



# Dementia 2014: A North East Perspective

## Summary Report

**NORTH EAST  
DEMENTIA  
ALLIANCE**



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July 2014

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## Introduction

This report will outline the status of dementia care in the North East of England as of July 2014. In particular, this report provides a summary of:

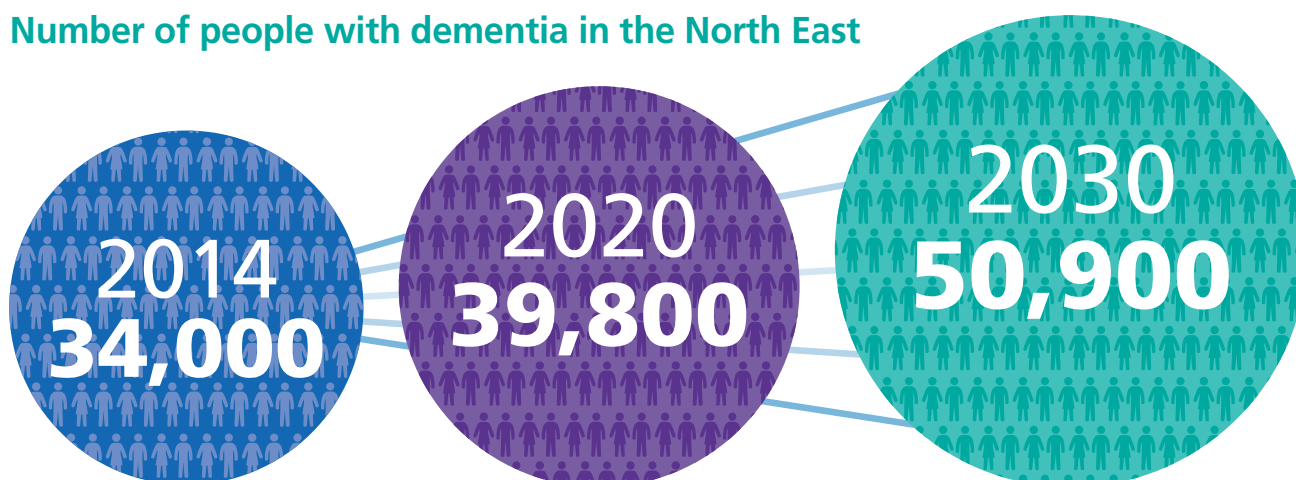
- Demographic trends
- The relevant English policy context
- The groups and organisations in North East England
- Dementia research in North East England
- Work to drive improvements in health and care in the North East of England
- The development of dementia friendly communities in the North East of England



This is the summary version of the report '*Dementia 2014: A North East Perspective.*' The full report can be downloaded from the Northern Rock Foundation's website at [www.nr-foundation.org.uk](http://www.nr-foundation.org.uk)

# Context

## Number of people with dementia in the North East



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 activities.

In 2014, it is predicted there are 34,000 people in the North East with some form of dementia; by 2030 it is estimated the number of people with some form of dementia will be 50,000; an increase of 50%.

Between 2008/09 and 2012/13 the proportion of people in the North East with a formal diagnosis of dementia increased by 35%, from 496 people per 100,000 to 669.

In 2012/13 the recorded prevalence of dementia in North East England was higher than the national rate of 569 people per 100,000.<sup>1</sup>

### Key policy background

'*Living well with dementia: A National Dementia Strategy*', published in February 2009, was a five-year strategy to enable improved care and support for people with dementia and carers.<sup>2</sup>

2014 marks the end of the formal implementation period of the National Dementia Strategy. There are no plans to automatically refresh or update the National Dementia Strategy; however, many of the strategy's objectives still need to be implemented.

The '*Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*,' published in 2012, provides the impetus for continued improvements in services for people with dementia.<sup>3</sup>

<sup>1</sup>Projecting Older People Population Information System / Projecting Adult Needs Service Information 2013

<sup>2</sup>Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. London: Department of Health

<sup>3</sup>Department of Health (2012) *Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*. Department of Health: London

# Key groups and organisations in the North East

## Regional groups

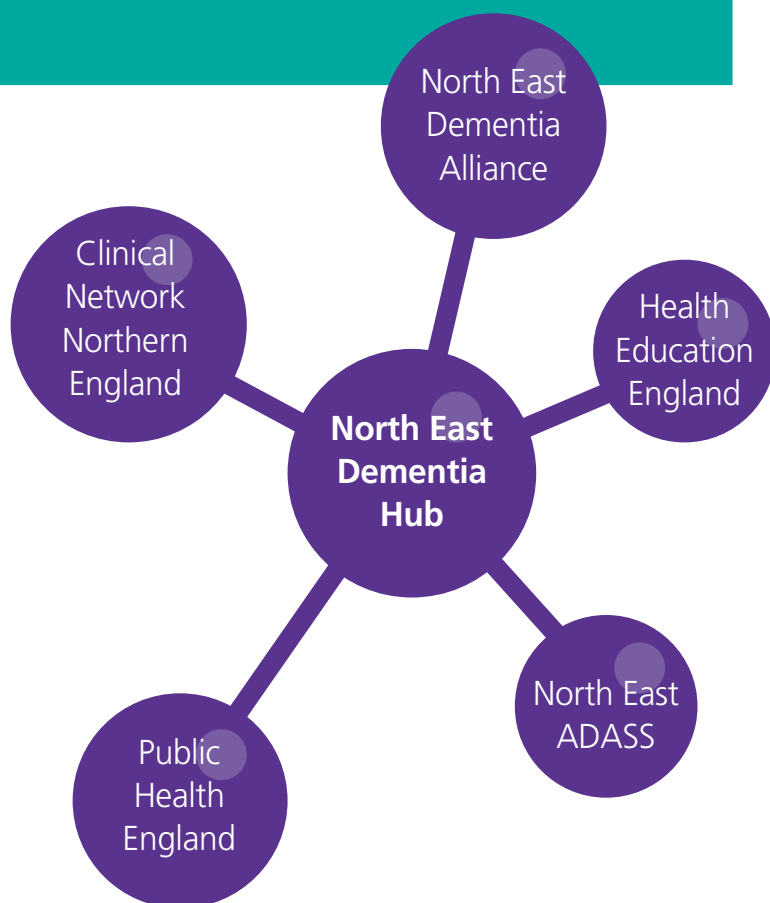
The North East benefits from strong regional cohesion and partnership working.

At a regional level there are three groups specifically dedicated to dementia<sup>4</sup>, while other regional groups and organisations have wider remits that include, but are not specific to, dementia.

There is some common membership between the groups which maximises joint working.

## Sub-regional and local groups and organisations

The improved care and support of people living with dementia in the North East is supported by a number of sub-regional groups and organisations, including local area teams, dementia collaboratives, clinical commissioning groups and other locality based groups and organisations.



## Case study: Dementia Collaboratives

Dementia Collaboratives in the North East aim to develop, implement and maintain large-scale system changes that lead to improved services for people living with dementia.

Collaboratives bring together key partners, including acute trusts, clinical commissioners, mental health trusts and local authorities. Other partners include independent sector providers, the third sector, carers and people with dementia.

To deliver improvements Dementia Collaboratives have adopted the North East Transformation System, a lean methodology. The approach uses Rapid Process Improvement Workshops (RPIW) to make

improvements in existing processes and 3P (production, preparation, process) events to develop new services.

This approach has allowed the Darlington Dementia Collaborative and the Stockton and Hartlepool Dementia Collaborative to achieve significant measurable results: for example, the lead in time between identifying a person who may need continuing health care to completion of the Decision Support Tool meeting was reduced from a 10 days average to 8.3 days average, a 17% improvement.<sup>5</sup>

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<sup>4</sup>The North East Dementia Leads, The North East Dementia Hub and the Dementia Themed Leads Group (ADASS)

<sup>5</sup>Murphy, C. (2013) North Tees Dementia Collaborative End of first year report: September 2012 – September 2013 (unpublished) p.11



## Recommendations on the context in the North East

- In September 2014 the Department of Health, together with the Alzheimer's Society, is expected to produce revised assumptions and figures relating to the number of people living with dementia in England. In light of these changes revised statistics for the North East should be produced by the North East Dementia Alliance, working with the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England and Public Health England Knowledge and Intelligence Team.

