



Dementia: A North East Perspective

Introduction

In July 2011, Northern Rock Foundation published a report by Debbie Smithⁱ outlining the status of dementia care in the North East, entitled “Dementia: A North East Perspective”. The report provided an overview of the work that was being undertaken to support people with dementia and their carers by statutory, independent, voluntary and education sectors. It highlighted progress made and gaps in service development and provision; setting this work against the English policy context and the views and experiences of people with dementia and their carers. This report has helped the Foundation to develop its future funding strategy. During the course of carrying out this work, it became clear that the report would also be useful to a much wider audience, who would need to take forward much of the work to ‘fill the identified gaps’.

This ‘Think’ piece takes the findings from the report, and subsequent analysis commissioned by the Foundation from Debbie Smith in her role as an independent consultant, and makes some suggestions about what the most useful next steps would be. We hope this ‘Think’ piece will stimulate debate, discussion and above all action to improve the lives of people with dementia and their carers across the North East.

Background

The “Dementia: A North East Perspective” report, by Debbie Smithⁱ sets out the major challenges that the North East will face when supporting people with dementia and their carers in future.

There will be a huge increase in the number of people with late onset dementia in the North East, from 31,840 in 2010 to 50,840 in 2030.ⁱⁱ

Supporting people to live well with dementia is a complex process. People need to be aware of what dementia is to get an early diagnosis. They then need support from diagnosis to end of life, which means that to live the best lives they can, they need to access many services from health, housing, social care and universal services.

The National Dementia Strategy was launched in 2009 and provides an implementation framework with seventeen objectives. Later that year, an ‘eighteenth’ objective was added, to reduce the inappropriate prescribing of anti-psychotic drugs to people with dementia.

The delivery and development of services is happening across the North East, at a time when significant policy and economic changes are taking place. Major changes include: public sector restructuring, proposals to give GPs responsibility for commissioning dementia services, voluntary sector budgetary pressures, threats to groups that have been delivering the national dementia strategy due to restructuring and the closure of some statutory organisations.

Issues that need to be addressed in the North East to improve the lives of people with dementia and their carers

- **There needs to be more effective regional leadership**

No single organisation in the North East has responsibility for implementing the National Dementia Strategy. A regional oversight board reviews the implementation. However, with changing structures and the complex nature of the strategy, the region needs the right leadership at the right level, to drive forward the National Dementia strategy and to improve the lives of people with dementia and their carers.

- **Services need more appropriately skilled staff**

People with dementia and their carers constantly raise the need for appropriately skilled staff, from GPs giving a diagnosis, to general hospital care and care home staff. There are some examples of good workforce development in all areas of service delivery, but this needs to be developed more strategically.

- **Innovation and best practice needs to be spread across the region**

Examples of innovation and best practice in commissioning, research, service delivery and development exist in the North East. Sharing this learning between different sectors in dementia care can lead to better outcomes for people with dementia and can improve cost effectiveness. However, this innovation and best practice is not always widely known about, shared or adopted. The region needs to utilise its existing resources in different organisations and individuals to drive forward change and development.

- **The voice of people with dementia and their carers needs to be strengthened**

Research with carers and people with dementia has identified that carers want to be actively involved and included in the planning of their care, to ensure high quality provision on a personal level and across their geographical area. With the right information and the right tools, people with dementia and their carers can provide challenge and ensure that services that are appropriate to their needs are developed and delivered. There are some good initiatives which involve people in monitoring current services and planning future ones, but these services are not widespread throughout the region and where they do exist their effectiveness is patchy. There is also a big question about how people will be able to influence the personalisation

agenda and their individual care and support, and arrangements which will arise from the implementation of the Health and Social Care Act, e.g. clinical commissioning and health and wellbeing boards.

- **We need to fill key gaps in information**

Good quality information, both quantitative and qualitative, is vital to planning effective services. The North East has already developed some basic dementia demographic information. However, there are some key gaps in our understanding, which need to be established:

The impact on the North East Region

- 1) The North East needs to establish the economic, health and social care implications of a significant increase in the number of people with late onset dementia.
- 2) A comprehensive and accurate figure for spend on dementia in the region is needed.

