

'Think' Piece

Dementia 2014: A North East Perspective



NORTH EAST
DEMENTIA
ALLIANCE



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Introduction

In June 2014, Northern Rock Foundation and the North East Dementia Alliance published a report by Debbie Smith and Peter Otter outlining the status of dementia care in North East England, entitled '*Dementia 2014: A North East Perspective*'. The report provided an overview of the work being undertaken to support people with dementia and their carers by the statutory, independent, voluntary and education sectors. It highlighted progress made and gave a series of recommendations; setting this work against the English policy context.

This 'Think' piece takes findings from the report and highlights some of the more difficult issues relating to dementia, which need to be considered, teased out and addressed. 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 region.

Background

There will be a significant increase in the number of people living with dementia in the North East, from 34,000 in 2014 to 50,900 in 2030.

Supporting people to live well with dementia is a complex process. People need to be aware of what dementia is to get a timely diagnosis. They then need support from diagnosis to end of life, which means living a quality life and accessing many services from health, housing, social care and 'universal' services.

From 2009 primary dementia policy came from the National Dementia Strategy¹ which provided an implementation framework with 17 objectives. This was supplemented, in 2012, by the '*Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*'.² This prioritised driving improvements in health and care, better research and the development of dementia friendly communities.

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 challenges include: commissioning for dementia health services by clinical commissioning groups, budgetary pressures, political uncertainty with a planned election in 2015 and the planned end of the implementation phase of the National Dementia Strategy in spring 2014.

This 'Think' piece highlights issues which go beyond one geographical or service area (a wider range of specific recommendations can be found in the main document). The issues highlighted are posed as questions and are those which are very often seen as the "knotty problems". Each question is followed by a series of statements to facilitate discussion and resolution.

¹Department of Health (2009) Living Well With Dementia: A National Dementia Strategy – Implementation Plan [Online] Available at: http://www.thinklocalactpersonal.org.uk/_library/Resources/SouthEast/Legacy/OP_Dementia/Living_Well_with_Dementia_National_Dementia_Strategy_Implementation_Plan_OPD_Document.pdf (Accessed 17 May 2014)

²Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015: A report on progress [Online] Available at: <http://media.dh.gov.uk/network/353/files/2012/11/The-Prime-Ministers-Challenge-on-Dementia-Delivering-major-improvements-in-dementia-care-and-research-by-2015-A-report-of-progress.pdf> (Accessed 17 May 2014)

1 How do we ensure full shared decision making with people with dementia?

- People living with dementia have the right to shape decisions affecting their life. This is a minimum, not a gold, standard. Is it therefore appropriate that other people make decisions without consulting with the person with dementia?
- A person's right to be involved in shared decision making should not be marginalised, yet we continue to see repeated examples of people living with dementia either not being involved, or being offered token levels of involvement.
- Reasons given by 'professionals' for not fully engaging people include limited timescales, limited resources and targets. These are all reasons which benefit the professional, not the person with dementia.
- Involving people with dementia at all levels is not easy. How do we best engage people with dementia in decisions about their care, as well as decisions about how strategy should be developed?
- How do we empower and support people with dementia? What practical issues need to be addressed, considering things like location, environment, timings and the forms of communication we use?
- The 2011 regional report³ on dementia provided a comprehensive view on what people with dementia thought about the services with which they were involved. The '*Dementia 2014: A North East Perspective*' report did not cover people's views as a comprehensive survey had not been completed. Have people's views changed since 2011? Should a comprehensive analysis of people's views be undertaken and, if so, how frequently?
- Minority groups and people in the latter stages of dementia are at particular risk of not being empowered or listened to. We need to take extra steps to ensure they are included.

³Smith, D. (2011) Dementia: A North East Perspective [Online] Available at: <http://www.nr-foundation.org.uk/wp-content/uploads/2011/08/Dementia-A-North-East-Perspective.pdf> (Accessed 17 May 2014)

2 How can we improve information sharing?

- Planning for dementia care can be hampered by inadequate information, with decisions sometimes being taken using out of date, or incomplete, information.
- Required information may be available but, for a number of reasons, it is not readily accessible. For example information might be held by specialists, not published, or not readily identified as being relevant to dementia care.
- Organisations which hold potentially useful information include primary and secondary health, adult social care, the emergency services, voluntary organisations and registered social landlords.
- Data protection and protocols for sharing information often restrict the use or exchange of information between organisations. This can result in individuals with dementia not getting the best care or support.
- The key causal relationships along the dementia care pathway need to be identified to assess what data needs to be collected: e.g. where there are reduced lengths of stay for people with dementia in hospital, does that impact on readmission rates?
- Should work be done to establish what information is available and where it is held and action taken to fill any gaps?
- Key information requirements need to be established for each stage of the dementia journey so that a series of cross organisational dash boards can be developed.

