

Dementia: A North East Perspective Executive Summary

**July 2011
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Executive Summary

Overview

This report provides an overview of the status of dementia in the North East of England. It provides:

- Context through demographic information, dementia types and economic challenges.
- Details of policies that are relevant to dementia, in particular, the National Dementia Strategy, and any related activity that has been undertaken within the North East to deliver or comply with the policies.
- Details of North East structures, research and regional wide dementia specific information that supports the implementation of the National Dementia Strategy.
- The seven North East dementia priorities and details of progress against them including the views of North East Stakeholders.
- Details of the remaining National Dementia Strategy objectives and progress against them including the view of North East Stakeholders.

1. Introduction

This report summarises the Dementia: A North East Perspective report by Debbie Smith. A full version of this report can be downloaded from Northern Rock Foundation's website: www.nr-foundation.org.uk.

This summary outlines the status of dementia care in the North East (NE) of England as of May 2011. The purpose of the report is to provide Northern Rock Foundation and organisations in the statutory, voluntary and education sectors with an overview of current work to support people with dementia and their carers.

The report does this by highlighting both progress made and gaps in service development and provision. This is reviewed against the relevant English policy context, in particular the National Dementia Strategy (NDS) and what NE stakeholders say they want in relation to dementia care and support.

2. What is dementia?

The term "dementia" is used to describe a collection of symptoms, including a decline in memory, reasoning and the ability to communicate and a gradual loss of the skills needed to carry out daily activities¹. These symptoms are caused by structural and chemical changes in the brain as a result of physical disease such as Alzheimer's. The different types of dementia include Alzheimer's Disease, cerebrovascular dementia, dementia with Lewy Bodies, frontotemporal and mixed dementias. Dementia is not a homogeneous condition and each type has its own cause and result in different

¹ London School of Economics. (2007) *Dementia UK – The Full Report*, London: Alzheimer's Society

symptoms. For example a person with Alzheimer's Disease in the early stages may become forgetful whilst the behaviour of a person with frontotemporal dementia may change more dramatically with the person seeming to be more unfeeling or selfish than usual. The most common form of dementia is Alzheimer's Disease affecting 63% of all people with dementia. Younger people are more likely to be diagnosed with vascular, frontotemporal, and Lewy Bodies type dementias. Certain groups of people including older people and those with learning disabilities are more likely to get dementia.

These factors need to be considered when commissioning services and working with individuals.

3. Demography

The statistics for the North East show:

- The number of people estimated to have young onset dementia² in 2009 was 688 at 2009 and is expected to reduce to 666 by 2030. These numbers are thought to be an underestimate.
- The number of people with late onset dementia³ was predicted to be 31,840 at 2010; the number actually diagnosed with dementia was 14,034.
- There is a predicted increase in the number of people with late onset dementia to 50,896 by 2030 or an increase of 19,056 in 20 years.
- The number of males with dementia is predicted to increase by 93% between 2009 and 2030.
- At 44% the North East (NE) has the highest percentage of people diagnosed with dementia against the predicted numbers. There are still significant steps to take to increase the rate of diagnosis.
- In 2010, it was estimated that 88 people with downs syndrome in the NE will have dementia.
- There are no figures relating to minority groups and dementia.

4. The National Dementia Strategy and policy context

The National Dementia Strategy (NDS) is the primary policy for dementia care in England. There are seventeen objectives which cover the whole dementia care pathway from raising awareness through diagnosis to 'end of life' care. These have been augmented by the addition of an "eighteenth" objective to reduce the inappropriate prescribing of antipsychotic medication to people with dementia.

The NE has identified seven priority areas:

- Good quality early diagnosis and intervention for all (objective 2)
- Improved community personal support services (objective 6)
- Improved quality of care for people with dementia in general hospitals (objective 8)
- Housing support, housing related services and telecare to support people with dementia (objective 10)
- Living well with dementia in care homes (objective 11)
- Improved 'end of life' care for people with dementia (objective 12)
- Reduction of the inappropriate prescribing of antipsychotic medication to people with dementia.

² Those under 65 years

³ Those 65 years and over

There are other key current policies that affect dementia care, which include the NHS operating framework 2011-12 and personalisation. In the NE, dementia specific responses to current policies include: provision of local dementia action plans, innovative work on outcomes, a regional project on dementia and community, and personal support.

