, females. In Great Yarmouth and Waveney these are 3,457 people, 1,177 males and 2,280, females.

- NICE has now published standards of care for people with dementia (2010).[3]

- Timely diagnosis is important for both patients and families to facilitate better understanding, improved access to medication, information and support services and to allow preparation for future care planning.

[3]The National Institute for Health and Clinical Excellence (NICE); Dementia quality standard June 2010 http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp

- There is a need for collaborative multiagency efforts (by physicians, carers and the general population) to close the gap between recorded and undiagnosed patients as the numbers of dementia sufferers rises, projected to nearly double by 2030.

5.0 Dementia in Hospitals:

- The numbers of people admitted to hospital with a *primary* diagnosis of dementia from Norfolk and Waveney have reduced in recent years and most were emergency admissions.
- In 2009/10, considering primary, secondary and tertiary diagnoses together, there were 1335 admissions of Norfolk residents aged 65 years and over with dementia. These were mainly emergency admissions, most directed from GPs and the remainder via A&E.
- More female patients (61.5%) were admitted than males (38.5%).
- Where dementia was not the primary cause of the admission, in 2009/10, the most common conditions were fractured femur or infection with a pneumococcal organism, which together accounted for one third of cases (579).
- The largest numbers of admissions were people aged 80 years and above of whom 90 were women and 44 were men.
- People admitted to hospital as emergencies were more likely to have a longer stay than following other routes of admission
- The type of dementia recorded most frequently was vascular dementia.
- No association could be found between admissions and socioeconomic data but there are slightly higher numbers from the Kings Lynn area, particularly males.

6.0 Dementia in social care settings:

- It is estimated that 63.5% of people with late-onset dementia live in their own home and 36.5% live in a care home[4].
- In Norfolk, there has been a year-on-year increase in the number of older people (aged 65+) recorded as having dementia among total number of people who use social care services and are of that age group.

[4] Alzheimer's Society. Dementia UK: The full report, 2007

- There were significant variations in the numbers of people aged 65 years and above who were recorded as having dementia accessing different community based services.

- In 2009/10, nearly twenty five thousand people aged 65 years and above used community services in Norfolk and 1864 (7.48%) of these people were recorded as having dementia. The break down of people with recorded dementia as a percentage of service users were;
  - 17.89% of persons aged 65 years and above who received day care
  - 18.16% of persons aged 65 years and above who received short-term residential care (not respite care)
  - 8.79% of persons aged 65 years and above who received home care
  - 4.09% of persons aged 65 years and above who received equipment and adaptations
  - 1.57% of persons aged 65 years and above who received professional support

- There has been increasing demand for more complicated and intensive care.

- In residential care the prevalence of dementia is estimated to be 79.9% amongst residents in Elderly Mentally Infirm (EMI) registered homes, 66.9% in nursing homes and 52.2% in residential homes[5].

7.0 Inequality and Dementia:

- The impact of deprivation on dementia has not been widely researched but there is evidence that in general older people with more deprived circumstances have more functional illness with poorer outcomes than those in more less deprived areas.

- Deprivation data alone on our local populations showed no clear association with estimated numbers of dementia sufferers.

- Hospital admissions with a primary diagnosis of dementia between 2006 and 2009 were higher from areas of middle affluence, but in relation to population estimates for dementia, it was the most deprived areas that had the highest admission rates (see chapter 5).

- Patients who were admitted between 2006 and 2009 primarily due to dementia were recorded predominantly as white British (92.1%). (see chapter 5)

[5]Alzheimer's Society. Dementia UK. The full report, 2007

- Death certificates record the highest death rate attributable to dementia per 10,000 population (3 year pooled average) amongst those from local areas in the second lowest quintile of deprivation in England. These rates are significantly higher than those recorded in the more deprived quintiles, 3, 4 and 5.

- A higher proportion of physicians than care givers or the general population believed that dementia symptoms are most often misinterpreted as normal signs of ageing, hence likelihood that dementia cases can be misdiagnosed. These observations support a need to prioritise raising the dementia awareness generally among professionals and the public.

8.0 Insights into dementia admissions using ACORN segmentation tool:

- Health commissioners are increasingly being asked to use market segmentation tools to analyse their populations, and to use social marketing as a means of encouraging behaviour change in their populations.

- Social marketing is described as 'an approach used to achieve and sustain behaviour goals on a range of social issues'[6].

- Using the ACORN market segmentation tool, dementia admissions (within NHS Norfolk) are investigated further to understanding of the people who are being admitted (in critical need of a service), highlight what possible social and health factors may have been present before the time of admission and where these are likely to be within the population at risk of developing dementia.

- The 2 key over-represented groups of persons with a dementia related admission in 2009/10 are Settled Suburbia and Affluent Greys. Affluent Greys accounted for 1 in 3 of NHS Norfolk's Dementia admissions whilst 1 in 6 of the admission was classified as 'Settled Suburbia'.

- It is likely that they represent groups of persons admitted with dementia as seen the admissions for 2009/10. Health ACORN segmentation showed that 37.5% of the dementia related admissions (in 2009/10) had "Possible Future Concerns" and those classified as having existing health problems form 23.1% of the total dementia admissions in 2009/10.

- The Affluent Greys are likely to be home owning older couples who consume high levels of fat & confectionery foods or affluent healthy pensioners who delight in dining out. On the other hand, Settle Suburbia tend to be Elderly

[6] National Social Marketing Centre http://www.nsmcentre.org.uk/what-is-social-marketing.html

persons living with associated health issues, or persons from less affluent neighbourhoods who are high fast food consumers live sedentary lifestyles, or Home owning pensioners who consume traditional diets.

- Media preferences for these groups are newspapers, internet and digital TV

9.0 Conclusions:

This analysis of local data endorse the findings of the Alzheimer's Society report from 2007, *Dementia UK*, that claimed that fewer than half of people with dementia ever received a diagnosis[i], despite dementia accounting for more years of disability than almost any other condition, including stroke, cardiovascular disease and cancer. The report went on to illustrate that dementia accounted for deaths of 10 per cent of men and 15 per cent of women over 65 and that by delaying disease onset by five years the number of dementia deaths in the UK would halve. The following points have informed the National Dementia Strategy that was published in 2009. Local implementation is rightly a key priority for health and social care services.

Key points to note focus heavily on timely diagnosis as:

- Timely diagnosis is important for enabling both patients and families to facilitate better understanding, improved access to medication, information and support services and to allow preparation for future care planning.
- Timely diagnosis facilitates access to medication, information and support services
- National guidance recommends early referral for specialist assessment (preferably to a memory clinic or old age psychiatrist) to ensure timely and accurate diagnosis.
- Brief cognitive assessment tools allow GPs to identify possible cases of dementia.

10.0 References:

[i] National Audit Office (2007) *Improving services and support for people with dementia*. London: The Stationery Office.