3. How do we ensure we focus on outcomes for people with dementia as the measure of success?

- Everything we do to improve care and support for people living with dementia needs to be evaluated in terms of the qualitative effect and outcomes impacting on people with dementia.
- Should we use the views of people with dementia as the drivers for change?
- We use a plethora of indicators to measure 'successful' implementation of dementia specific initiatives e.g.
 - Guidelines - NICE
 - Standards - The hospital standards and memory services accreditation standards from the Royal College of Psychiatrists
 - Principles - Common core principles for supporting someone with dementia (Skills for Care / Skills for Health)
 - Outcomes - National Dementia Action Alliance, Health, Social Care and Public Health
- Some indicators, such as diagnosis rates, are common across different parts of the system.
- The report '*Dementia 2014: A North East Perspective*' identified a range of services which appeared to benefit people with dementia. Evaluation of these services was often restricted to quantitative measures, such as numbers of staff, or information about service contacts. There was very little information available regarding the benefits or outcomes for the person with dementia.
- Measuring qualitative outcomes is particularly challenging for services for people with dementia. Methods can include dementia mapping but these are often time consuming and resource intensive.
- Using the key information a series of cross organisational dashboards (an at-a-glance view of key indicators relevant to that part of the process) can be developed, which should include qualitative indicators.

4. How do we develop a workforce which is equipped to meet the needs of people with dementia?

- Workforce is a cross cutting theme affecting health, social care and the third sector.
- The workforce section of '*Dementia 2014: A North East Perspective*' focused primarily on staff training.
- Current initiatives include awareness training for health staff and the promotion of person centred approaches to care. These need to be continuously supported as staff groups change over time.
- It is important that values based recruitment becomes embedded into an organisation's recruitment process.
- Broader workforce issues also need to be considered including recruitment, retention, remuneration, supervision and appraisal of staff.
- Many issues relating to the workforce are common across organisations such as recruitment, retention and remuneration and, therefore, there should be opportunities to work together to solve these issues.

5. How do we make sure best practice is adopted?

- Why do neighbouring organisations fail to adopt some very useful practices, models and services which have clearly evaluated benefits for people living with dementia?
- Why are some organisations not engaged with wider partners to exchange ideas and good practice to support the person living with dementia?
- Health and social care services say they commission services on the basis of positive evidence of good practice. However, commissioners continue to choose providers who do not have the evidence base to prove their effectiveness or positive impact for people with dementia.
- When promoting what works well it is equally important to know what doesn't work and to make partners aware of this.
- There are opportunities to share best practice via the Dementia Hub, the North East Dementia Alliance, the Mental Health, Dementia and Neurological Clinical Network and at events with partners.
- There are issues about the definition of best practice; however, we feel that this shouldn't stand in the way of considering a specific service or approach which has resulted in positive outcomes for the person living with dementia.
- We need to look nationally and internationally at good practice.

6. How do we maximise resources to develop the right care and support for people living with dementia?

- An honest debate around funding services for people with dementia needs to take place between key partners; in particular, health and social care.
- There is evidence that early intervention and short term investment can result in longer term benefits e.g. supporting respite care to reduce the need for permanent residential care later in the journey of the person with dementia. What action is being taken as a result of this?
- What are the true costs of care across the system in the North East? What is the economic impact? What are the costs to carers? What are the additional health care costs?
- The benefits of regional working have been clearly outlined in the report '*Dementia 2014: A North East Perspective*'. Under current arrangements there is no regional funding for project work across the whole system.
- With reduced budgets and short term planning arrangements the third sector is under considerable financial pressure. Yet it is a provider of key services for people with dementia and carers. How can we continue to support the third sector?
- How do we tap into those resources which are not traditionally thought of as supporting people living with dementia e.g. housing, fire and rescue, police, universities and businesses?

7. How do we develop more joined up working at both a service and planning level?

- People live in one locality – not in service streams!
- People living with dementia and carers consistently say they want a seamless service. They want to go to one point of contact and don't want to have to go to a series of different organisations.
- Developing a dementia pathway is a useful way of ensuring service development can be viewed from the perspective of the person with dementia.
- The '*Dementia 2014: North East Perspective*' report reviewed at least seven local plans per locality, which include actions relating to improving dementia care and support.
- Some locality planning groups bring together key partners to develop a co-ordinated action plan for dementia care. These groups do not cover the whole of the North East, some are under review and most joint plans are out of date.
- Local plans which make reference to dementia are often based around key national policy objectives, without considering the local issues.
- There is some regional co-ordination of dementia priorities and work through the North East Dementia Alliance and the Mental Health, Dementia and Neurological Conditions Clinical Network.

8. How do we identify our regional dementia priorities?

- A variety of actions and improvements to dementia care and support need to be addressed but these can not be seen in isolation.
- Regional priorities need to be decided by people living with dementia, as well as professionals.
- When setting regional priorities we need to consider the following:
 - Would the benefit be greater if the action were addressed across the region and by more than one organisation?
 - Would there be significant cost savings, which could be re-invested in even better dementia care?
 - Would the result be greater sustainability of dementia care?
- Would the improvement deliver better care to more people whilst being sensitive to those from minority communities?
- Issues that could be considered a priority include:
 - 'Universal' health services
 - Housing
 - Safeguarding vulnerable adults including advanced decisions and lasting powers of attorney
 - End of life care
 - Personalisation
 - Information / data sharing
 - Hospital care

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More information

Full and summary copies of the '*Dementia 2014: A North East Perspective*' report by Debbie J Smith and Peter Otter can be downloaded from the Foundation's website at www.nr-foundation.org.uk/resources/dementia-report

For more information about Northern Rock Foundation's work on dementia please contact Northern Rock Foundation at the address below.

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