Other relevant forthcoming policies include the Health and Social Care Bill, Social Care Bill and legislation linked to public health. Subject to legislation, one of the most significant impacts of these changes is that the commissioning of NHS dementia services will sit with GPs. In the NE there have already been some changes to structures in preparation for the changes which will be required to deliver the proposed new legislation e.g. development of GP consortia and foundation trusts. How these will support dementia care is yet to be determined.

5. Economics of dementia care and support

Establishing the amount of spending on care and support for people with dementia and their carers is very difficult. Any figures should be viewed with caution. The amount spent on supporting people with dementia and their carers in the UK has been estimated as £17.03 billion per annum or £25,472 per person with late onset dementia. In the NE a figure of £143 million has been assessed as being spent on dementia care using relevant NHS and local authority costs.

There are nationally developed approaches to making savings in dementia care that could be adopted. For example, in Darlington their Dementia Collaborative has reduced the length of stay for people in one of their older person's hospital wards by an average of five days.

The NE third sector organisations are beginning to feel the impact of the current economic climate. This could effect the service provision for people with dementia and their longer-term viability.

6. Research in the region relating to dementia

The NE has a very strong dementia research base in Newcastle and Northumbria Universities. Their research focuses on brain ageing and includes work on causes, treatment, and care and support for people with dementia and their carers. These universities are also strongly linked to national initiatives on dementia.

7. Structures which support the implementation of the National Dementia Strategy

There are three regional groups dedicated to the implementation of the NDS. Each has a particular focus either on strategy, development & implementation or on commissioning. Two additional regional groups are not dementia specific but play a significant part in implementation; one having a focus on health the other on social care. Dementia Forums are being developed across the NE by the Alzheimer's Society. These will be used to collect the views of local people to enable local accountability. Seven out of the twelve geographical localities in the NE reported they have multi-agency groups responsible for the implementation of the NDS in their area. The future of some regional groups is uncertain over the next year or so.

8. Getting a whole picture of dementia in the North East

There are three key sources of NE wide dementia information. These are:

- “Readiness to Implement” – a baseline self-assessment of the 12 localities position in relation to the NDS objectives 1 to 15.
- Locality Plans – ten plans of how those localities are going to implement the NDS.
- “Developing a comprehensive evidence base for the future commissioning of dementia services in the NE” – a collection of information to assist with commissioning of community and personal support services.

9. Stakeholders views on dementia care in the North East

Results are available for four key NE based consultation exercises about dementia. They outline stakeholders views, primarily what people with dementia and their carers want, and their experiences. One report specifically gives the views of people with a Learning Disability. The contents are felt to be representative and current, as views are often re-inforced in the various reports and are echoed in later reports, despite the consultation exercises being carried out up to two years apart. These are used throughout this report as a reference point, providing the views of in excess of 500 people. There is, however, little evidence in the reports that people in minority communities were consulted.

10. Service providers in the North East

There are a variety of providers of services for people with dementia and their carers. In the statutory sector there are four health trusts who provide secondary mental health services and twelve local authorities providing both specialist and universal services, which include assessment of need and service provision. Around ten third sector organisations provide over sixty services. There are ‘not for profit’ organisations providing both housing and housing services, but a full regional picture is not currently available. Significant private sector organisations are providing care home and domiciliary services. Again a full current regional picture is not available. It is important that this picture is developed as a foundation for future work. There is also one known user lead organisation (using the Department of Health definition) for people with dementia and their carers.

11. The four National Dementia Strategy Priorities

The four agreed national priorities are:

- Good quality early diagnosis and intervention for all (objective 2)
- Improved quality of care for people with dementia in general hospitals (objective 8)
- Living well with dementia in care homes (objective 11)
- Reduction of the inappropriate prescribing of antipsychotic medication to people with dementia.

These are defined in the dementia strategy implementation guidance⁴ and the NHS Operating Framework⁵.

