

# **Dementia: A North East Perspective**

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Section	Title	Page
	<b>Executive Summary</b>	7
1	<b>Introduction</b>	13
2	<b>Context</b>	14
2.1	What is Dementia?	14
2.2	Demographic Information	17
2.2.1	Young people with dementia	17
2.2.2	Late onset dementia	17
2.2.3	Gender	19
2.2.4	People with Learning Disabilities	19
2.2.5	Black and Ethnic Minority Communities	20
2.2.6	Other Minority Groups	20
2.2.7	Diagnosis rates	20
2.3	Summary	20
3	<b>The National Dementia Strategy, Implementation Guidance and current policy areas inclusive of dementia</b>	21
3.1	The National Dementia Strategy	21
3.1.1	National Dementia Strategy overall purpose and objectives	21
3.1.2	The National Dementia Strategy priority objectives	23
3.1.3	What are the North East National Dementia Strategy priority objectives and why they were chosen?	23
3.2	National Dementia Strategy Implementation Guidance - Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy	24
Expl	Outcomes project - Gateshead	25
3.3	The NHS Operating Framework 2011-2012	25
Expl	NE Locality Dementia Action Plans	26
3.4	Personalisation	26
Expl	Personalisation and objective 6	27
3.5	The Health and Social Care Bill	28
Expl	GP Consortia in the North East	30
Expl	Helping GPs	30
Expl	Foundation Trust Status	30
3.6	Other forthcoming legislation	30
3.7	Summary	31
4	<b>NDS Economic Challenges</b>	32
4.1	National Context	32
4.2	Regional Estimate of Spend	33
Expl	Reducing Costs in a General Hospital in the North East	33
Expl	The Impact of the Current Economic Climate on the Third Sector in the North East	34
4.3	Summary	34
5	<b>Research in the North East</b>	36

5.1	Research base	36
5.1.1	Newcastle University	36
5.1.2	Northumbria University	37
5.1.3	Other Universities	37
5.2	Summary	37
6	<b>Key North East National Dementia Strategy structures</b>	38
6.1	North East Key National Dementia Strategy Implementation Structures	38
6.2	REGIONAL GROUPS	38
6.2.1	The North East Dementia Oversight Board	38
6.2.2	The North East Dementia Alliance	38
6.2.3	The North East Dementia Leads Group	39
6.2.4	The Mental Health Clinical Innovation Team	39
6.2.5	North East Association of Directors of Adult Social Services (ADASS)	39
6.3	SUB REGIONAL GROUPS	40
6.3.1	North East Community Dementia Forum	40
6.4	LOCALITY GROUPS	40
6.4.1	North East Locality Arrangements for Overseeing the Implementation of the National Dementia Strategy	40
6.5	Summary	41
7	<b>North East Region Wide Information</b>	42
7.1	Available Information	42
7.2	Baseline assessment results from using the North East Mapping Tool	42
7.3	Locality Action Plans	43
7.4	A Resource for Commissioners – Objective 6	43
7.5	Summary	44
8	<b>What the people of North East England said is important to them</b>	45
8.1	Stakeholder information	45
8.2	Listening to You – National Dementia Strategy – North East Listening and Engagement Events Feedback	45
8.3	National Dementia Strategy. A report of consultation with people with learning disabilities in the North East. What we think of the Government's Plan	46
8.4	We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers	46
8.5	National Dementia Strategy: North East Experiences of Dementia Services 2010 – a Report on Focus Groups with Users and Carers	47
8.6	Summary	47
9	<b>Dementia Service Providers in the North East</b>	48
9.1	Introduction	48
9.2	The Statutory Sector	48
9.2.1	Specialist Mental Health Services	48

9.2.2	Local Authorities	49
9.3	The Third Sector	49
9.4	Not for profit	50
9.5	Commercial and for profit organisations	50
9.6	User Led Organisations	51
9.7	Summary	51
10	<b>The Priority Objectives - Position against National Dementia Strategy Objectives (diagnosis, general hospital care, care homes and reducing the use of antipsychotic medication)</b>	52
10.1	Introduction	52
10.2	Good quality early diagnosis for all - objective 2	53
10.2.1	What people in the North East told us about what they want in relation to objective 2	53
10.2.2	The position based on the baseline assessment	54
10.2.3	What the locality action plans tell us	55
10.2.4	Regional activities to deliver objective 2	55
10.2.5	Known local examples of practice or activities	55
10.2.6	Summary of objective 2	56
10.3	Improved quality of care in general hospitals - objective 8	56
10.3.1	What people in the North East told us about what they want in relation to objective 8	56
10.3.2	The position based on the baseline assessment	57
10.3.3	What the locality action plans tell us	57
10.3.4	Regional activities to deliver objective 8	58
10.3.5	Known local examples of practice or activities	58
10.3.6	Summary	59
10.4	Living well with dementia in care homes - objective 11	59
10.4.1	What people in the North East told us about what they want in relation to objective 11	59
10.4.2	The position based on the baseline assessment	61
10.4.3	What the locality action plans tell us	61
10.4.4	Regional activities to deliver the objective 11	62
10.4.5	Known local examples of practice or activities	63
10.4.6	Summary	64
10.5	Reduced use of antipsychotic medication	64
10.5.1	What people in the North East told us about what they want in relation to the reduction of antipsychotic medication	65
10.5.2	The position based on the baseline assessment	66
10.4.3	What the locality action plans tell us	66
10.5.4	Regional activities to deliver a reduction in the use of antipsychotic medication	66
10.5.5	Known examples of practice or activities	66
10.5.6	Summary	67
11	<b>The other objectives which make up the seven North East regional priority objectives</b>	68
11.1	Community and Personal Support - objective 6	68

11.1.1	What people in the North East told us about what they want in relation to objective 6	69
11.1.2	Position based on the baseline assessment	70
11.1.3	What the locality action plans tell us	70
11.1.4	Regional activities to deliver objective 6	71
11.1.5	Known examples of practice or activities	71
11.1.6	Summary	72
11.2	Housing and Telecare. Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers – objective 10	73
11.2.1	What people in the North East told us about what they want in relation to objective 10	73
11.2.2	Position based on baseline assessment	74
11.2.3	What the locality action plans tell us	75
11.2.4	Regional activities to deliver objective 10	76
11.2.5	Known local examples of practice or activities	76
11.2.6	Summary	76
11.3	End of Life Care – objective 12	77
11.3.1	What people in the North East told us about what they want in relation to objective 12	77
11.3.2	The position based on the baseline assessment	78
11.3.3	What the locality action plans tell us	78
11.3.4	Regional activities to deliver objective 12	78
11.3.5	Know local examples of practice or activities	79
11.3.6	Summary	79
12	<b>Remaining National Dementia Strategy areas where there can be significant local and regional impact</b>	80
12.1	Support and information for people with dementia and their carers	81
12.1.1	What people in the North East told us they want in relation to Support and Information for people with dementia and their carers	81
12.1.2	The position based on baseline assessment	82
12.1.3	What the locality action plans tell us	83
12.1.4	Regional activities to deliver support and information for people with dementia and their carers	84
12.1.5	Known examples of practice or activities	85
12.1.6	Summary	86
12.2	Improved Intermediate Care for people with dementia - objective 9	87
12.2.1	What the people in the North East told us about what they want in relation to objective 9	87
12.2.2	The position based on baseline assessment	87
12.2.3	What the locality action plans tell us	88
12.2.4	Regional activities to deliver objective 9	88
12.2.5	Known local examples of practice or activities	88
12.2.6	Summary	89

12.3	Informed and Effective Workforce for people with dementia - objective 13	89
12.3.1	What the people in the North East told us about what they want in relation to objective 13	89
12.3.2	The position based on baseline assessment	90
12.3.3	What the locality action plans tell us	90
12.3.4	Regional activities to deliver objective 13	91
12.3.5	Known local examples of practice or activities	91
12.3.6	Summary	91
12.4	A Joint Commissioning Strategy for Dementia - objective 14	92
12.4.1	What people in the North East told us they want in relation to objective 14	92
12.4.2	The position based on the baseline assessment	92
12.4.3	What the locality action plans tell us	92
12.4.4	Regional activities to deliver objective 14	92
12.4.5	Known local examples of practice or activities	93
12.4.6	Summary	93
13	Objectives where there is less influence to be exerted by localities and the region	94
13.1	Introduction	94
13.1.1	Improved assessment and regulation of health and care services (objective 15)	94
13.1.2	A clear picture of research evidence and needs (objective 16)	94
13.1.3	Effective national and regional support for implementation of the strategy (objective 17)	94
13.2	Summary	95
	Bibliography	96
	Appendix A Activity in the North East Under the Relevant objective	100
	Appendix B The report structure	103

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## Executive Summary

### Overview

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

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

### 1. Introduction

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

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

### 2. What is dementia?

The term “dementia” is used to describe a collection of symptoms, including a decline in memory, reasoning and the ability to communicate and a gradual loss of the skills needed to carry out daily activities<sup>1</sup>. These symptoms are caused by structural and chemical changes in the brain as a result of physical disease such as Alzheimer’s. The different types of dementia include Alzheimer’s Disease, cerebrovascular dementia, dementia with Lewy Bodies, frontotemporal and mixed dementias. Dementia is not a homogeneous condition and each type has its own cause and result in different symptoms. For example a person with Alzheimer’s Disease in the early stages may become forgetful whilst the behaviour of a person with frontotemporal dementia may change more dramatically with the person seeming to be more unfeeling or selfish than usual. The most common form of dementia is Alzheimer’s Disease affecting 63% of all people with dementia. Younger people are more likely to be diagnosed with vascular,

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<sup>1</sup> London School of Economics. (2007) *Dementia UK – The Full Report*, London: Alzheimer’s Society

frontotemporal, and Lewy Bodies type dementias. Certain groups of people including older people and those with learning disabilities are more likely to get dementia.