## Recommendations on the English policy context

- The National Dementia Strategy implementation period has come to an end. However, dementia still needs to remain a priority. The North East Dementia Alliance should seek to influence Government to develop policy based on an integrated holistic pathway approach.
- The 'NHS Outcomes Framework 2014/15' and the 'Public Health Outcomes Frameworks 2013/16' include dementia as a priority. Key organisations, including the Mental Health, Dementia and Neurological Conditions Strategic Clinical Network Northern England and the North East Dementia Alliance, need to support but, ultimately, call to account the organisations responsible for the delivery of these objectives in the North East.
- There are four dementia specific 'Calls to Action'. Key organisations need to act upon the calls and use them to deliver positive outcomes for people living with dementia.

## Recommendations on the groups and organisations in the North East

- Dementia Collaboratives are showing positive outcomes using the North East Transformation System (NETs) including rapid process improvement methodology. This is not being taken up across the region. There is a need to share learning and look at the feasibility of establishing Dementia Collaboratives across the North East. The Mental Health, Dementia and Neurological Clinical Network, North East Dementia Alliance and the ADASS themed network should consider how to take this forward.
- Funding to maintain the Dementia Hub and North East Dementia Alliance is available until November 2015. There is a need to consider obtaining resources to carry out project work and to maintain the structures after November 2015.
- In May 2014 the North East Dementia Alliance registered with the National Dementia Action Alliance. The North East Dementia Alliance needs to review its membership to ensure it is engaging with the appropriate stakeholders across the North East.
- Active joint action planning groups are not in every locality despite having the benefits of looking at the whole pathway and allowing agencies to bring their plans together. Local planning groups should be in each locality to develop and coordinate local joint dementia plans.
- All CCGs prioritise dementia. Some areas use scrutiny groups and Healthwatch as effective partners to drive up the quality of care and support. This priority should remain and scrutiny groups and Healthwatch should be seen as key partners in improving quality of care and support for people living with dementia.

# Research

Promoting research is one of the key focuses of the Prime Minister's Challenge on Dementia and the importance of research at a national level can be seen in the funding announcements that accompanied the G8 summit on dementia.

Despite its national importance, research is only mentioned in four out of the 10 local joint dementia plans in the North East.

The region benefits from a number of universities conducting research that supports improvements in the lives of people with dementia and carers. These include the Institute of Health and Society and the Institute for Ageing and Health at Newcastle University.

Northumbria University carries out extensive practice based research in collaboration with housing and care providers.

All memory services in the North East are registered as having an interest in supporting people with dementia to take part in research studies however there are substantial differences in the number of research studies to which memory services have recruited people (see table 1).

## Key institutions supporting the delivery of clinical research in the North East

The NIHR Newcastle Dementia Biomedical Research Centre (a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University)

The NIHR Newcastle Dementia Biomedical Research Unit in Lewy Body Dementia (a partnership between Newcastle upon Tyne Hospitals NHS Foundation Trust and Newcastle University)

The NIHR Clinical Research Network: North East and North Cumbria, Dementias and Neurodegenerative Diseases Research Network (DeNDRoN)

The Newcastle Brain Tissue Resource.

Memory services in the North East	Number of studies to which the memory service recruited in the 12 months prior to September 2013
Darlington Community Mental Health Team	2
Derwentside Community Mental Health Team	0
Durham and CLS Community Mental Health Team	2
Durham and CLS Community Mental Health Team	0
Easington Community Mental Health Team	2
Hartlepool Community Mental Health Team	1
Lustrum Vale Memory Clinic	10
Middlesbrough Community Mental Health Team	1
Newcastle Memory Assessment and Management Service	4
Northumberland Planned Care Group	-
Northumberland Tyne and Wear NHS Trust - Memory Protection Service	8
North Shields Memory Clinic	5
Redcar and Cleveland Community Mental Health Team	2
<b>Average for England</b>	<b>4</b>

**Table 1:** The number of research studies that memory services in the North East recruited. Source: Royal College of Psychiatrists (2013) English National Memory Services Audit Report. London: Royal College of Psychiatrists with additional information from providers in the North East.

## Recommendations on dementia research in the North East

- Only four out of the 10 joint dementia plans in the North East make reference to research, despite it being a national priority. Locally, joint dementia groups could consider what contribution they could make to research, such as encouraging people living with dementia to become involved in research.
- DeNDRoN and memory services support the recruitment of people with dementia to research studies. This work needs to be built on and new initiatives, such as the ENRICH project, that engage care homes, need to be supported by care home providers and commissioners.
- Significant research is being carried out in the North East. It is important to ensure that research findings are disseminated and translated into practice across the region. The universities and the North East Dementia Hub should play key roles in this, with significant partners including the North East Dementia Alliance and the Mental Health, Dementia and Neurological Clinical Network.



# Awareness and understanding

Increasing professional and public awareness of dementia is objective 1 of the National Dementia Strategy and commitment 8 of the Prime Minister's Challenge on Dementia states that *"from autumn 2012, we will invest in a nationwide campaign to raise awareness of dementia, to be sustained to 2015"*.

Increased awareness of dementia is mentioned in two Joint Strategic Needs Assessments in the North East, both of which highlight the need to increase understanding about how improved health can reduce the risk of dementia.

In May 2014 work was undertaken in the North East to support national awareness campaigns including the campaign led by Public Health and

Alzheimer's Society and local events to support Dementia Awareness Week. There is little large scale awareness raising outside of these national initiatives.

**As of April 2014, 336 Dementia Friends information sessions had taken place in the North East of England creating 4,140 Dementia Friends.**

In the North East there has been little evaluation of the effectiveness of any awareness campaigns other than records taken of the number of people attending events or Dementia Friends sessions.

## **Recommendations** on increasing public awareness and understanding of dementia in the North East

- National awareness campaigns are providing a spring board for raising awareness in the region. North East organisations should continue to capitalise on national initiatives and consider how to evaluate their success. They should also consider what other awareness raising activities are taking place outside of these campaigns.
- There are more than 4,000 Dementia Friends in the North East. The North East Dementia Alliance and partners should work with the Alzheimer's Society to increase the number of Dementia Friends and see how they can be used to increase awareness of dementia and contribute to improved quality of life for people living with dementia in the region.
- There is an emerging drive to consider the impact of good general health on the prevention of dementia. Locally, this has been highlighted in Joint Strategic Needs Assessments. Any emerging evidence needs to be collated and shared with regional stakeholders and embedded in any awareness campaign and prevention strategies.



# Identification, referral and timely diagnosis

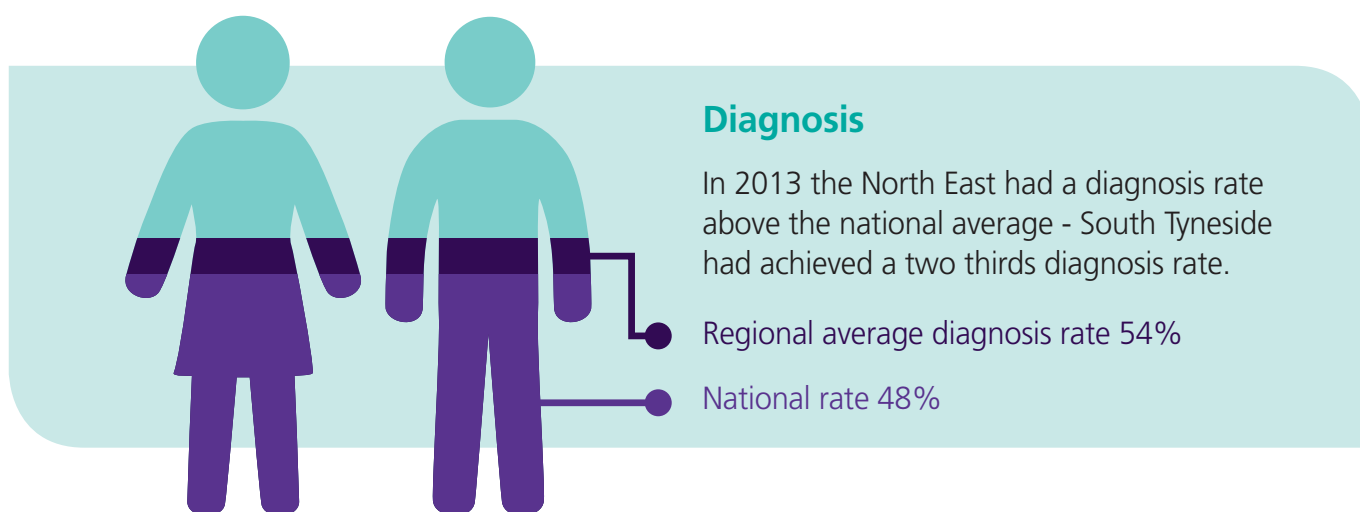
## North East diagnosis rates

Good-quality early diagnosis and intervention for all is Objective 2 of the National Dementia Strategy and Commitment 1 of the Prime Minister's Challenge on Dementia is "increased diagnosis rates through regular checks for over-65s".