Demographic Information

- 3) The prevalence of people with dementia from black and minority ethnic communities and people with dementia from the lesbian, gay, bisexual and transgender communities needs to be established as a priority.
- 4) The number of people believed to have young onset dementia (under 65) is available, but it is not thought to be an accurate figure.
- 5) There is a lack of demographic information relating to people who have dementia in prisons and people who have dementia in rural communities.
- 6) We need to know the number of people with dementia who are prescribed antipsychotic medication.

The experiences of people with dementia

- 7) Research is needed into the experiences of people with dementia from black and minority ethnic communities and people with dementia from the lesbian, gay, bisexual and transgender communities. We also need to know the types of services that these groups of people would like to see developed.

- 8) With the numbers of males with late onset dementia (aged over 65) increasing over the period between 2009 to 2030 by 93%, we need to know what the impact will be of an increasing number of males with dementia on health, social care and other systems.

Service Provision

- 9) We need to establish a picture of care home provision (type, ownership and spread) and registered social landlords (type of provision accommodating people with dementia, both specialist and generic) in the North East.
 - 10) We need to know whether small care homes provide more effective care than others.
 - 11) Extra care housing provision has been developed for people with dementia. There is no central North East data base on the effectiveness of this for commissioners to access.
 - 12) We need to know the benefits to dementia care and support of using section 75 of the National Health Act 2006, which relates to partnership arrangements between health agencies and local authorities.
 - 13) We need to establish where in-reach services into hospital and care homes are, what they do and their outputs and outcomes.
 - 14) We need to know whether intermediate care services are fully inclusive of people with dementia and where there is good practice that can be shared.
- **The voluntary sector needs to be funded so that it can continue to deliver the most effective low level support services**

Many services which are delivered by voluntary organisations for people with dementia and their carers, such as dementia cafés, dementia advisers and arts projects, are not statutory requirements and may be subject to cuts. It seems likely that in the current economic situation, it will be more difficult for voluntary organisations to raise funds to support this work. It is likely that low level support for people with dementia will reduce. There needs to be a strategic response to these issues to ensure that the most effective services, that have the biggest impact on the lives of people with dementia and their carers, are able to continue.

- **We need to support the areas with the greatest numbers of people with dementia**

Following a review of demographic information, action plans and views of stakeholders, Durham and Northumberland have been identified as areas with particular needs. These two areas have the greatest numbers of people with late onset dementia (5,905 and 4,160 respectively; ((Jackson, M. 2009))ⁱⁱⁱ which equates to one third of the North East's total population of people with dementia. It is predicted that by 2030 there will be 10,529 people in Durham and 7,961 people in Northumberland with late onset dementia. Currently, there are no published dementia action plans or locality planning groups for either area.

Conclusion

This report has highlighted a number of priorities that need to be addressed, to ensure that people with dementia and their carers get good services wherever they live in the North East and whatever communities they come from. How we will support people with dementia and their carers is one of the most pressing health and social care challenges facing the North East. However, here in the North East we have some excellent examples of research, practice and commissioning going on that we can spread across the region. We also have a committed community of people that wants to take this work forward and very committed people with dementia, and their carers, who want to play a bigger role in the development of their own care and the development of services.

During the summer and autumn of 2011, Northern Rock Foundation will be talking to a wide range of organisations from the health, statutory and voluntary sectors to highlight the issues raised in this 'Think' piece and to explore how the issues identified can be addressed.

ⁱ Smith, D. (2011); Dementia: A North East Perspective, Available at: www.nr-foundation.org.uk

ⁱⁱ Jackson, M. (2011); Dementia North East Demographic Update, Available at: www.phine.org.uk or www.nr-foundation.org.uk

ⁱⁱⁱ Jackson, M. (2009); Dementia North East England A Demographic and Service Profile, Available at: www.phine.org.uk or www.nr-foundation.org.uk

More information

Full and summary copies of the 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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