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

### **3. Demography**

The statistics for the North East show:

- The number of people estimated to have young onset dementia<sup>2</sup> in 2009 was 688 at 2009 and is expected to reduce to 666 by 2030. These numbers are thought to be an underestimate.
- The number of people with late onset dementia<sup>3</sup> was predicted to be 31,840 at 2010; the number actually diagnosed with dementia was 14,034.
- There is a predicted increase in the number of people with late onset dementia to 50,896 by 2030 or an increase of 19,056 in 20 years.
- The number of males with dementia is predicted to increase by 93% between 2009 and 2030.
- At 44% the North East (NE) has the highest percentage of people diagnosed with dementia against the predicted numbers. There are still significant steps to take to increase the rate of diagnosis.
- In 2010, it was estimated that 88 people with downs syndrome in the NE will have dementia.
- There are no figures relating to minority groups and dementia.

### **4. The National Dementia Strategy and policy context**

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

The NE has identified seven priority areas:

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

There are other key current policies that affect dementia care, which include the NHS operating framework 2011-12 and personalisation. In the NE, dementia specific responses to current policies include: provision of local dementia action plans,

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<sup>2</sup> Those under 65 years

<sup>3</sup> Those 65 years and over



innovative work on outcomes, a regional project on dementia and community, and personal support.

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

## **5. Economics of dementia care and support**

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

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

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

## **6. Research in the region relating to dementia**

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

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

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

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

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

- "Readiness to Implement" – a baseline self-assessment of the 12 localities position in relation to the NDS objectives 1 to 15.
- Locality Plans – ten plans of how those localities are going to implement the NDS.

- “Developing a comprehensive evidence base for the future commissioning of dementia services in the NE” – a collection of information to assist with commissioning of community and personal support services.

### **9. Stakeholders views on dementia care in the North East**

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

### **10. Service providers in the North East**

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

### **11. The four National Dementia Strategy Priorities**

The four agreed national priorities are:

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

These are defined in the dementia strategy implementation guidance<sup>4</sup> and the NHS Operating Framework<sup>5</sup>.

The North East response to the first priority has been to develop a memory service specification for use across the NE and pathways are being developed for early diagnosis. A national audit of memory services is due to take place from May 2011 that will also give a full regional picture. GPs are seen as key to early diagnosis but stakeholders report both positive and negative experiences. There are some initiatives which are supporting GPs to deliver a diagnosis. Dementia pathways are being

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

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

developed in general hospitals and in-reach services are available to some, however the coverage and quality is unknown. Contracts and development of quality standards are being used to drive up quality in care homes. Some detailed regional work has been carried out on how to implement the care home objective that can be built on. There are some good examples of training and development to support improvements in early diagnosis, good quality hospital care and support in care homes. However there doesn't appear to be a strategic approach to training and development in these areas.

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

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

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

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

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

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

## **13. Details of the remaining objectives**

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

*Support and Information:* The NDS objectives linked to the themes of support and information for people with dementia and carers are considered together (objectives 1,3,4,5). Across the North East some public and professional awareness initiatives are being undertaken but they need to be stepped up. When it comes to information provided to people with dementia and their carers it needs to be timely and in an accessible form. The opportunity to have access to someone to talk to "face to face" to give information and guidance is also seen as being desirable. There are dementia advisors in various parts of the region but the spread and effectiveness is not known.

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

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

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

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

#### **14. Nationally led objectives**

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

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

## 1. Introduction

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

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

The report is structured in sections. In sections 2 to 9 the report outlines the context in terms of the demography, policy, economic challenges, research and content, and sources of regional information relating to dementia.

Sections 10 to 13 highlight stakeholder's views, in relation to progress of the NE against the 17 NDS objectives.

## 2. Context

### In the North East

- The most common form of dementia is Alzheimer's Disease comprising 63% of all people with dementia.
- The number of people estimated to have young onset dementia in 2009 was 688 at 2009 and is expected to reduce to 666 by 2030.
- The number of people with late onset dementia was predicted to be 31,840 in 2010; the number actually diagnosed with dementia was 14,034.
- There is a predicted increase in the number of people with late onset dementia to 50,896 by 2030.
- The number of males with dementia is predicted to increase by 93% between 2009 and 2030.
- At 44% the NE has the highest percentage of people diagnosed with dementia against the predicted numbers.
- It was projected that in 2010, 88 people with downs syndrome had dementia.

This section gives a definition of dementia and its various types. It then provides dementia demographic information for the NE relating to young and late onset dementia, by gender and for people with learning disability along with diagnosis rates. It highlights the limited availability of any data relating to black and minority ethnic groups and other minority groups.

### 2.1 What is Dementia?

The term "dementia" is used to describe a collection of symptoms, including a decline in memory, reasoning and the ability to communicate and a gradual loss of the skills needed to carry out daily activities<sup>6</sup>. These symptoms are caused by structural and chemical changes in the brain as a result of physical disease such as Alzheimer's. Dementia can affect people of any age, but is most common in older people. Young onset dementia includes anyone under the age of 65 diagnosed with dementia; this is comparatively rare, accounting for 2.2% of all people with dementia in the UK<sup>7</sup>.

There are a variety of types of dementia caused by different diseases of the brain. As these affect the brain in diverse ways, they produce different symptoms.

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<sup>6</sup> London School of Economics. (2007) *Dementia UK – The Full Report* London: Alzheimer's Society

<sup>7</sup> London School of Economics. (2007) *Dementia UK – The Full Report*, London: Alzheimer's Society p 27

The following table summarises the different types of dementia, the cause, and the number of people with the specific type of dementia in the NE and the percentage of people in the North East with dementia.

**Nature and extent of types of Dementia in the North East – Table One**

<b>Dementia types</b>	<b>Cause</b>	<b>Effects</b>	<b>Actual number of People NE<sup>8</sup></b>	<b>NE %<sup>9</sup></b>
<i>Alzheimer's Disease</i>	This occurs when the chemistry and structure of the brain change and result in brain cells dying.	This disease begins by changing a person's behaviour in small ways, for example forgetting or repeating things. Over time the person will become increasingly dependent on others and may have difficulty eating and swallowing. They may develop continence problems and experience loss of communication skills.	18,724	63%
<i>Cerebrovascular Dementia (Vascular)</i>	The cause is strokes or small blood vessel disease, which affects the supply of oxygen to the brain.	When the dementia is caused by a single stroke, this is called single infarct dementia. The symptoms will depend on what part of the brain is damaged. For example if the part of the brain damaged is responsible for speech the person may have difficulties communicating. When vascular dementia is caused by a series of small strokes this is known as multi-infarct dementia. The person may not notice any symptoms or the symptoms may be temporary. However, overall the development of symptoms is similar to Alzheimer's Disease and can often result in stepped or sudden change deterioration rather than gradual deterioration.	4,976	17%
<i>Mixed Dementia</i>	This is a combination of more than one type of dementia.	The effects may be a combination of any of the dementia types listed in this table.	3,079	10%

<sup>8</sup> Jackson, M. (2009) *Dementia North East England A Demographic and Service Profile*. p16.

<sup>9</sup> Jackson, M. (2009) *Dementia North East England A Demographic and Service Profile*. p16.

Note these are percentages for the whole NE dementia population. As young onset dementia only accounts for 2.2% of the dementia population the percentage types are different for this group.

<i>Dementia with Lewy Bodies</i>	This is caused by tiny spherical protein deposits inside nerve cells in the brain.	An individual with Lewy Bodies may experience problems with attention and alertness, often having spatial disorientation and experience difficulty in planning ahead and co-ordinating mental activities. The person may experience hallucinations. Although memory is often affected, it is typically less so than in Alzheimer's Disease.	1,199	4%
<i>Fronto-temporal Dementia</i>	This is a rare form of dementia affecting the front of the brain.	The person is less likely to become forgetful than with Alzheimer's Disease. Behaviour can change more dramatically for example the person with frontotemporal dementia may seem more selfish or unfeeling than usual or sexually uninhibited.	400	1%
<i>Parkinson's Dementia</i>	Parkinson's Dementia is caused by a loss of neurons in a region of the brain that negatively affects the ability to properly employ adept motor skills.	Dementia in Parkinson's is often associated with difficulty in problem solving and planning activities. Parkinson's has some similarities with Lewy Bodies.	502	2%
<i>Other types of dementia</i>	These include alcohol related dementia (including Korsakoff's Syndrome* and Creutzfeld-Jacob Disease or CJD +.	* Although Korsakoff's Syndrome is not strictly speaking a dementia, people with the condition experience loss of short-term memory, mood changes and loss of interest in or concern about emotional, social, or physical life.  + Within weeks a person infected with CJD may complain of clumsiness and feeling muddled, become unsteady in walking, and exhibit slow or slurred speech. The symptoms progress to jerky movements, shakiness, and stiffness of limbs, incontinence and the loss of ability to move or speak.	893	3%



## 2.2 Demographic Information

### 2.2.1 Young people with dementia

The number of young people (under the age of 65) in the NE estimated to have dementia in 2009 was 688<sup>10</sup>. This is expected to drop by 3% to 666 by 2030. This group of people are sometimes referred to as people with young onset dementia. This reduction compares to a 12% rise in the total number of people with dementia in England as a whole. The fall in numbers in the NE is likely to be related to the decline in the general population of under 65 year olds rather than in improvements in the prevalence rates of dementia for this age group.