There is a national ambition to achieve a two thirds diagnosis rate by 2015.

The importance of diagnosis is reflected in its frequent inclusion in local plans, for example diagnosis is mentioned in some form in the commissioning intentions of all CCGs in the North East and all local joint dementia plans.

In 2013 the average diagnosis rate for the North East (54%) was above the national average for England (48%).



## Improving diagnosis rates in the North East

There are some structures in place to help improve the identification, referral and diagnosis of people with dementia in the North East such as:

- The NHS Health Check programme
- GP Enhanced Service contracts for the facilitation of timely diagnosis and support for people with dementia
- The Commissioning for Quality and Innovation (CQUIN) payment framework for finding people with dementia, assessing and investigating their symptoms and referring for support

The North East has a good provision of memory services covering all localities within the region.

### 13 out of 14 memory services



provide an assessment within 6 weeks of referral (target based on the Memory Service National Accreditation Programme)

## Recommendations on identification, referral and timely diagnosis in the North East

- The average North East diagnosis rate at 2013 was 54%. In September 2014, on release of the national revised dementia prevalence figures, partners in the North East will need to recalculate the diagnosis rate and develop plans to achieve the ambition of a two-thirds diagnosis rate.
- There needs to be continued work towards achieving a two-thirds diagnosis rate across the North East. This work could be supported by learning from South Tyneside, which has already achieved a two-thirds diagnosis rate and other areas, including Scotland, where dementia diagnosis rates are high.
- A number of key groups in the North East have timely diagnosis as a priority work area. The Mental Health, Dementia and Neurological Clinical Network, ADASS and the North East Dementia Alliance need to ensure their plans complement each other, with the overall objective of improved care for people with dementia.
- Information about the GP enhanced services is due in autumn 2014. As information about the outputs and outcomes from the health checks and GP enhanced service emerges, any learning needs to be used to bring about change.
- Work is planned to assess the efficiency of the memory services in the North East and their capacity to close the dementia diagnosis gap. The Clinical Network for Mental Health, Dementia and Neurological Conditions needs to consider any recommendations and take appropriate action.
- There is little information about the quality of the diagnosis experience from the perspective of the person with dementia and their carer. There is a need to explore any information available in order to ensure that work around diagnosis is not limited only to quantitative measurements of diagnosis rates, but also includes work on improving the quality of the experience.



## Post diagnosis information and support

The National Dementia Strategy includes the following objectives:

- Good, quality information for those diagnosed with dementia and their carers (Objective 3)
- Enabling easy access to care, support and advice following diagnosis (Objective 4)
- Development of structured peer support and learning networks (Objective 5)

All 10 local joint dementia plans make reference to the provision of information and support at the time of diagnosis.

Following a diagnosis, 12 out of the 14 memory services in the North East offer Cognitive Stimulation Therapy.

There are advice and support services available in all localities across the North East. However, there is no evidence to assess the effectiveness of the information and support service in terms of the accessibility of the service or the outcomes for people with dementia.

Many of the services offering post-diagnosis support are provided by third sector organisations.

Data from 2011 suggests that the prescribing of anti-dementia medication in the North East was at a lower level than the national average.

**Where appropriate, all 14 memory services in the North East initiate the use of anti-dementia medication following a diagnosis.**

## Personalisation

Objective 6 of the National Dementia Strategy suggests people with dementia can benefit from the implementation of the personalisation programme.

Personal budgets, which can be taken in various forms, are a key plank of the personalisation programme. However, a number of national reports indicate there are major barriers to people with dementia taking up personal budgets.

The Prime Minister's Challenge highlights that carers should be encouraged to take a personal budget as this could help carers to meet their support needs.<sup>6</sup>

**A sector-led improvement master class on dementia and personalisation is planned for 2014.**

Statistics show that the take up of direct payments, one type of personal budget, is very low among people with dementia in the North East (see table 2).

Local Authority	Numbers of people aged 65 and over with dementia, who had a direct payment on 31st March 2013
Darlington	1
Durham	79
Gateshead	13
Hartlepool	5
Middlesbrough	19
Newcastle Upon Tyne	21
North Tyneside	4
Northumberland	30
Redcar and Cleveland	5
South Tyneside	43
Stockton-on-Tees	0
Sunderland	6

**Table 2:** Number of people aged 65 and over with dementia that had a Direct Payment on 31st March 2013, by local authority. Source: Data from the Referrals, Assessments and Packages of Care (RAP) returns submitted by local authorities to Information Centre NHS covering the period 1st April 2012 to 31st March 2013.

<sup>6</sup>Department of Health (2012) Prime Minister's Challenge on Dementia: Delivering major improvements in dementia care and research by 2015. Department of Health: London p.21

## Recommendations on post diagnosis information and support in the North East

- Post-diagnosis information and support is being provided across the region but it is not known if these services are effective with particular regard to outcomes for the individual. Locally joint dementia planning groups need to assess, with people living with dementia and their carers, if services are meeting the needs of their localities and any such evaluation should also consider the sustainability of local services, given that much of it is provided by the third sector.
- A North East audit of anti-dementia medication prescribing was last carried out in 2011. An updated audit of anti-dementia medication prescribing needs to be carried out. Any recommendations made should then be considered by groups including the Mental Health, Dementia and Neurological Clinical Network.

## Recommendations on the implementation of the personalisation agenda for people with dementia in the North East

- The personalisation of social care has the potential to have a great impact on the lives of people with dementia and their carers. For this report, it has not been possible to analyse all of the available information on personalisation so it is not possible to give an accurate assessment of its effect on the lives of people with dementia and those who care for them. In order to provide this accurate assessment, the dementia themed network should lead on work to collate, analyse and review all of the available data on personalisation.
- Anecdotal information indicates databases used to collect personalisation data don't always record a person's diagnosis of dementia. There is a need to explore the accuracy of coding/classification activity with an aim of improving accuracy and, therefore, reliability of data. Key partners exploring this would be the 'Think local, act personal', dementia and performance ADASS themed networks.
- There are identified barriers to the take up of personal budgets but national reports provide some recommendations to help overcome these barriers. Partners in the North East need to consider the barriers and recommendations and improve the take up of personal budgets among people with dementia and their carers who wish to take advantage of them.
- Current data provides us with some information about the take up of personal budgets. Work needs to be done to look at outcomes for people with dementia who are using personal budgets with more emphasis on qualitative, as well as quantitative, measures.
- Some carers of people with dementia may be entitled to personal budgets in their own right. Any service developments around personalisation need to be inclusive of carers of people with dementia.
- New approaches to personalisation are being implemented and piloted e.g. the use of individual service funds (ISF) and direct payments, which can be used to purchase care home places. These approaches need to consider people with dementia and their carers in their evaluation and need to be implemented.
- Health budgets are emerging. While no specific examples of people with dementia using personal health budgets are presented in this report, a watching brief needs to be kept to ensure people with dementia get the maximum benefits from these initiatives.
- A sector-led improvement master class on dementia and personalisation is planned for 2014. This master class needs to take account of the contents of this report.

## Care in the community

Objective 6 of the National Dementia Strategy highlights the need for *“an appropriate range of services to support people with dementia living at home and their carers”*.

Commitment 4 of the Prime Minister’s Challenge on Dementia outlines an intention to create a *“Dementia Care and Support Compact signed by leading care home and home care providers”*.

Five out of the 10 local joint dementia plans in the North East highlight the need for actions to review or up-skill domiciliary care workers that provide support to people with dementia.

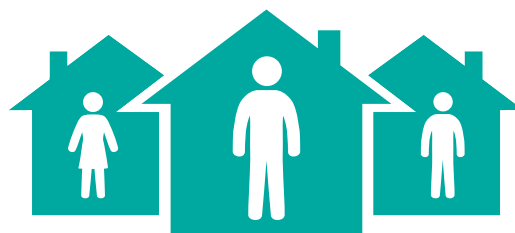
There are dementia specific day services in every locality across the North East.

The North East has a good range of community services supporting a person’s broader well-being. These include art, music and sport-based activities and social groups, such as dementia cafés.