The North East response to the first priority has been to develop a memory service specification for use across the NE and pathways are being developed for early diagnosis. A national audit of memory services is due to take place from May 2011 that

⁴ Department of Health. (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. Department of Health:London

⁵ Department of Health. (2011) *The Operating Framework for the NHS in England 2011/12*. Department of Health:London

will also give a full regional picture. GPs are seen as key to early diagnosis but stakeholders report both positive and negative experiences. There are some initiatives which are supporting GPs to deliver a diagnosis. Dementia pathways are being developed in general hospitals and in-reach services are available to some, however the coverage and quality is unknown. Contracts and development of quality standards are being used to drive up quality in care homes. Some detailed regional work has been carried out on how to implement the care home objective that can be built on. There are some good examples of training and development to support improvements in early diagnosis, good quality hospital care and support in care homes. However there doesn't appear to be a strategic approach to training and development in these areas.

A strategic approach to reducing inappropriate prescribing of antipsychotic medication has been adopted and is being led by the Mental Health Clinical Innovations Team. However there is currently no baseline data on the number of people with dementia who are being prescribed antipsychotic medication.

12. North East additional priority objectives to the four priority areas

The North East has adopted three additional objectives to make up the seven North East priorities. These are:

- Improved community personal support services (objective 6)
- Housing support, housing related services and telecare to support people with dementia (objective 10)
- Improved 'end of life' care for people with dementia (objective 12)

In the region Personalisation is seen as key to the implementation of good community and personal support. People with dementia and their carers prioritise the need to have appropriate respite and domiciliary care. However, eleven of the twelve localities feel that community provision is "sufficient" for people with dementia. There are a number of registered social landlords providing housing services but a full regional picture has not been established. Good 'end of life' care is considered to be important but, particularly for carers, having the conversations about 'end of life' with someone with dementia are seen as being difficult. The needs of people with dementia are said to be included in 'end of life' initiatives in the region.

People with dementia and their carers have said they want more information on personal budgets, telecare and 'end of life' care. More training is required in relation to personalisation, telecare and 'end of life' care needs.

13. Details of the remaining objectives

There are eight remaining objectives in the NDS where responsibility for implementation lies with the region or localities. They cluster around support and information, with objectives linked to intermediate care, workforce development and joint commissioning plans.

Support and Information: The NDS objectives linked to the themes of support and information for people with dementia and carers are considered together (objectives 1,3,4,5). Across the North East some public and professional awareness initiatives are being undertaken but they need to be stepped up. When it comes to information provided to people with dementia and their carers it needs to be timely and in an accessible form. The opportunity to have access to someone to talk to "face to face" to

give information and guidance is also seen as being desirable. There are dementia advisors in various parts of the region but the spread and effectiveness is not known.

Carers: Carers are considered in objective 7. The consultation tells us that they want to be listened to as a partner in the support and care of the person with dementia. Carers are currently supported through generic carers' initiatives and a number of services specifically for carers of people with dementia. Learning networks for people with dementia and their carers are thought to be available in 50% of the region.

Intermediate Care: The National Dementia Strategy states that intermediate care should be accessible to people with dementia. Stakeholders in the North East suggest that support needs to be provided to people with dementia both to prevent admission to hospital if at all possible and on discharge. Many intermediate care services in the region acknowledge they don't fully meet the needs of people with dementia. They are therefore being reviewed to ensure they are inclusive of people with dementia.

Workforce: The need for staff training and development in dementia care is a strong and reoccurring theme. Training should be made available to all people who come into contact with people with dementia across professions and along the pathway. Some carers would like to be involved in developing and delivering training. A dementia learning and development pathway is being developed but there is little evidence of a strategic approach to dementia workforce development.

Joint commissioning plans: Stakeholders want a single system of care and support along the whole pathway for people with dementia.

14. Nationally led objectives

There are three NDS objectives that are led nationally. These relate to service regulation, dementia research, and resources to support the implementation of the strategy.

North East specific responses include the development of quality standards for regulated providers and provision of a senior implementation support post until May 2012. Within the region research is being carried out in universities, to help fill dementia research gaps.

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More information

Full and summary copies of Dementia: A North East perspective report by Debbie Smith can be downloaded from the Foundation's website at www.nr-foundation.org.uk

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This report was written by Debbie Smith in her capacity as an independent consultant.

This report was commissioned by Northern Rock Foundation as part of the Foundations policy and research work. The views expressed, however, are those of the authors and not necessarily those of the Foundation.