Only around a third of young people with dementia have Alzheimer's dementia, compared to two thirds of people with late onset dementia. Younger people are more likely to be diagnosed with vascular, frontotemporal, and Lewy Bodies dementia along with Kosakoff's Syndrome. Approximately one fifth of young people with dementia have the rarer forms<sup>11</sup>.

### 2.2.2 Late onset dementia

The single greatest risk factor for developing dementia is age. As the NE demographic profile changes there will be significant increase in the numbers of people with late onset dementia (65 years old and over). The NE is one of the most rapidly ageing regions in the country:

- In 2005 19% of women in the NE were over 65. (The second highest percentage in England).
- In 2005 15% of men in the NE were over 65. (The third highest percentage in England).
- The number of people in the NE over 65 is projected to rise by 47% between 2004 – 2029. This is the only age group projected to grow in size in the NE over the next 15 years<sup>12</sup>.

The number of people in the NE predicted to have late onset dementia in 2009 was 30,254. This represents around 5% of the total predicted for England. By 2030 the predicted numbers of people with dementia in the NE is expected to increase to 50,896. This is an additional 20,642 individuals or a 68% increase on the 2009 figure. This compares to a national average increase of 72% over the same period.

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<sup>10</sup> Based on anecdotal information from early onset dementia services in the NE and information provided by the Alzheimer's Society it is thought that these predictions relating to the number of people with young onset dementia may be low. The Alzheimer's Society and the Dementia UK report both suggest the true national figure may be up to three times higher which would impact on the regional estimates London School of Economics. (2007) *Dementia UK – The Full Report*, London:Alzheimers Society pg 27

<sup>11</sup>London School of Economics. (2007) *Dementia UK – The Full Report*, London:Alzheimers Society p27

<sup>12</sup> Office for National Statistics (2010) *Correction Notice Regional Trends 42 2010 Ageing across the UK Production errors* [Online] Available at : <http://www.statistics.gov.uk> (Accessed 14 June 2011)

## Numbers Predicted to Have Late Onset Dementia - Chart One

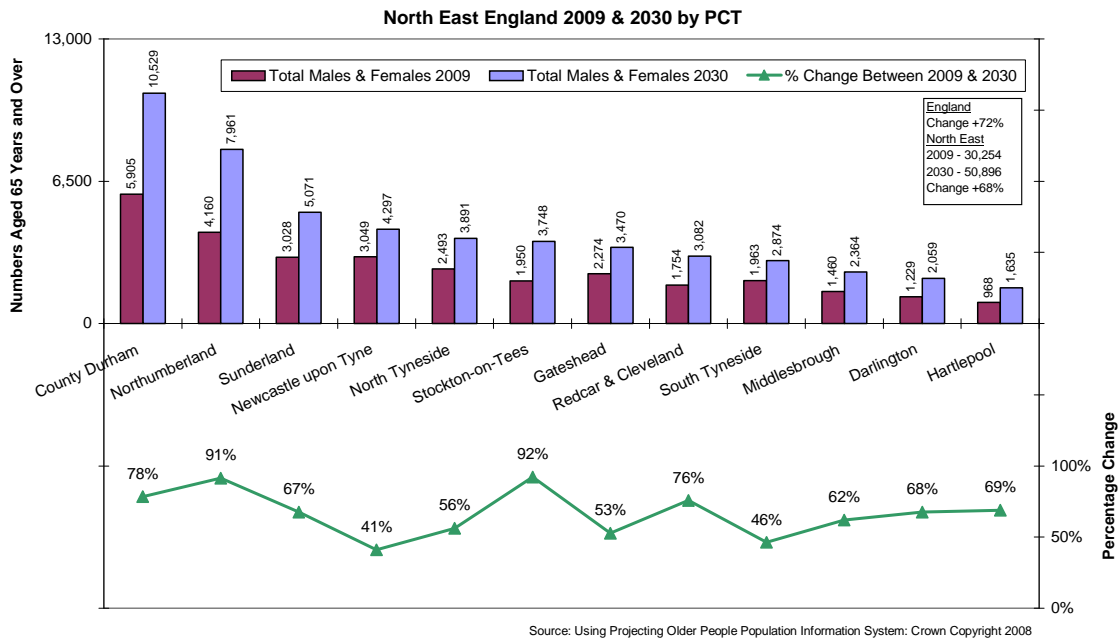
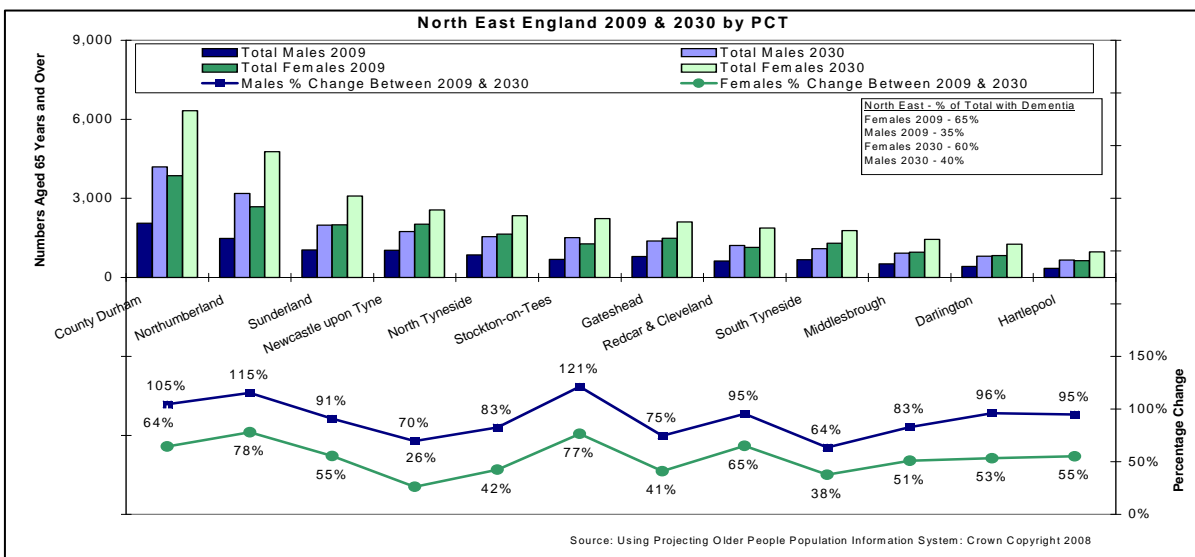


Chart One illustrates that the largest actual numbers of people with late onset dementia in the NE live in County Durham, Northumberland, Sunderland and Newcastle. The largest increases in the predicted numbers of people with late onset dementia in the NE between 2009 and 2030 are expected in Stockton (92%) and Northumberland (91%). The predicted increases in County Durham (78%) and Redcar & Cleveland (76%) will also exceed the national average increase of 72%. The areas in the NE with the lowest expected increases in the numbers with late onset dementia are in the urban areas of Newcastle (41%), South Tyneside (46%), Gateshead (53%) and North Tyneside (56%).

## Numbers Predicted to Have Late Onset Dementia by Gender- Chart Two



### 2.2.3 Gender

Chart Two shows that in 2009 the greater proportion (65%) of people with late onset dementia in the NE were female, with this ratio being consistent across all localities in the NE.

By 2030 the numbers of males with late onset dementia will have increased more rapidly than the numbers of females. It is predicted that over the period 2009 to 2030, the number of males with late onset dementia will increase by 93%, with the number of females increasing by 55%.

Over this period, the rates of increase for males in the locality areas varies from 64% in Middlesbrough to 121% in Stockton, while those for females vary from 26% increase in Newcastle to 78% in Northumberland.

### 2.2.4 People with Learning Disabilities

People with learning disabilities are living longer and therefore enduring the physical and mental health problems associated with ageing. They are at high risk of developing dementia and from a much younger age than the general population.

People who have Down's Syndrome are at higher risk of developing dementia particularly Alzheimer's disease. Research tells us that over 50% of people with Down's Syndrome will have dementia by the age of 55<sup>13</sup>. The onset of the disease commences much earlier with symptoms appearing in some form around the 30 - 40 years age group. Life expectancy from diagnosis to death can be between 3-5 years. In 2010 it was projected that 88 people in the NE who had Down's Syndrome had Alzheimer's Disease.

This table shows numbers by age band and year.