There has been little evidence of work undertaken in the North East to improve ‘universal’ primary health care services for people with dementia. Continence services, pharmacy, dental, optometry and audiology services can all help people living with dementia to remain in their own homes. There is a need for further work to identify how these services can be delivered in a manner appropriate for people with dementia.

# 191

registered domiciliary care providers in the North East for care provided to people with dementia and people aged 65 plus



### Case study: Smarter Homes Stockton-on-Tees

Working in partnership with Tees, Esk and Wear Valleys NHS Foundation Trust and local homecare agencies, Stockton Borough Council launched the ‘Smarter Homes for the Future’ pilot in 2011.

The project provided home care staff and other professionals with specialist dementia training so they would be able to advise people with dementia about adaptations to make their homes more dementia friendly. These adaptations included the use of assistive technology, dementia-friendly design principles and the effective utilisation of colour, contrast and clarity, to support the person with dementia to remain at home for longer.

A 2012 evaluation of the project found there had been little or no deterioration in the clients’ quality of life and cognition throughout the six month evaluation. In addition, the implementation of ‘Design for Living’ principles and assistive technology was stated to have resulted in a positive impact on the mental well-being of the clients and reduced pressure on family members.

In May 2014 a group was established to mainstream the core principles of the project through key social care and health staff.

For further information contact [natalie.shaw@stockton.gov.uk](mailto:natalie.shaw@stockton.gov.uk)



## Recommendations on community care for people living with dementia in the North East

- Within each locality across the region varying services provide support to enable people to remain in their own homes. Each joint local planning group needs to consider the geographical spread and type of services which would best meet the needs of people living with dementia in their area. This analysis should be based on meaningful consultation with people living with dementia and carers within each locality. A gap analysis needs to take place and then an action plan needs to be implemented to fill the gaps.
- Many of the projects supporting a person's broader well-being are provided by the third sector. In the current time of financial austerity their long term feasibility needs to be assessed and these projects should be supported, where appropriate.
- The up-skilling of domiciliary care staff has been identified as a requirement in a number of local dementia action plans. Any development activity should take account of the Skills for Care guide for leaders and managers in the domiciliary care workforce working with people with dementia.
- No analysis of 'universal' primary care health services has been included in this report. Appropriate provision of these services; including improved continence services, pharmacy, dental, optometry and audiology services, can help people living with dementia to remain in their own home. There is a need for further work to identify how these services can be delivered in a manner appropriate for people with dementia.



# Housing and assistive technology

While the majority of people diagnosed with dementia will be living in their own homes, there is a higher risk that people will enter residential care if they can not be supported adequately at home.

Objective 10 of the National Dementia Strategy outlines the need to consider *“the potential for housing support, housing-related services and telecare to support people with dementia and their carers”*.

Thirty eight housing associations in the North East are members of the National Housing Federation. These associations provide 161,900 homes, including 19,924 designated properties for older people (including sheltered housing and extra-care schemes).

Not all people with dementia live in specialist housing and it is necessary to consider the use of home improvement agencies in supporting home owners living in the community. There is also a need to recognise that a person’s housing needs may change as their condition progresses.

Across the North East there are some examples of innovative work to improve the provision of appropriate housing for people with dementia (these include initiatives from the private, public and charitable sectors). However, these innovative practices need to be shared across the region.

**The North East has the potential to build on existing examples of successful cross-sector working between housing, health and social care, such as the 2014 conference ‘Transforming Dementia Care: The housing contribution’.**

The use of assistive technology, such as telecare and telehealth, has become increasingly common and is becoming a mainstream service offered by housing providers.

## Case study: **Gentoo Healthwise Project**

Gentoo, a large housing and support provider in Sunderland, has developed Healthwise; a case management system for people living with dementia. The computer-based information system allows frontline staff to input details of relevant call-outs and interactions with residents. The system enables Gentoo to flag up problems, using an early warning system, and refer people to other agencies at an early stage.

Gentoo has a Wellbeing Team which deals with Healthwise referrals. The members of the Wellbeing Team have received training in dementia care and have been trained to complete basic cognition tests.

*“The training helped me to recognise the signs of dementia and then refer the customer onto*

*Healthwise”* (Neighbourhood manager Gentoo).

Through Healthwise, Gentoo aims to increase dementia diagnosis rates, raise awareness of dementia and support people with memory problems to remain in their own home for longer.

Gentoo has eight Healthwise software licences, which it shares with other registered housing providers as part of the evaluation of its effectiveness. The National Housing Federation is supporting Gentoo and other registered housing providers to roll out use of the software as an integrated approach to early intervention in dementia care in other areas of the North East.

For further information contact [lindsay.gibbins@gentoo-group.com](mailto:lindsay.gibbins@gentoo-group.com)

## Recommendations on the provision of appropriate housing and assistive technology for people living with dementia in the North East

- Technology can support people with dementia to live in their own homes. Health, social care and housing providers need to work collaboratively - maximising opportunities for the appropriate use of technology to support people to live in their own homes.
- A growing number of case studies and an increasing amount of research highlight successful housing options for people with dementia in the social housing sector. The learning from this needs to continue to be disseminated among commissioners and housing providers.
- The evidence indicates that most people over the age of 65 are home owners and that two thirds of people with dementia live in their own home. Many of these people would prefer to be able to live in their own home for as long as possible. To help achieve this, a whole range of support services will be needed, from providing assistive technology, or adaptations to the fabric of the house to advice on mortgages, equity release schemes and what housing options might be most suitable for each individual.
- People already living in social rented housing are more likely to have better access to advice and information than owner occupiers and/or people in the private rented sector (the latter may be particularly vulnerable to living in poorly maintained housing). Support and advice about housing issues needs to be given to people in the private rented housing sector.
- The North East has the potential to build on existing examples of successful cross-sector working between housing, health and social care. The first area of focus should be Gentoo Healthwise, working with the National Housing Federation, the North East Dementia Alliance and Public Health England Knowledge and Intelligence Team to test out the learning from this project.



# Intermediate care and reablement

Improved intermediate care for people with dementia is Objective 9 of the National Dementia Strategy.

Since the launch of the National Dementia Strategy, reablement has become a key mechanism for supporting people with dementia to maximise their independence following illness or injury.

The most frequent actions in relation to intermediate care and reablement in local joint dementia plans in the North East relate to the need to ensure any of these generic services can be accessed and used by people living with dementia (this is mentioned in five out of the 10 plans).

In February 2013 Peopletoo published its Regional Reablement Review, which evaluated the reablement programmes in each of the 12 localities within the North East. The review found a difference of approach in each locality including a difference in the ways in which services responded to the needs of people with dementia.<sup>7</sup>

Some localities in the North East have taken steps to ensure generic reablement services are made more accessible to people with dementia, while others have developed specialist reablement services for people with dementia. There is a need for further work to evidence which approach provides the best outcomes for people with dementia.

**A regional reablement group was established by the North East ADASS in 2011.**

Although the regional reablement group is not dementia specific it provides the opportunity for local authority officers to share best practice.

For further information on the regional reablement group contact  
[ian.hall@northeastcouncils.gov.uk](mailto:ian.hall@northeastcouncils.gov.uk)

## **Recommendations** on the provision of intermediate care and reablement for people living with dementia in the North East

- Case studies from the North East highlight different models to support the delivery of intermediate care and reablement services that are inclusive of people living with dementia. The evidence of their outputs and outcomes (against resource input) should be collated and shared. This work should include key organisations including the Dementia Hub, the Regional Reablement Group, CCGs, the Dementia Leads Group and the North East Dementia Alliance.

<sup>7</sup>Peopletoo (2013) NEPO Regional Re-ablement Review: Phase 1 Report (Unpublished)



# Care homes

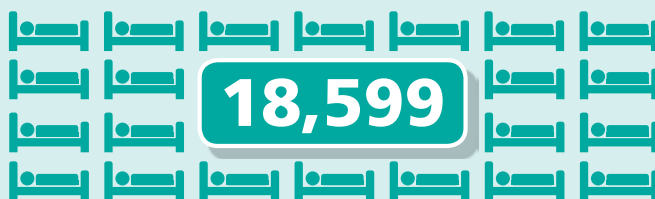
## Care homes in the North East

Living well with dementia in care homes is Objective 11 of the National Dementia Strategy. In addition, Commitment 4 of the Prime Minister's Challenge on Dementia outlines an intention to create a "Dementia Care and Support Compact signed by leading care home and home care providers".

Local joint dementia plans in the North East focus on the importance of using external systems to improve the quality of care delivered in care homes. This includes the use of audits, liaison services and contract management.