<b>Table Two: Projected numbers of individuals with Down's syndrome and dementia</b>					
<b>North East England by Age Band</b>					
	<b>2008</b>	<b>2010</b>	<b>2015</b>	<b>2020</b>	<b>2025</b>
People aged 45-54 predicted to have Down's syndrome and dementia	30	30	30	28	24
People aged 55-64 predicted to have Down's syndrome and dementia	56	57	57	66	65
People aged 65 and over predicted to have Down's syndrome and dementia	1	1	1	2	2
Source: POPPI & PANSI – Department of Health – Crown Copyright 2007					

The prevalence of dementia in people with other forms of learning disability is also higher than in the general population. Onset commences around 10 years earlier than that of the general population<sup>14</sup>.

<sup>13</sup> Baker,J (2010) *South Tees Learning Disability, Dementia Development Report Executive Summary* [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed 17 June 2011)

<sup>14</sup>Baker,J (2010) *South Tees Learning Disability, Dementia Development Report Executive Summary* [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed 17 June 2011)

### 2.2.5 Black and Ethnic Minority Communities

There is no NE based data relating to the number of people who have dementia who are from the black and ethnic minority groups. The dementia UK report estimated that there were 11,392 people from black and minority ethnic (BME) groups with dementia in the UK. Of that population 6.1% of all people with dementia among BME groups have young onset dementia, compared with only 2.2% for the UK population as a whole, reflecting the younger age profile of BME communities<sup>15</sup>. In the North East there is currently one known support worker specifically working with people from BME communities with dementia<sup>16</sup>.

### 2.2.6 Other Minority Groups

There is no demographic information relating to dementia about people from other minority communities including people from the lesbian, gay, bisexual and transgender community, people in rural areas, or prisoners.

### 2.2.7 Diagnosis rates

Using the Alzheimer's Society and Dementia UK figures, 31,840 people in the NE were predicted to have dementia in 2010. The 'Quality and Outcomes Framework' registers, held by GPs, show that in 2010 14,034<sup>17</sup> people had a diagnosis of dementia. This is 44% of the predicted numbers and is the highest rate in England, where the average diagnostic rate is 39%<sup>18</sup>. The locality with the highest diagnosis rate is Darlington with 52% and the locality with the lowest diagnostic rate is Hartlepool with 39% of the numbers predicted.

## 2.3 Summary

This section has shown that dementia is not a homogeneous condition as there are a number of different types of dementia which each have their own causes and result in different symptoms. Younger age groups tend to be affected by different types of dementia than older groups. These factors need to be considered when commissioning services and working with individuals.

Numbers of people with young onset dementia are estimated to be around 688 but indications are that these figures may be underestimated. It is predicted that there will be a significant increase of 20,642 in the number of people with late onset dementia between 2009 and 2030. The number of males with dementia will increase more rapidly than females whilst overall dementia will remain most common in females. Regional estimates are available for the number of people with a learning disability and dementia but there are no figures for other minority groups and dementia.

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<sup>15</sup> London School of Economics. (2007) *Dementia UK – The Full Report*, London:Alzheimers Society

<sup>16</sup> This worker is employed by the Alzheimer's Society and works in Stockton.

<sup>17</sup> NHS Information Centre (2010) *NHS Quality and Outcomes Framework (QOF) indicator number DEM1*[Online] Available at: <https://mqi.ic.nhs.uk/> (Accessed 14 June 2011)

<sup>18</sup> Alzheimer's Society and Tesco (2011) *Mapping the Dementia Gap*. [Online] Available at <http://alzheimers.org.uk/dementiamap> ( Accessed 13 June 2011)

### 3. The National Dementia Strategy, Implementation Guidance and current policy areas inclusive of dementia

This section provides an overview of The National Dementia Strategy (NDS), Implementation Guidance and key current policies which include or have a significant impact on dementia care and support. After each policy area there is a reflection on how the NE has responded to, or what building blocks there are, to support the delivery of the policy. This includes some examples of projects or initiatives that support policy implementation.

#### 3.1 The National Dementia Strategy

- The National Dementia Care Strategy (NDS) is the primary policy for dementia care in England.
- The NE has seven NDS key priorities.
- Key current policies affecting dementia care include the NHS operating framework and personalisation.
- In the NE dementia specific responses to current policy include:
  - provision of locality action plans,
  - innovative work on outcomes and
  - a regional project on dementia and community and personal support.
- Other forthcoming key policies include the health and social care bill, the social care bill and legislation linked to public health. These will have a significant impact on commissioning services.
- Some “structural elements” are in place which it is anticipated will be required as part of new legislation e.g. development of GP consortia and foundation trusts. How these support dementia care is yet to be determined.

##### 3.1.1 National Dementia Strategy overall purpose and objectives

The dementia strategy for England, “Living well with dementia: A National Dementia Strategy” (NDS)<sup>19</sup> was published in 2009. This five-year strategy launched under the Labour Government, has been endorsed by the Coalition Government. They have also

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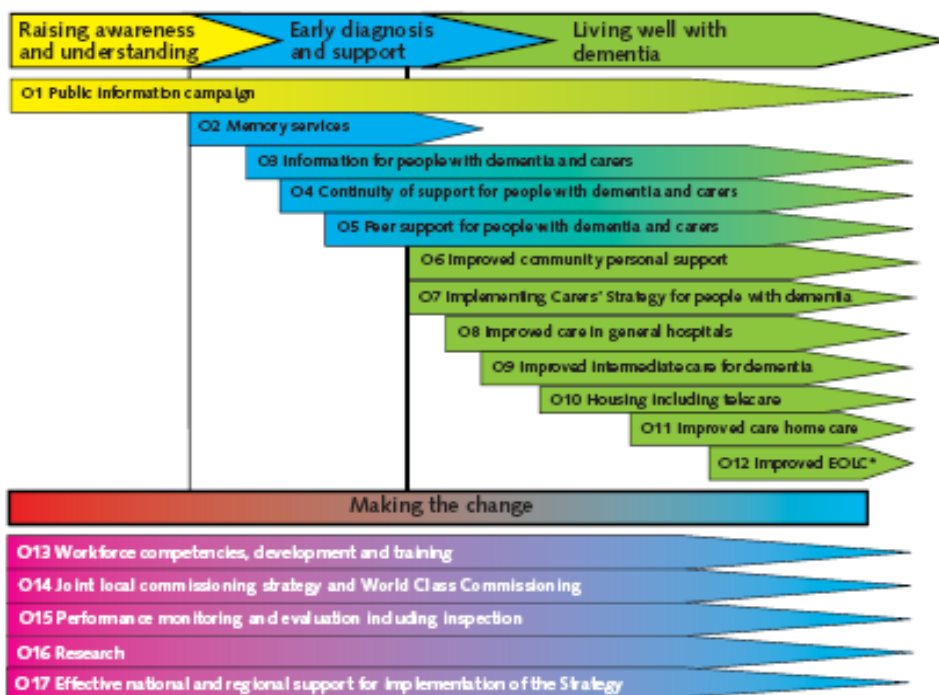
<sup>19</sup>Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London

gone on to include dementia in the NHS operating framework<sup>20</sup> and publish a second version of the implementation guidance<sup>21</sup>.

The NDS has been produced to enable the commissioning of services along a defined pathway from raising awareness about dementia amongst the public, through diagnosis and provision of appropriate support and services to good 'end of life' care. It is relevant to all people with dementia and their carers no matter what support or services they receive.

The aim of the NDS is to ensure that significant improvements are made to dementia services across three key areas: improved awareness, earlier diagnosis and intervention, and a higher quality of care. The Strategy has 17 key objectives. It is anticipated that once the objectives have been implemented, "...largely at a local level, [this] should result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia"<sup>22</sup>.

The diagram below shows the 17 objectives



\*End of life care

In October 2009 the need to reduce the inappropriate prescribing of antipsychotic medication for people with dementia was also recognised as a significant area in its own right following the publication of "Time For Action"<sup>23</sup> and this was added to the list as the "eighteenth objective".

<sup>20</sup>Department of Health. (2011) *The Operating Framework for the NHS in England 2011/12*. Department of Health:London

<sup>21</sup> Department of Health. (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. Department of Health:London

<sup>22</sup>Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London

<sup>23</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

### 3.1.2 The National Dementia Strategy priority objectives

Four national priority objectives were identified by The Department of Health in their implementation plan for “Living Well with Dementia” in September 2010<sup>24</sup> and subsequently confirmed in the NHS operating framework for 2011-12<sup>25</sup>. They were:

- Good-quality early diagnosis and intervention for all (objective 2);
- Improved quality of care in general hospitals (objective 8);
- Living well with dementia in care homes (objective 11); and
- Reduced use of antipsychotic medication.

### 3.1.3 What are the North East National Dementia Strategy priority objectives and why were they chosen?

Seven priority objectives have been identified by the key groups leading implementation of the NDS in the NE.

In October 2009, the NE Dementia Oversight Board<sup>26</sup> set out the priorities for the NE. The Board accepted the recommendations of the NE Dementia Alliance<sup>27</sup>. The Alliance based its recommendations on the results of the NE Listening and Engagement exercise (where 250 stakeholders expressed what they would like to see in relation to dementia care<sup>28</sup>), the seven priorities set out in the national dementia strategy<sup>29</sup> and the findings from a NE self-assessment exercise where the twelve localities in the NE carried out a service assessment exercise<sup>30</sup>. The priority objectives for the North East were agreed as:

- **Good quality early diagnosis and intervention for all (objective 2)**  
This had been a priority area throughout the listening and engagement events, the self-assessment and was one of the original seven national priorities. The NE Dementia Alliance group saw this as a clear priority and recognised the importance of getting the “start of the journey” right.
- **Improved community personal support services (objective 6)**  
In 2009 there appeared to be no coherent approach to the development of community personal support services in the NE and with so many key initiatives, including personalisation, it was felt to be a critical area of work, which could benefit from a NE based approach.
- **Improved quality of care for people with dementia in general hospitals**

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<sup>24</sup> Department of Health. (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy. Department of Health:London

<sup>25</sup>Department of Health. (2011) *The Operating Framework for the NHS in England 2011/12*. Department of Health:London

<sup>26</sup> Details of the Board can be seen in section 6

<sup>27</sup> Details of the Board can be seen in section 6

<sup>28</sup>Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society.

<sup>29</sup>Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London

<sup>30</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health

**(objective 8)** Many of the case examples given in the listening and engagement events related to poor practice in general hospitals. It was felt a more co-ordinated approach was needed.

- **Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers should be one of the priorities (objective 10)**

This objective was prioritised as the Oversight Board wanted to deliver to people with dementia their wish to remain in their own home. In addition, with the changing demography there could be significant financial pressures which could be reduced if early intervention and support was available. The delivery of this objective would also aid the successful implementation of “*objective 6: Improved community personal support services.*”

- **Living well with dementia in care homes (objective 11)**

Many of the case examples given in the listening and engagement events related to poor practice in care homes. Work had already been undertaken across the NE to support implementation of the care home objective<sup>31</sup> but given the views expressed during the listening and engaging events, it was felt this should be one of the priorities.

- **Improved end of life care for people with dementia (objective 12)**

End of life care had not specifically featured in either the listening and engaging exercise, the priorities in the NDS or the self-assessment, but strong views put forward by the carers representative, third sector providers and the acute care representatives stressed that improved end of life care should be a priority.

- Following the publication of “Time For Action”<sup>32</sup> the reduction of the inappropriate prescribing of antipsychotic medication to people with dementia was added as a seventh NE priority.

Details of what is happening in the NE in relation to each of the above objective can be found in sections 10 and 11.

### **3.2 National Dementia Strategy Implementation Guidance - Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy**

“Quality outcomes for people with dementia: building on the work of the National Dementia Strategy”<sup>33</sup> is the Department of Health’s revised implementation plan for the NDS. It updates the previous implementation plan for the strategy, which was published in July 2009. The current plan outlines the four national priority areas (as 3.1.2 section above), plans for improving outcomes and the availability of enablers to facilitate change.

This national guidance includes an expectation that PCTs and their partners publish locally how they are delivering local outcomes for people with dementia. This is intended to make commissioners more accountable to the people they serve.

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<sup>31</sup> Department of Health (2009) *Living Well With Dementia Views From the North East. North East Views On How To Implement Objective 11 of the National Dementia Strategy.*[Online] Available at [www.dhcarenetworks.org.uk](http://www.dhcarenetworks.org.uk) Accessed:17 June 2011).

<sup>32</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>33</sup>Department of Health. (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy.* Department of Health:London



The Department of Health, following the publication of the implementation plan, is working in consultation with partner organisations to identify key outcomes which people with dementia and their carers expect. Nine draft outcomes for the person with dementia were included in the implementation document<sup>34</sup>. Examples include “I was diagnosed early”, “Those around me and looking after me are well supported”, “I am treated with dignity and respect” and “I know what I can do to help myself and who else can help”.

The Department of Health will also be developing specific, measurable indicators across health and social care, which underpin the nine outcomes. The indicators will build on existing work such as the 2006 NICE/SCIE guideline, the NICE Quality Standard published in June 2010 and work undertaken by the Alzheimer’s Society.

The section of the NDS Implementation Plan which highlights enablers for change outlines support for implementation. Examples include the development of the NHS National Quality Board, appointment of National Dementia Champions and the publication of National Dementia Declaration with associated organisational action plans.

#### **Outcomes project - Gateshead**

“What is important to you? Improving quality of life and evidencing outcomes for people with dementia”

The project is developing tools to evaluate outcomes for the person with dementia who uses the Dementia Community Opportunity Groups. These provide local support for people with newly diagnosed dementia to access activities, hobbies, peer support and companionship in Gateshead. The project will produce evidence of the effectiveness of these initiatives that can be shared across the region. The project also aims to produce a robust evaluation tool that can be used to measure the effectiveness of other similar services.

Project Lead Contact: Scott Vigurs, Operational Services Manager, Mental Health Concern

Tel: 0191 217 0377 e-mail: [Scott.vigurs@mentalhealthconcern.org](mailto:Scott.vigurs@mentalhealthconcern.org)

### **3.3 The NHS Operating Framework 2011-2012**

The NHS operating framework is published every year and outlines the business and planning arrangements for the NHS. It includes the national priorities.

The NHS operating framework for 2011-2012 states that:

“People with dementia and their carers need information to help them understand the range and quality of local services. NHS organisations are expected to make progress

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<sup>34</sup> Department of Health. (2010) *Quality outcomes for people with dementia: building on the work of the National Dementia Strategy*. Department of Health: London p12

on the National Dementia Strategy, including the four priority areas as set out in the implementation plan published in September 2010<sup>35</sup>.

The framework reinforces the requirement for the NHS commissioners and providers to publish locally how they are delivering services in line with the implementation plan (see section 3.2). It also states NHS organisations should agree with their social care commissioning partners those aspects of the dementia strategy which could be delivered by using section 75 of the 2006 National Health Service Act. This section enables money to be pooled between health bodies and health-related local authority services, functions delegated and resources and management structures integrated.

### **North East Locality Dementia Action Plans**

As of April 2011 locality dementia action plans for ten out of the twelve localities in the NE can be found on the Social Care section of the PHINE website<sup>36</sup> and seven can be found on the NE pages of the dementia information portal website<sup>37</sup>. One plan, County Durham's Joint Commissioning Strategy for older people with mental health conditions, is available on the County Durham Site. This is not a dementia specific plan but is inclusive of dementia care.

As of March 2011, there are two dementia specific locality plans which were unavailable (either still under development or awaiting final approval from relevant stakeholders).

All published plans outline how the localities are going to deliver good quality early diagnosis and intervention, improved quality of care in general hospital and living well with dementia in care homes (for more details see section 10). Six of the nine published plans have actions in relation to reducing the inappropriate prescribing of antipsychotic drugs (for more details see section 10.5). None of the published action plans specifically mention using section 75 of the 2006 National Health Service Act. However they all make reference to joint working including joint strategies<sup>38</sup>, joint commissioning posts<sup>39</sup> and agreed strategic priorities<sup>40</sup>.

### **3.4 Personalisation**

Personalisation, personal budgets, and *Putting People First* are key to the delivery of care for people with dementia. The White Paper *Our Health, Our Care, Our Say*

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<sup>35</sup> Department of Health. (2011) *The Operating Framework for the NHS in England 2011/12*. Department of Health:London pg 27 :3.21

<sup>36</sup>Public Health Intelligence North East (2011) *Social Care North East* [Online] Available at : <http://www.phine.org.uk> (Accessed: 14 June 2011)

<sup>37</sup>Department of Health (2011) *Dementia Information Portal* [Online] Available at <http://www.dementia.dh.gov.uk> (Accessed: 14 June 2011)

<sup>38</sup> Darlington Borough Council (2009) *Joint Action for those with a Mental Health Problem 2009-2012 Action Plan* [Online] Available at: <http://www.darlington.gov.uk> (Accessed:22 June 2011)

<sup>39</sup> Stockton on Tees Action Plan for Delivery of the National Dementia Strategy (2010) [Online] Available at :<http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>40</sup> Mental Health Services for Older People (2010)*Mental Health Services for Older People in Middlesbrough Implementation plan 2009-2014* [Online] Available at: <http://www.darlington.gov.uk> (Accessed:22 June 2011)

(2006)<sup>41</sup> set out proposals for large scale reform of health and social care services. It stressed that service users, including people with dementia, should have choice and control over the support they receive, and that social care should enhance people's independence. The paper's four main goals were:

- Better prevention services with earlier intervention
- Giving people more choice and control over the care they receive
- Tackling inequalities and improving access to community services
- More support for people with long term needs

The White Paper<sup>42</sup> introduced individual budgets (which have since evolved into personal budgets), putting users at the centre of decision-making about their social care needs and how these can best be met. The paper also indicated that more resources would be shifted into prevention and health promotion, and that more services should be delivered away from hospitals and in community settings and people's own homes. Another priority was to provide for better co-ordination and integration of services at local level, with more joint planning and delivery from the NHS and local councils.