As of June 2014 397 care and nursing homes in the North East that specialise in, or otherwise provide services for, adults with dementia, were registered with the Care Quality Commission.

In May 2014 there were 18,599 beds in care and nursing homes providing a service for people with dementia (aged 65 years or older)



## Improving care homes in the North East

The North East ADASS Dementia Themed Network is undertaking a programme of work, during 2014/15, to improve the delivery of person-centred care for people with dementia in care homes in the North East.

In 2014/15, staff in 240 out of 583 care/nursing homes, supporting those with dementia and/or who are aged 65 and over, will be offered person centred training.

Examples of more specific initiatives aimed at improving the lives of people with dementia in care homes in the North East include arts and reading-based projects in care homes and initiatives to make the physical environment of

care homes more dementia friendly. As these initiatives were targeted within specific localities there is an opportunity for the North East Dementia Alliance to share learning from these projects across the North East.

The NIHR Clinical Research Network: North East and North Cumbria, Dementias and Neurodegenerative Diseases Research Network (DeNDRoN) is linking care homes to the ENRICH (Enabling Research in Care Homes) initiative, to involve people with dementia living in care homes in research.

For further information on the ENRICH initiative contact [margaret.piggott@nhs.net](mailto:margaret.piggott@nhs.net)



In 2014/15, staff in 240 out of 583 care/nursing homes, supporting those with dementia and/or who are aged 65 and over, will be offered person centred training



## Recommendations on the provision of care and support for people living with dementia in care homes in the North East

- The information available does not tell us what occupancy levels are in care homes, or the triggers for admission to a care home. This information would support commissioners to deliver better services and it needs to be identified and, where possible, sourced.
- The North East ADASS and North East Dementia Alliance have commissioned person centred training for 240 care and nursing homes in the region in 2014/15. An evaluation of the outcome of this work needs to be completed and appropriate actions need to be taken as a result of this review.
- A statistical care home report was published in November 2011. This needs to be revised and updated.
- A regional workshop in 2013 brought together professionals from health and social care with the aim of improving the quality of care delivered in care homes across the North East. This approach needs to be built on to improve care for people living with dementia in all care homes in the North East.

## General hospitals

Objective 8 of the National Dementia Strategy sets out the need for *“improved quality of care for people with dementia in general hospitals”* while Commitment 2 of the Prime Minister’s Challenge on Dementia outlines the provision of *“financial rewards for hospitals offering quality dementia care”*.

All but one of the Strategic Plan Documents for 2013/14 for the eight acute NHS Foundation Trusts in the North East included an explicit reference to meeting the needs of people with dementia. However, not all the North East’s acute hospital trusts have dementia strategies, action plans, working groups or dementia leads.

Across the North East the number of people being admitted to hospital as an emergency, where the primary diagnosis was recorded as dementia, has decreased by 34.1% between 2006/07 and 2011/12.

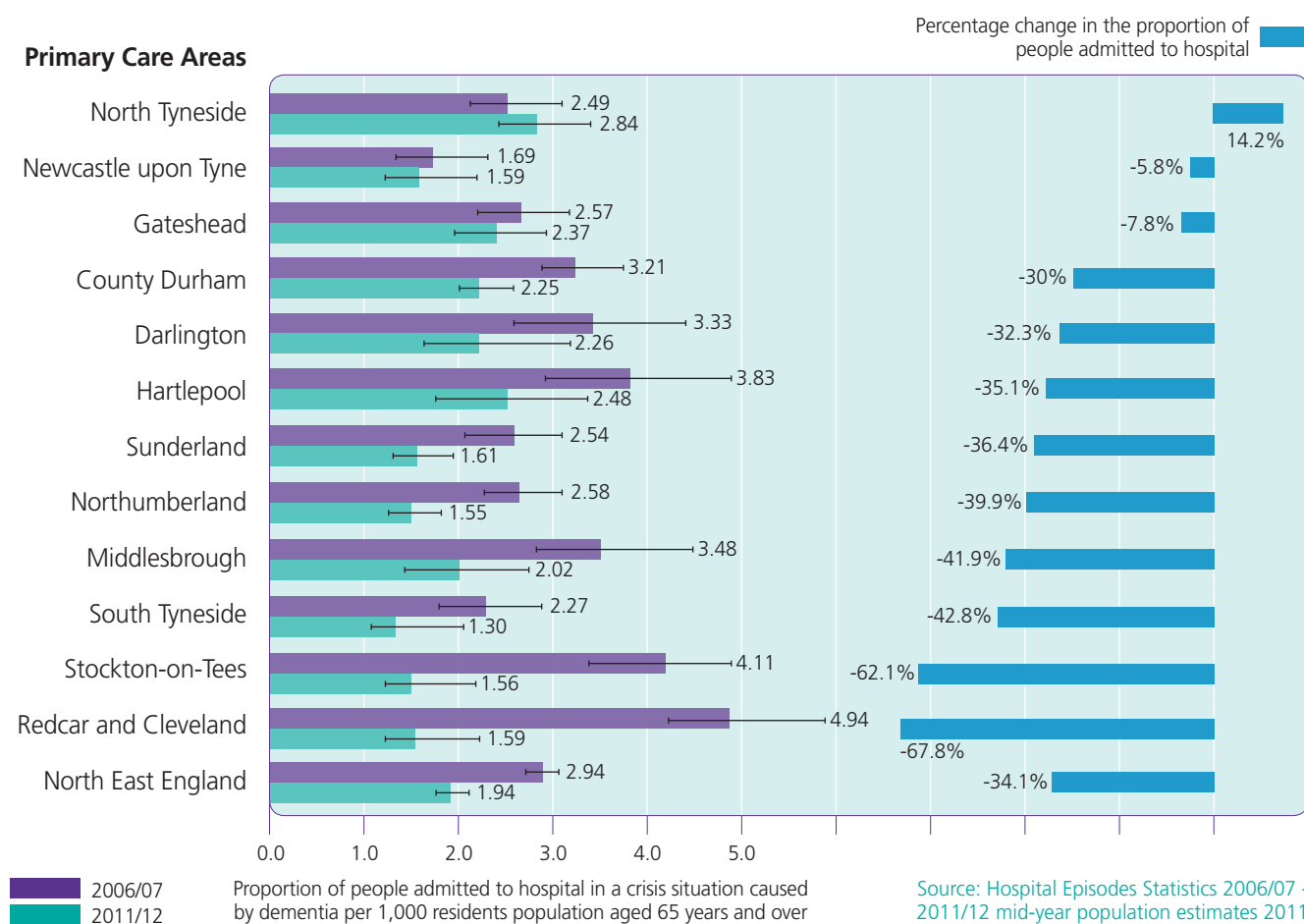
**All North East acute NHS foundation trusts have committed to the call to action ‘The Right Care: creating dementia friendly hospitals’.**

Examples of work undertaken to improve the care of people with dementia in North East hospitals include initiatives to make the physical environment of hospitals more dementia friendly and the implementation of ‘Forget me not’, ‘This is me’ and ‘All about me’ schemes.

Additional detailed data needs to be compiled to gain a more comprehensive understanding of the care of people with dementia in general hospitals. Examples of areas where further data is needed include re-admission rates, length of stay and mortality in hospitals.

## Inpatient Hospital Admissions in Crisis Situation Caused by Dementia

2006/07 - 2011/12 Primary Care Areas in North East England



### Recommendations on the care of people with dementia in general hospitals in the North East

- Not all hospital trusts have identifiable structures to support improvements in hospital care for people with dementia. Hospital trusts should work to develop dementia strategies, action plans and working groups and appoint identified dementia leads.
- Some initiatives have been taken forward to improve care in general hospitals in the North East. These interventions need to be shared and implemented across all trusts. This work could be supported by the regional Dementia Hub and the Mental Health, Dementia and Neurological Clinical Network.
- This report includes limited data relating to emergency hospital admissions. Further detailed data needs to be compiled to gain a more comprehensive understanding of the care of people with dementia in general hospital. The Mental Health, Dementia and Neurological Clinical Network should identify the key indicators and should access these data sets. Where actions are needed, the Mental Health, Dementia and Neurological Clinical Network needs to lead on these changes.

# Liaison services

Objective 8 of the National Dementia Strategy (improved quality of care for people with dementia in general hospitals) highlights the need for *“the commissioning of specialist liaison older people’s mental health teams to work in general hospitals”*.

The Rapid Assessment, Interface and Discharge (an economically evaluated psychiatric liaison service model developed in Birmingham) is being replicated, in part or in full, across the North East.

The Royal College of Psychiatrists has an accreditation programme for psychiatric liaison services (PLAN). In the North East the Older Person’s Mental Health Liaison service working in the Queen Elizabeth Hospital in Gateshead is the only older person’s liaison team with accreditation.

**A business case for the use of the psychiatric liaison model has been developed for the area served by Northumberland Tyne and Wear NHS Foundation Trust. The evaluation indicated the introduction of liaison services could lead to considerable resources being released.<sup>8</sup>**

There has been investment in liaison services across the region; however, it is unclear if coverage is comprehensive and what the full benefits have been, particularly for people living with dementia.

<sup>8</sup>North of England Mental Health Development Unit (2013) Outline Strategic Business Case for Development of Psychiatric Liaison Services: Across the geographical area served by Northumberland, Tyne and Wear NHS Foundation Trust [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014)

## Recommendations on the provision of liaison services in the North East

- It is unclear if the cover of psychiatric liaison services is comprehensive and whether the provision of liaison services extends into care homes. A comprehensive mapping exercise of the liaison services in the North East should take place, including staffing levels and mix and times of operation. The Mental Health, Dementia and Neurological Clinical Network and CCGs would be key partners in this.
- In conjunction with a full mapping of psychiatric liaison services, an evaluation of the full benefits, particularly for people living with dementia, needs to be completed. The Mental Health, Dementia and Neurological Clinical Network and CCGs would be key partners in this.

## Specialist mental health services

In the North East there are two dedicated NHS specialist mental health service providers and two additional trusts providing mental health services. The four trusts give full geographical coverage of the North East.

The average number of beds available in the four trusts for mental illness has slightly reduced between 2011 and 2014 (ranging from 1,887 to 1,591).<sup>9</sup>

It has not been possible to identify how many beds are used by people with dementia.

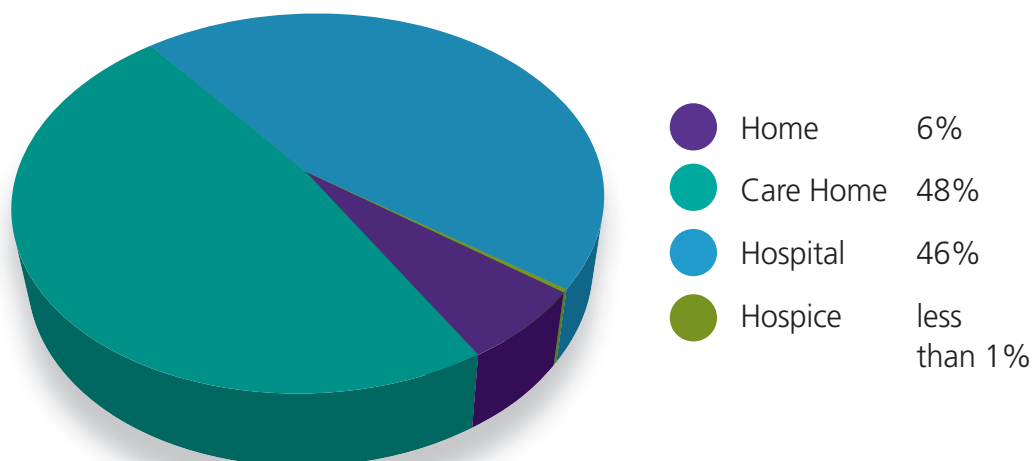
<sup>9</sup>NHS England [Online] Available at: <http://www.england.nhs.uk/statistics/statistical-work-areas/bed-availability-and-occupancy/> (Accessed 17 May 2014)

### Recommendations on the provision of specialist mental health services for people living with dementia in the North East

- Indications are that the number of beds for people with mental health needs in the North East, including those which would be used by people with dementia, has reduced. Further work needs to be undertaken to establish the bed provision for people with dementia and any changes in provision across the North East.
- In light of the reduction in beds provided by specialist mental health providers there is a need to look at whether people with dementia are receiving appropriate support. Alternative support may be provided through specialist mental health community services. A review of community mental health services (for people with dementia) should be considered alongside an assessment of the number of beds.
- During the research for this report no information was identified relating to the outcomes of any service changes for people with dementia and their carers. If changes are found to have taken place a retrospective review of the impact on people with dementia needs to be undertaken.

## End of life care

Place of death for people in the North East, for whom Alzheimer's disease, dementia or senility are listed as either the underlying cause of death or as a contributory cause of death<sup>10</sup>



<sup>10</sup>Source: National End of Life Care Intelligence Network: End of Life Care Local Authority Profiles 2012 [Online] Available at: [http://www.endoflifecare-intelligence.org.uk/end\\_of\\_life\\_care\\_profiles/la\\_profiles\\_2012](http://www.endoflifecare-intelligence.org.uk/end_of_life_care_profiles/la_profiles_2012) (Accessed 17 May 2014)

Improved end of life care for people with dementia is Objective 12 of the National Dementia Strategy.

Eight out of the 10 joint dementia plans in the North East focus on advanced care planning referencing advance care planning directives and 'Deciding Right'.

In 2012 the number of deaths in the North East where Alzheimer's disease or other dementia are listed as either the underlying cause of death, or as a contributory cause of death, was 2,242.

### **SEED, a significant national research project about end of life care and dementia, is being led from Newcastle University.**

For further information see the project's website at <http://research.ncl.ac.uk/seed/>

Examples of work to improve end of life care for people with dementia in the North East range from regional approaches to replace the Liverpool Care Pathway, to the employment of an Admiral Nurse by a hospice in Durham.

### **Recommendations on the provision of end of life care for people living with dementia in the North East**

- Giving people with dementia the opportunity to consider and record their end of life wishes is a key area of work. Any work which is carried out by the End of Life Regional Group needs to engage with people living with dementia and those working with people with dementia.
- 'Deciding Right' is a regionally recognised system. The Mental Health, Dementia and Neurological Clinical Network needs to support the implementation of this with people with dementia.
- The most detailed data about numbers of people dying from dementia and place of death in this report is from 2010. This also includes people dying with senility as a cause. Key data sets need to be identified to give the most useful data and then it needs to be sourced. This may include place of death and length of stay in location before death. The End of Life Regional Group and the Mental Health, Dementia and Neurological Clinical Network would be key partners in identifying and sourcing this data.
- Statistics on the place of death for people for whom Alzheimer's disease, dementia or senility are listed, show 46% are dying in hospital. Work needs to be undertaken to ensure people with dementia are dying in their place of choice, where possible.
- The SEED project is a significant research project. Newcastle University needs to consider the support that can be provided by other groups in the North East. Findings from the project need to be shared with key groups in the North East, including the Mental Health, Dementia and Neurological Network.
- A number of small scale projects are leading to better outcomes for people living with dementia. The findings from these projects need to be shared with partners.



# Dementia friendly communities

The initial driver for the creation of dementia friendly communities was the Prime Minister's Challenge, which included the aim that *"by 2015, up to 20 cities, towns and villages are to have signed up to become more dementia-friendly"*.

There is a national recognition process for dementia friendly communities. In the North East both Stockton-on-Tees and Corbridge are registered with the national recognition process for dementia friendly communities.

In 2012 the North East Dementia Alliance published the report *'Knowing the Foundations of Dementia Friendly Communities for the North*

*East'*<sup>11</sup> and held two regional conferences to promote the development of dementia friendly communities across the region.

There have been a number of innovative and successful projects in the region, which have followed different approaches. There is now a need to review which approaches have been effective in making communities more dementia friendly and to then share this learning with communities across the North East.

## Case study: Northumbria University

Northumbria University has committed to becoming a dementia friendly university and, in partnership with the Central England University, is looking at dementia friendly design and how it can be utilised to support care homes to become more dementia friendly. The University has committed to delivering Dementia Friends sessions to all nursing students.

The University reached the final of the Alzheimer's Society's national Dementia Friendly Awards 2014.

For further information contact [isabel.quinn@northumbria.ac.uk](mailto:isabel.quinn@northumbria.ac.uk) or [sue.tiplady@northumbria.ac.uk](mailto:sue.tiplady@northumbria.ac.uk)

## Recommendations on the development of dementia friendly communities in the North East

- There are a number of tools and resources to help develop dementia friendly communities. These need to be shared to prevent duplication.
- A number of dementia friendly communities projects have been sponsored by the North East Dementia Alliance and others in the North East. There is a need to establish what is successful and how we measure success.
- In the North East two communities have registered with the national recognition process. Other towns and communities need to register and commit to becoming more dementia friendly.