Putting People First<sup>43</sup> was a "concordat" published in December 2007 that set out a vision for transforming adult social care. It was endorsed by key partners including relevant central Government ministers, the NHS Chief Executive and the Association of Directors of Adult Social Services (ADASS). The concordat endorsed the development of a system focused on prevention, early intervention, 'reablement' and ongoing support services tailored to individuals. The emphasis was placed firmly on achieving better outcomes for service users and making better use of resources. To realise these objectives the Putting People First programme was introduced. The Coalition Government endorsed the principles of Putting People First as one of their main priorities for the reform and modernisation of health and social care.

The Coalition Government introduced a further policy document, "Think Local, Act Personal" in 2010. This document continued to encourage reform through integrated service delivery and partnership working. This provides further impetus to support the contribution of the person with dementia, their families, carers, friends and the wider community.

#### **Personalisation and objective 6**

The NE Joint Improvement Partnership and the Department of Health Social Care jointly funded a community and personal support project. There are three legacy products i) Development of a comprehensive evidence base for future commissioning of Dementia services in the North East" ii) "Supporting the implementation of Personalisation changes in the North East that are fully inclusive of people with Dementia and their Carers" and iii) An on line training resource about personalisation and dementia. These resources are available to all interested stakeholders<sup>44</sup>.

<sup>41</sup>Department of Health (2006) *Our Health, Our Care, Our Say*. Crown:London

<sup>42</sup>Department of Health (2006) *Our Health, Our Care, Our Say*. Crown:London

<sup>43</sup>HM Government et al (2007) *Putting People First, A shared vision and commitment to the adult social care*. Crown:London

<sup>44</sup> Public Health Intelligence North East (2011) *Social Care North East* [Online] Available at : <http://www.phine.org.uk/group.php?gid=173&resources> (Accessed: 14 June 2011)

The number of people who have a personal budget via a direct payment with dementia is not known in the NE. “Five Dementia Leads report the numbers of people in the areas accessing personal budgets, although it was not always possible to differentiate those with dementia from the general population accessing personal budgets”<sup>45</sup>

More details of what is happening in relation to personalisation can be found in chapter 11.

### 3.5 The Health and Social Care Bill

The Health and Social Care Bill was introduced into Parliament in January 2011. The Bill embodies the Government’s vision to reform the NHS so that it is built around patients (“No decisions about me, without me”<sup>46</sup>), led by health professionals and focused on delivering world-class healthcare outcomes.

Key proposals in the Bill include:

- Developing GP consortia across England which will be responsible for commissioning healthcare for their patients. GP consortia will control 80% of the NHS budget and this will include commissioning health services for people with dementia.
- A new NHS Commissioning Board to replace the current NHS Management Board.
- Local Health and Well Being Boards will be established which will bring together GP commissioners, Public Health, Local Authorities and patient and public groups. These boards will shape local priorities and review performance.
- Making the NHS more accountable to patients and the public by establishing a new independent body, Healthwatch, that can look into complaints and scrutinises the performance of local health providers.
- A requirement for all hospitals in England to become foundation trust hospitals.
- Strategic Health Authorities to be abolished by 2012; Primary Care Trusts to be abolished by 2013 and the numbers of arms length bodies, such as the Health Protection Agency, to be reduced by incorporating them into existing structures.

Nationally the Alzheimer’s Society has submitted evidence to the Public Bill Committee<sup>47</sup>, which will scrutinise the Health and Social Care Bill, about how it could be more inclusive of, and achieve better outcomes for, people with dementia and their carers. The Alzheimer’s Society evidence raises the following questions and suggestions:

- Whether the funding provided to HealthWatch is also to provide advice and information includes funding for people to make choices about health and care services?
- The need to have multi-disciplinary dementia commissioning.

<sup>45</sup> Agencia Consulting Ltd (2011) *Developing a comprehensive evidence base for the future commissioning of dementia services in the North East*. P39:7.2

<sup>46</sup> Department of Health (2010) *Equality and Excellence: Liberating the NHS*. Department of Health:London.

<sup>47</sup> Alzheimer’s Society (2011) *Health and Social Care Bill Memorandum submitted by the Alzheimer’s Society (HS 108)* [Online] Available at [www.publications.parliament.uk/pa/cm201011/cmpublic/health/memo/m108.htm](http://www.publications.parliament.uk/pa/cm201011/cmpublic/health/memo/m108.htm) (Accessed:17 June 2011)

- The need to have strong Local Authority representation on GP consortia.
- The need for membership of the National Commissioning Board to include someone with expertise in older people's health and care issues.
- The need for quality to improve standards; commissioning should not be tariff driven.
- The ability of HealthWatch or the Health and Wellbeing Board to petition if a designated service is too important to fail or cease to be provided.
- Ensuring the regulatory burden is not too great for service providers and can be inclusive of third sector organisations.
- The need to require the GP consortia to have regard to the NICE dementia quality standards whilst having the same duty to fund NICE recommended drug treatment that exists under the current system for PCTs. This is of particular significance to people with dementia following NICE's new draft guidance (January 2011) extending access to drug treatments. NICE guidance needs to be inclusive of social care interventions and NICE staff need to have expertise in social care interventions.

The Institute for Public Policy Research in their report "Dementia Care in London"<sup>48</sup> warns that proposed Health and Social Care Bill reforms could make things worse for people with dementia unless safeguards are introduced as a matter of urgency. The report warns that particular systems need to be put in place to strengthen the links between health and social care to ensure a more integrated service and a seamless care pathway for people with dementia. The report makes a number of recommendations which should be considered in turn to reflect work in the NE:

- The new Health and Wellbeing Boards should make dementia a priority
- Co-location of health and social care services needs to be rolled out to ensure closer working between GPs and other providers
- Local authorities need to retain a role in scrutinising dementia care provision
- People with dementia and their carers should hold their own personal budgets to pay for their social services

In April 2011 the Government launched a two month "listening exercise" on NHS modernisation, to hear the views of patients, the public and health professionals. Following the exercise in June 2011, the Government agreed to reinstate the Secretary of State's legal responsibility for the NHS and to provide greater powers for Health and Wellbeing Boards and a more significant role for patients within them;

The competition body, Monitor, are to have a focus on protecting patient interests rather than competition and proposals now include additional safeguards against price competition and "cherry picking" with every commissioning group now needing to have a governing body.

In addition it was accepted that commissioning groups may not be established in time to meet the 2013 deadline but that all GP practices would be members of either an authorised clinical commissioning group or a 'shadow' commissioning group by April 2013.

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<sup>48</sup> Sachrajda, A. (2011) *Dementia Care in London*. London: IPPR

### **GP Consortia in the North East**

As at March 2011 nine GP pathfinder consortia had been identified in the NE<sup>49</sup>. At this stage it was too early for the consortia to outline their priorities publically and say if dementia is a priority for them. However, the NE Joint Strategic Needs Assessments (JSNA's), which provide the public health framework for commissioning in each locality, all mention dementia; so all localities will be aware of dementia needs in their areas. It is important that these assessments are refreshed to ensure their continued validity so that commissioners can develop plans to meet the dementia needs in their area.

### **Helping GPs**

"Dementia - Timely Diagnosis & Conversations with Patients and Carers"

NHS South of Tyne and Wear have commissioned a development seminar for GPs. It is a practically based half day, designed and delivered by Dr Malcolm Thomas from Effective Professional Interactions Ltd and Professor Louise Robinson from Newcastle University. The aim of the seminar is to increase GPs' confidence and skill in introducing the possibility of dementia to patients and their carers and having effective conversations with them.

NHS South of Tyne and Wear ran a seminar for lead GPs in their area in Spring 2011. The intention is to hold another seven throughout the early Summer of 2011, all aimed at local GPs.

For more details

Contact: Dr Malcolm Thomas [mithomas@doctors.org.uk](mailto:mithomas@doctors.org.uk) or see [www.effectivepi.co.uk](http://www.effectivepi.co.uk)  
Dr Thomas works across the UK.

### **Foundation Trust Status**

All NHS Acute Trusts in the NE have Foundation status which means that they are performance managed by their local Primary Care Trust and regulated by Monitor<sup>48.5</sup>. As things stand with the proposed new structures for the NHS, there will be a number of opportunities for patient groups to have a say in how their local services are commissioned and delivered. Patients and the public can also be elected to their foundation trust board as individuals or in a group with special interests.

### **3.6 Other forthcoming legislation**

Later in 2011, further legislation is to be introduced to establish a Public Health Service for England and transfer responsibility for Public Health from the NHS to local authorities. By integrating public health into local government, it is proposed that the wider economic and environmental determinants of public health can be addressed more directly.

The Government is also proposing to introduce a Social Care Bill, which will consolidate all the existing social care legislation and set out how social care is to be funded into the twenty-first century.

### 3.7 Summary

The Government has expressed its support for the aims of the NDS, recognising the increase in numbers of people with dementia as one of the biggest challenges in health and social care. The government clearly sees personalisation of social care as the way forward and continues to promote the principles of “Putting People First”.

Major legislation has been introduced to reform the NHS; the main consequence of which is that GP commissioning consortia will take over responsibility for the majority of the NHS budget, including dementia care. Serious concerns have been expressed about aspects of the Bill and in April 2011 the Government embarked on a “listening exercise” to hear what those concerns were and to reflect on them. Whether and to what extent the Health and Social Care Bill is amended remains to be seen.