<sup>11</sup>Prior, P. (2012) *Knowing the Foundations of Dementia Friendly Communities for the North East* [Online] Available at: [http://www.phine.org.uk/uploads/doc/vid\\_16756\\_Dementia\\_Friendly\\_Communities\\_Report\\_Final.pdf](http://www.phine.org.uk/uploads/doc/vid_16756_Dementia_Friendly_Communities_Report_Final.pdf) (Accessed 17 May 2014)

# Workforce

An informed and effective workforce for people with dementia is objective 13 of the National Dementia Strategy and is included in the Prime Minister's Challenge.

All the local joint dementia plans in the North East include actions relating to workforce development.

In 2013 there were approximately 65,000 adult social care workers providing direct care and 58,000 patient facing health staff in the North East.

In 2012 more than 83% of the adult social care workforce in the North East were in the independent sector.<sup>12</sup>

The percentage of the adult social care workforce in the North East (working with people with dementia) that had no qualification was smaller than the percentage for the whole of England (30.5% compared to 40.5%).

A number of national initiatives support workforce development, including the 'Common Core Principles for Supporting People with Dementia,' produced by Skills for Care and Skills for Health and Health Education England's targets to increase dementia awareness across the health workforce.<sup>13</sup>

**The North East Dementia Alliance has produced two reports on the dementia workforce in the North East. The first provides recommendations for the North East Dementia Alliance and the second gives guidance on values-based recruitment.<sup>14</sup>**

Percentage of adult social care workforce from the North East working with people with dementia at qualification level 2 / level 3 higher than England as a whole<sup>15</sup>



Workforce for England: Level 2 - 28.9%



Workforce for North East: Level 2 - 32.1%



Workforce for England: Level 3 - 14.3%



Workforce for North East: Level 3 - 19.5%

<sup>12</sup>Skills for Care (2013) North East report, 2013: From the National Minimum Data Set for Social Care (NMDS-SC) [Online] Available at: <http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/NorthEastregionalreport2013vweb.pdf> (Accessed 17 May 2014)

<sup>13</sup>Department of Health (2014) Delivering high quality, effective, compassionate care: Developing the right people with the right skills and the right values: A mandate from the Government to Health Education England: April 2014 to March 2015 [Online] Available at: [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/310170/DH\\_HEE\\_Mandate.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/310170/DH_HEE_Mandate.pdf) (Accessed 17 May 2014)

<sup>14</sup>North of England Mental Health Development Unit (2013) Working with people with dementia and their carers: Values Based Recruitment [Online] Available at: <http://www.nemhdu.org.uk/publications/> (Accessed 17 May 2014)

<sup>15</sup>Skills for Care (2013) North East report, 2013: From the National Minimum Data Set for Social Care (NMDS-SC) [Online] Available at: <http://www.skillsforcare.org.uk/Document-library/NMDS-SC,-workforce-intelligence-and-innovation/NMDS-SC/NorthEastregionalreport2013vweb.pdf> (Accessed 17 May 2014)

## Recommendations on workforce

- There are national targets for the training of health care staff. Health Education North East needs to continue to work with providers to ensure these targets are met.
- A dementia skills framework is being developed, as part of the NHS mandate. Once developed, the training provided in the North East needs to be delivered in line with this national framework.
- The North East Dementia Alliance has published a values-based recruitment toolkit. Providers and commissioners need to consider its usefulness for their organisation. Health organisations can also link with the NHS Employers Organisation to be part of its 'recruiting to values' project.
- The North East Dementia Alliance is working with ADASS and the Tyne and Wear Care Alliance to deliver person centred training to 240 care homes in the North East. The evaluation of this work needs to be considered to assess additional training and support needs among care home staff.
- People living with dementia and carers have supported the delivery of training to nursing students at Northumbria University. Anecdotal evidence suggests this approach has resulted in positive outcomes. There is a need for a formal evaluation of the impact of this approach with the possibility of replicating this model of training in other workforce settings.

## Involving, engaging and empowering people with dementia and their carers

### Case study: Participation and Engagement Programme

The North East Dementia Alliance commissioned a pilot programme, aiming to empower people living with dementia and their carers to take control of their own care and support and influence service and policy development.

The pilot programme, which has been developed by the North of England Mental Health Development Unit and Karen Picking and Associates, runs over four sessions. The pilot programme supported people living with dementia and their carers to develop the confidence and skills to shape services, increase understanding of available services and develop a wellbeing plan.

Each person on the programme had their own learning objectives and was supported to achieve them.

The pilot's first cohort joined the programme in May 2014. This included 20 people who were carers or people with dementia. Links are being made between participants and strategy groups so that they can influence future services.

A second programme will run in the autumn of 2014, followed by an evaluation of the pilot programme.

For further information contact [paul.johnson@nemhdu.org.uk](mailto:paul.johnson@nemhdu.org.uk)

The National Dementia Strategy highlights the need to involve people with dementia and carers in the commissioning of services.

The strategy states that engagement should move beyond consultation to meaningful roles in priority setting, monitoring and service design. However, only three localities in the North East have, within their action plans, the aim to achieve this level of engagement.

There is only one user led organisation for people with dementia recorded in the North East. There is a need to support the further development of user led groups across the region.

There are a number of opportunities for people with dementia and carers to influence service development through forums in the North East.

The Clinical Research Network: North East and North Cumbria has a Patient, Carer and Public Involvement Panel for DeNDRoN, which is consulted about what and how clinical research in dementia is carried out.

The North East Dementia Alliance has developed a participation and engagement programme for people with dementia and family carers.

There is a need to explore how people with dementia who have limited communications skills can be engaged and empowered.

There is the need to ensure more meaningful engagement and the further empowerment of people with dementia in the North East.

### **Recommendations** on the involvement, engagement and empowerment of people living with dementia and their carers in the North East

- The Dementia Engagement and Empowerment Project (DEEP) provides opportunities to support groups of people with dementia to try to change services and policies affecting the lives of people with dementia. The North East Dementia Alliance should work with this project to see what benefits can be brought to people living with dementia in the North East.
- A minority of local action plans contain a commitment to improve the engagement and empowerment of people living with dementia by supporting people to take on meaningful roles in priority setting, monitoring and service design. All local plans should reflect a similar level of commitment.
- The North East Dementia Alliance has commissioned the development and delivery of a participation and engagement programme for people with dementia and their carers. If the evaluation of the pilot finds the course to be successful, resources should be sought to run it on a regular basis, across the region, taking into account any recommendations from the evaluation.
- There is only one user led organisation recorded in the North East for people with dementia and carers. The North East Dementia Alliance should continue to work with the Dementia Engagement and Empowerment Programme (DEEP) to support the further development of user led groups across the North East.
- Many consultation and involvement activities are responding to a predetermined agenda. Consideration needs to be given to how people with dementia can be meaningfully engaged. This applies to service providers and commissioners.
- People with dementia and their carers have been consulted and involved with the facilitation of Healthwatch. All engagement routes and methods need to be considered.
- No examples of engaging and empowering people with dementia in the North East, who also have limited communications skills, have been included in this section. Examples of how this can be carried out effectively need to be identified and shared. Key to this would be the North East Dementia Alliance, the Alzheimer's Society, the Clinical Network and care home providers and commissioners.

# Minority communities

It is estimated that, in the North East, in 2013 there were:

- 694 people of working age with dementia
- 353 people from a non-white ethnic background with dementia
- Between 540-756 lesbian, gay or bisexual people with dementia
- Five transgender people with dementia
- 175 people with dementia who had religious beliefs other than Christian, and 781 who were likely to have no religious belief
- 16,560 individuals with dementia who had a longstanding illness, disability or infirmity<sup>16</sup>

There is a general legislative and policy framework to promote equality, including access to health and social care services.

Many local areas have improved care and support for people with dementia from minority communities as a priority in their local plans.

The North East Dementia Alliance has undertaken some work to improve the support and care of people from minority communities living with dementia in the North East, this includes:

- A statistical analysis to identify the potential number of people with dementia from minority communities in the North East
- A research report to identify good practice relating to the support and care of people with dementia from minority communities in the North East
- A DVD to support awareness and training on the issues faced by people with dementia from minority communities

## Case study: Embracing Difference: Dementia Care for Minority Communities

In spring 2013 the North East Dementia Alliance commissioned the theatre company Open Clasp to produce the DVD *'Embracing Difference: Dementia Care for Minority Communities'*. The DVD was produced as a training resource to enhance the quality of care and support provided for people living with dementia from minority communities.