Additional legislation is also planned which will affect health and social care and have an impact on dementia care.

In the NE there have been some clear strategic and local responses to the NDS and implementation guidance. Regarding other policy areas and proposed policy changes which effect or will effect dementia care in some cases projects and responses have been across the whole region (for example the work on community and personal support) while some responses have been on a locality basis (for example the development of GP pathfinder consortia) .

## 4. National Dementia Strategy Economic Challenges

- Establishing the amount of spending on caring and supporting people with dementia and their carers is very difficult. Any figures should be viewed with caution.
- The amount spent on supporting people with dementia and their carers in the UK has been estimated as £17.03 billion per annum or £25,472 per person with late onset dementia.
- In the NE the figure of £143m has been estimated as being spent on dementia care using specific NHS and local authority costs.
- There are nationally developed approaches to making savings in dementia care.
- One example is Darlington Dementia Collaborative who have reduced the length of stay for people in one of their older person's wards.
- The NE third sector organisations are beginning to feel the impact of the current economic climate, which could effect their service provision for people with dementia and their longer-term viability.

### 4.1 National Context

With the predicted increasing numbers of people with dementia coupled with the current economic climate there are going to be increasing pressures on resources. In September 2010, Paul Burstow MP, Minister of State for Care Services, said in relation to spending on dementia, "We spend £8.2 billion a year caring for those affected. In this tough economic climate, we must be realistic... It's not about extra resources but how we can think smarter using the resources we already have."

Establishing cost and spend linked to one client group is notoriously difficult with the problem of deciding what should be included in any costings. There is an additional problem in the case of dementia which is in identifying the true number of people who have it. Social care and health information systems do not necessarily list which clients have dementia and there is a problem with under diagnosis. Both of these factors make it difficult to attribute accurate costs to dementia care<sup>49</sup>.

The previously cited Dementia UK report estimated that the total annual cost per person with dementia in different settings could be gauged as follows: (Source: Dementia UK The Full Report pg xviii)

People in the community with mild dementia	£16,689
People in the community with moderate dementia	£25,877
People in the community with severe dementia	£37,473
People in care homes	£31,296

<sup>49</sup> See section 2.2.7



Total UK costs are calculated to be £17.03 billion per annum or an average of £25,472 per person with late onset dementia<sup>50</sup>. Costs included in this estimate were those provided by formal care agencies as well as the financial value of unpaid informal care provided by family and friends.

There are a number of national reports which highlight how financial savings can be made. The report “Counting the Cost – Caring for People with Dementia in Hospital Wards – Alzheimer’s Society 2009” finds that supporting people with dementia to leave hospital one week sooner than they currently do could result in savings of at least £80 million a year.

The National Audit Office advocated a ‘spend to save’ approach. This includes upfront investment in services for early diagnosis and intervention, improved specialist community services, and funding to ensure appropriate referral and treatment of people with dementia in general hospitals that would enable long-term cost savings from the prevention of unnecessary transition into care homes as well as shorter stays in hospital<sup>51</sup>.

## 4.2 Regional Estimate of Spend

### **Reducing Costs in a General Hospital in the NE**

Darlington Memorial Hospital provides an example of where cost savings have been made by reducing the length of stay for people with dementia in an acute setting. As a result of the work of the Darlington Dementia Collaborative (see section 10.2 for more details), the length of stay was reduced from 15.5 days in March 2010 to 10.7 days by October 2010

“Developing a comprehensive evidence base for the future commissioning of dementia services in the North East – February 2011”<sup>52</sup> attempts to give some idea of the cost in the NE of providing support and treatment to people with dementia. Taking account of the cost to the NHS of organic conditions (due to damage or deterioration of the brain tissue these include dementia but also include other conditions including brain trauma caused by injury) and local authority care homes, dementia is estimated to cost £143m across the NE. If these costs increase in proportion to the rise in dementia prevalence, it could add £70m to the total by 2025<sup>53</sup>. This is a conservative estimate of the potential extra costs if services are not remodelled.

<sup>50</sup> London School of Economics. (2007) *Dementia UK – The Full Report*, London:Alzheimers Society

<sup>51</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London

<sup>52</sup> Agencia Consulting Ltd (2011) *Developing a comprehensive evidence base for the future*

<sup>53</sup>To compensate for the gaps in information, most of the financial conclusions have been made based on PCT figures for organic spend extracted from programme budgets and on care home costs and estimates based on LA returns of the questionnaire sent to Dementia Leads. The total of both LA and PCT costs added together is £143 million.

### **The Impact of the Current Economic Climate on the Third Sector in the North East**

There is no comprehensive information on the impact of the current economic situation on those third sector organisations which specifically provide services for people with dementia and their carers. However, based on information provided by the Alzheimer's Society in the NE it is evident that dementia care organisations have experienced some cuts to funding for the financial year 2010-11 which has led to some reductions in the level of service provided. Further evidence of this comes from a survey, "Surviving in the Big Society", carried out by Voluntary Organisation's Network North East (VONNE) and published in 2010. The survey received replies from 141 NE third sector organisations and found that:

- 62% had seen a decrease in funding in the previous 12 months
- Over one third have made staff redundant in the previous 12 months
- Nearly half are using their reserves to maintain services
- 69% have experienced an increase in demand for their services

The survey also showed that for financial year 2011-2012:

- 64% expect to, or are considering, closing at least one service
- 50% will be, or are considering, reducing the number of beneficiaries they support
- 26% may close fully in the next 12 months

The Northern Rock Foundation's Third Sector Trends Study highlighted that in 2010 the third sector in the NE had an over reliance on statutory funding when compared to other parts of the country. The VONNE report states that 65% of third sector organisations rely on the public sector for over 25% of their annual income and 45% of organisations rely on the public sector for over half of their annual income. This could make the sector very vulnerable to the planned public sector funding cuts "

VONNE state "The heavy reliance on public sector funding is likely to lead to large scale closures of services, loss of skilled staff and the ultimate closure of some organisations, when the cuts bite over the next few months. This is at a time when demand for services has never been higher. VONNE warns that the most vulnerable in communities are likely to suffer as services are lost" .

For more information on third sector providers please see section 9.3.

From this information we can't assume that dementia services won't be cut in the third sector. In addition issues may arise indirectly from cuts in spending. For example eligibility for services is being raised, meaning older people are accessing fewer day services, leading to the services not being viable and closing.

### **4.3 Summary**

There are clear financial pressures on both commissioners and providers as the number of people with dementia are set to significantly increase in the NE and as pressures increase on public sector spending. Broad estimates have been made that if services for people with dementia are not redesigned in the NE then the cost of NHS organised services and local authority care home costs could increase by £70m

between 2010 and 2025. There are some models both nationally and in the region which can be adopted to reduce costs.

By far the biggest challenge facing third sector dementia care providers are the cuts in government spending at national and local levels. Third sector organisations in the NE are already beginning to feel the effects of these cuts and the fear is there are more to come, which may begin to threaten their viability.

## 5. Research in the North East

- The North East has a very strong research base in Newcastle and Northumbria Universities.
- Research focuses on brain ageing and includes work on cause, treatment and care and support for people with dementia and their carers.
- These Universities are strongly linked to national initiatives on dementia.

### 5.1 Research base

This section highlights the extent and type of dementia research which has been or is being undertaken in two of the NE universities. Other universities also carry out research but at the time of writing the report no detailed information was available.

#### 5.1.1 Newcastle University

Newcastle University is both nationally and internationally recognised as a centre of excellence for dementia research, carrying out research into the causes, possible cures and care of people with dementia. Dementia research at the university is conducted at the Institute for Ageing and Health (IAH) and the Institute of Health and Society (IHS). Studies include drug trials and research into the experiences of people with dementia and their families in accessing current health and social care services and how the quality of this care can be improved.

The IAH has supported the development and implementation of the NDS in the region. This includes chairing the previous regional development and implementation group (now the Dementia Alliance), which was funded and supported by the Department of Health.

The University also provides expertise to national dementia programmes such as the development of the “commissioning toolkit”, the Royal College of Psychiatrist’s audit on acute hospital care and end of life care. In addition, the Royal College of GPs national champion for older people is based at the university.

Newcastle University also has considerable expertise in the development of technologies to support an ageing population including people with dementia as well as projects to support housing for people with dementia. The University is working with local communities to undertake innovative research on developing a person centred outcomes framework for dementia care.

Further details about the nature of the research and specific projects currently being funded can be found at:

<http://www.ncl.ac.uk/iah/>

<http://www.ncl.ac.uk/ihs/>

Along with university College London, Newcastle University co-hosts the National Institute of Health Research national disease specific research network DeNDRoN (the Dementias and Neurodegenerative Diseases Research Network). DeNDRoN is responsible for increasing and facilitating research into dementia in the UK in both

primary and secondary care settings and hosts disease specific research groups focusing on dementia, Parkinson's disease and motor neurone disease. For more information see:

<http://www.dendron.org.uk/rn/ne.html>

### **5.1.2 Northumbria University**

At Northumbria University, the Community, Health & Education Studies Research Centre undertakes a range of research in dementia care and has a particular focus on qualitative research. Recent and current studies include the national evaluation of peer support networks and dementia advisors within the National Dementia Strategy and the development of a social disability focused group intervention for people living with dementia. The Centre has a wide range of doctoral students, including research into end of life care, self-identify, and cultural aspects of caring for a person with dementia. There is a particularly strong programme of work concerning risk management in dementia care.