The DVD features three scenes highlighting issues relating to the care of people living with dementia from Bangladeshi communities, Traveller communities and lesbian, gay, bisexual and transgender communities.

To ensure the DVD's content reflected the collective experiences of people living with dementia from minority communities, the script was informed by research conducted by Open Clasp's Artistic Director. This research included interviews with carers and care staff. The DVD was also informed by research previously conducted by the North East Dementia Alliance.

An independent evaluation of the DVD found that it was well received with 80% of respondents stating that it was a good learning tool with high artistic content.

The DVD is free to organisations in the North East. To order a copy please contact [NEDA@newcastle.ac.uk](mailto:NEDA@newcastle.ac.uk)

<sup>16</sup>Jackson, M (2012) Dementia in Minority Communities in North East England [Online] [http://www.nepho.org.uk/uploads/doc/vid\\_16758\\_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf](http://www.nepho.org.uk/uploads/doc/vid_16758_Dementia%20in%20Minority%20Communities%20in%20North%20East%20England%20Aug%202012.pdf) (Accessed 17 May 2014)



## Recommendations on the care and support of people living with dementia from minority communities in the North East

- *'Embracing Difference: Dementia Care for Minority Communities'* has been evaluated. In order to inform future work the North East Dementia Alliance needs to consider the recommendations that came out of the DVD's evaluation.
- In relation to minority communities, the main focus of local plans is to improve services and support for people from Black and Asian Minority Ethnic communities. It is critical that this continues; however, work needs to be undertaken to consider and support other groups as well. For example, the estimated number of people from the LGBT community with dementia could be as high as one and a half times that of the BME community and little action is being taken in relation to this group.
- Four local joint dementia plans have included actions to improve the support and care of people with a learning disability and dementia. Opportunities to work with long established learning disability groups need to be utilised.
- In the North East there are few examples of services which are particularly sensitive to the needs of people with dementia from minority communities. Services which are for people with dementia from minority communities, or which are particularly sensitive to the needs of people from minority communities (from both the North East and in other parts of the country), need to be showcased to encourage the wider adoption of these practices.
- There is a lack of information about the number of people living with dementia from Gypsy and Traveller communities in the North East. There is also little information about how to improve the support and care of people living with dementia from Gypsy and Traveller communities. The North East Dementia Alliance should support further research to identify the number of people with dementia from Gypsy and Traveller communities in the North East to establish what steps could be taken to improve the support and care of people living with dementia from this community.



## Antipsychotic medication

In 2009 the Department of Health published *'The use of antipsychotic medication for people with dementia: time for action,'*<sup>17</sup> which highlighted the need for improvements in the way that antipsychotic medication is used to help people with dementia.

**Between 2006/11 there was a decline in the prescribing of antipsychotic medication to people with dementia across North East England with most reporting Primary Care Trusts below the national prescribing rate.**

Approaches to reducing the inappropriate

<sup>17</sup>Banergee, S. (2009) *The use of antipsychotic medication for people with dementia: Time for action - A report for the Minister of State for Care Services.* London: The Stationary Office

<sup>18</sup>Brechin, D. Murphy, G. James, I. and Codner, J. (2013) *Alternatives to Antipsychotic Medication: Psychological Approaches on Managing Psychological and Behavioural Distress in People with Dementia* [Online] Available at: [http://www.psige.org/public/files/BPS%20FPoP%20-%20Alternatives%20to%20Anti-Psychotic%20Medication%20-%20report%20-%20March%202013\(1\).pdf](http://www.psige.org/public/files/BPS%20FPoP%20-%20Alternatives%20to%20Anti-Psychotic%20Medication%20-%20report%20-%20March%202013(1).pdf) (Accessed 17 May 2014)

prescribing of antipsychotic medication in the North East have included a regional stakeholder event in 2011 and the awarding, via the North East Dementia Alliance, of funding to support small scale projects.

Non-pharmacological interventions, such as the use of the stepped care model, have been implemented to address some of the symptoms that might otherwise result in the use of antipsychotic medication.<sup>18</sup>

There is a need for more up to date statistics and supporting analysis relating to the prescribing of antipsychotic medication in the North East.

## Carers

The legislative framework to support all carers is provided by the Carers Equal Opportunities Act 2004.

The National Dementia Strategy and the Prime Minister's Challenge both have extensive references to support for carers and there has been a national *'Carers' Call to Action'*.

All local joint dementia plans in the North East have actions relating to supporting carers of people with dementia.

There are education and support services for carers across the region, including CrISP, support provided by the memory clinics, dementia advisors and access to psychological therapies.

More specialised projects for carers of people with dementia are also being delivered in the region: for example, the Family Carers Matter project, which supports people to develop records of life stories with the person with dementia and the participation and engagement programme.

## Safeguarding

*'No Secrets'*<sup>19</sup>, *'Statement of Government Policy on Adult Safeguarding'*<sup>20</sup> and Deprivation of Liberty Safeguards provided the operational framework for safeguarding people with dementia. The 2014 Care Act introduced new safeguarding measures.

**Between 2009/10 and 2012/13 the number of deprivation of liberty requests relating to people with dementia in the North East increased from 451 applications to 742.**

The North East ADASS has a region wide adult safeguarding themed network.

There is limited statistical or other information relating to the safeguarding of people with dementia in the North East.

The research conducted for this report revealed little coordinated regional work being undertaken in the North East relating to the safeguarding of people living with dementia. This is particularly problematic given the vulnerable position of some people living with dementia.

## Recommendations on the use of antipsychotic medication in the North East

- Regional statistics are available from 2011 regarding the prescribing of antipsychotic medication. There is a need for more up to date statistics and supporting analysis. The Mental Health, Dementia and Neurological Clinical Network would be a key partner in leading this.
- A regional event was held in 2011. The actions developed from the event need to be revisited and, where necessary, completed. Outcomes and learning need to be shared across the region.
- The North East Dementia Alliance has funded a number of small scale projects to help reduce the inappropriate prescribing of antipsychotic medication. The outcomes of these projects need to be shared.

## Recommendations on the provision of services for carers of people living with dementia in the North East

- There appears to be a spread of different services for carers within each locality across the region; however, each locality group needs to undertake consultation to identify local need. Locality groups should also review existing service provision to identify the geographical spread and type of services being provided to ensure needs are being met.
- Respite is one of the key areas highlighted in the joint dementia action plans; however, little reference is made to respite provision in this section due to the limited research time for the project. Locality groups should give particular attention to respite services when carrying out an audit of services for carers of people with dementia.
- The 'Carers' Call to Action' has been launched. This could provide a useful catalyst to highlight issues relating to carers of people with dementia and could influence change. Organisations and individuals in the North East should consider signing up
- The North East ADASS has a carers themed network. Any work considered by the themed network needs to be inclusive of carers of people with dementia and their specific needs must be considered.
- Although Improving Access to Psychological Therapies (IAPT) services are available in all localities within the North East it is not possible to identify whether these are being targeted at carers of people with dementia, or the extent to which carers of people with dementia are using these services. To gain a clearer understanding it would be useful if services delivering IAPT routinely monitored and reported on the numbers of carers for people with dementia who use the service. The North East Dementia Alliance should work with the North East IAPT provider forum and Health Education North East psychological therapies sub group to encourage and implement this.

## Recommendations on the safeguarding of people living with dementia in the North East

- The Care Act 2014 has amended the legislative framework governing safeguarding. Providers and safeguarding leads need to consider the impact on these changes for people living with dementia. A key group to consider this will be the ADASS Adult Safeguarding Themed Network.
- Not all local joint dementia plans have safeguarding as part of their actions. All localities need to ensure that the safeguarding of people living with dementia is included in their plans.
- Limited statistical information regarding safeguarding was presented in this report. More statistical information, in the first instance, needs to be brought together to explore the positive aspect as well as issues regarding the safeguarding of people with dementia in the North East.
- There is an ADASS Safeguarding Themed Network in the North East. Joint working needs to take place between the North East Dementia Alliance and the Mental Health, Dementia and Neurological Clinical Network to ensure people with dementia are appropriately safeguarded.

<sup>19</sup>Department of Health (2000) No Secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults from abuse. London: Department of Health

<sup>20</sup>Department of Health (2011) Statement of Government Policy on Adult Safeguarding [Online] Available at: <https://www.gov.uk/government/publications/adult-safeguarding-statement-of-government-policy> (Accessed 17 May 2014)



## 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](http://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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