For more information see:

<http://www.northumbria.ac.uk/sd/academic/sches/research/ches/>

### **5.1.3 Other Universities**

There are number of other universities in the region who are carrying out research on dementia, however at the time of writing the report no further information was available.

## **5.2 Summary**

There is an excellent research base in the NE which can be capitalised on locally, to translate evidence into practice.

## 6. Key North East National Dementia Strategy Structures

- There are three regional groups dedicated to the implementation of the NDS. Each has a particular focus on strategy, development, commissioning or implementation.
- Two regional groups are not dementia specific but play a significant part in implementation of dementia support, one having a focus on mental health the other on social care.
- Dementia Forums are being developed across the NE. These will be used to collect the views of local people to enable local accountability.
- Seven out of the twelve localities in the NE reported they have groups responsible for the implementation of the NDS in their area.
- The future of some regional groups is uncertain from 2011

### 6.1 NE Key NDS implementation structures

There are a number of NE regional, sub regional and locality groups who lead the implementation of the NDS.

### 6.2 Regional groups

There are five regional groups who have a key role in implementing the NDS in the NE. Three of them are specifically dedicated to dementia whilst the other two have a role in mental health and social care but their remits cover dementia. There is common membership to the groups to maximise synergy between them. This section outlines their role and membership.

#### 6.2.1 The NE Dementia Oversight Board

This is the NE strategic Board which oversees the implementation of the NDS in the region. The Group is chaired and administered by the Deputy Regional Director of Social Care for the Department of Health. Membership includes the Association of Directors of Adult Social Services NE lead for dementia, the chair of the Dementia Alliance, the Alzheimer's Society and the NE Strategic Health Authority (SHA) Lead for dementia. The Board have determined the regional priority objectives, developed strategic homes for each of the priority objectives and ensure implementation progress is being made. The Board has planned meetings until the end of March 2012 .

#### 6.2.2 The NE Dementia Alliance

This group, originally the NE stakeholder group, first met in September 2008 to consider how the NDS could be implemented as fully and as quickly as possible in the NE. It changed to an alliance model in Spring 2011 with a purpose of continuing its existing role and to encompass the principles of the dementia declaration<sup>54</sup>. Close links are made to the dementia forums in the NE to ensure two-way feedback. The group's work has included giving advice to the Oversight Board, providing contributions to baseline

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<sup>54</sup> Dementia Action Alliance (2011) *National Dementia Declaration* [Online] available at <http://www.dementiaaction.org>. (Accessed 14<sup>th</sup> June 2011)

activity work, commissioning two demographic and service profiles<sup>55 56</sup>, developing a response on implementing the care home objective<sup>57</sup> and disseminating good practice by arranging regional events. The group is made up of stakeholders including representatives of people with dementia, their carers, the NE Strategic Health Authority, local authorities and the third sector. The group was originally developed through support from the Department of Health and 'Years Ahead' (the Regional Forum on Ageing) hosted by Newcastle University. A small amount of funding has been allocated to support the work of the group from April 2011 to March 2012. This will be administered by Newcastle University.

### **6.2.3 The NE Dementia Leads Group**

This is a group formed in March 2009 to support the implementation of the national dementia strategy in NE localities. The group led the development of a mapping tool which was used by health and social care communities to assess their own progress in delivering the national strategy<sup>58</sup>. This group acts as a forum for sharing good practice and information and in assessing progress. The group is made up of dementia leads from each primary care trust and local authority in the NE. In some cases this may be the same person. In March 2011 the group were considering their future because of changes to the regional support which had been available to them.

### **6.2.4 The Mental Health Clinical Innovation Team**

The Mental Health Clinical Innovation Team (CIT) group was developed as a result of the review of the NHS in England led by Lord Ara Darzi along with other work across the NE. This group has focused on clinical pathways and is hosted by the Strategic Health Authority (SHA). As part of its work the group has identified the need to improve dementia services. As a first step, the group commissioned a self-assessment mapping tool for dementia provision. In 2010 the group held an 'accelerated solutions' event where key priorities for early intervention for dementia were identified. In Spring 2011 the group held a 'fast focus' event on reducing the inappropriate use of antipsychotic medication people with dementia. The group provides strategic leadership in early diagnosis and treatment (objective 2) and reducing the inappropriate prescribing of antipsychotic medication. If the proposed dissolution of the SHAs happened in 2012 the group would have to consider its future.

### **6.2.5 NE Association of Directors of Adult Social Services (ADASS)**

This is a regional group of directors of adult social services. Their work covers a range of adult client groups including dementia. The group provide strategic leadership for three of the NDS objectives (community and personal support: objective 6, housing and telecare: objective 10, and care homes: objective 11). They have been key in working with the NE Regional Improvement and Efficiency Partnership (RIEP) to sponsor projects which will improve the quality of life of people with dementia. Projects have included a community and personal support project<sup>59</sup>, "purposeful walking" - which involved using telecare<sup>60</sup>, and a project to develop enhanced quality standards for

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<sup>55</sup> Jackson, M. (2009) *Dementia North East England A Demographic and Service*

<sup>56</sup> Jackson, M. (2011) *Dementia North East Demographic Update*

<sup>57</sup> Department of Health (2009) *Living Well With Dementia Views From the North East*. London: Department of Health

<sup>58</sup> Department of Health (2011) *NE Region National Dementia Strategy - Self Assessment Tool* [Online] Available at <http://www.dementia.dh.gov.uk> (Accessed 14 June 2011)

<sup>59</sup> See section 11.1 (Community and Personal Support)

<sup>60</sup> See section 11.2 (Telecare)

regulated services<sup>61</sup>. Funding for these projects has come through the RIEP which was financed until March 2011. The ending of funding for the RIEP will have an impact on the work this group is able to do.

### **6.3 Sub-regional Groups**

This sub section outlines groups which don't fully cover the NE but cover more than one of the twelve localities.

#### **6.3.1 NE Community Dementia Forum Alzheimer's Society**

From Spring 2011, the Alzheimer's Society have been developing Community Dementia Forums in the NE. The aim of these forums is to collect vital information from local people to get a better understanding of the problems and issues around dementia for service users and their carers. This information can then be used to help make radical changes in service provision. It is anticipated that these groups will contribute to the challenging of commissioners to ensure effective services, and will help ensure local accountability for the delivery of the NDS. The forums meet quarterly and have open membership. Feedback from the forums will go to the NE Dementia Alliance (for details see section 6.2.2) and influence the regional agenda; information will also come from the Alliance to the forums. The forums are supported as part of the core activity of the NE Alzheimer's Society.

For more information on the NE Forums contact the Alzheimer's Society Area Office in Newcastle on 0191 2751950.

### **6.4 Locality Groups**

There are twelve geographical localities linked to local authority and primary care trust boundaries in the NE. There are a number of groups linked to these localities which are responsible for overseeing the implementation of the NDS. This fits with the Department of Health's role and its priorities during 2010/11 for supporting local delivery of and local accountability for the implementation the NDS<sup>62</sup>.

#### **6.4.1 NE locality Arrangements for overseeing the implementation of the NDS**

Seven of the twelve localities report that they have a group which has responsibility for the implementation of the NDS including development and delivery of plans. The groups differ in their makeup from broad stakeholder groups (e.g. Middlesbrough and Stockton) to senior officer groups (e.g. Gateshead). Of the five localities who have not reported having a group, two are reviewing their implementation structures following internal restructures within the local authorities (North Tyneside and Darlington) and one locality is planning a group (Northumberland). There is no information available on the arrangements in Newcastle and Durham to oversee the implementation of the NDS. For all 12 localities there is at least one identified contact person who has responsibility for implementing the NDS from the primary care trust or local authority or in some cases both. A document collating the locality groups and contacts, as at 31<sup>st</sup> March 2011 can be found on the Social Care Section of the PHINE web site<sup>63</sup>.

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<sup>61</sup> See section 10.4 (Care Homes)

<sup>62</sup> Department of Health. (2010) Quality outcomes for people with dementia: building on the work of the National Dementia Strategy. Department of Health: London P5

<sup>63</sup> North East Locality Groups (2011) Dementia Strategy [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed: 17 June 2011)



## 6.5 Summary

The NE already has strong, broad based groups around dementia care; the individual work of these groups and their well developed links with each other mean that the region has a robust and flexible structure to help implement the NDS. The fact that the Stakeholder Group has become an Alliance shows that NE groups continue to adapt to better address the needs of people with dementia and their carers.

One area of concern for the future is whether the proposed GP commissioning consortia will continue to support the existence of some of the groups looking at dementia. At the moment, the Clinical Innovation Teams are hosted through the Strategic Health Authority but, under the Health and Social Care Bill, these will be abolished in 2012 and it is not clear yet whether they will be replaced or what their replacement will be. When GPs take responsibility for commissioning healthcare, they may adopt different models of collaborative working from those currently in place. Given the flexibility already displayed by these groups such adaptations may not be a problem; however, it would be vital that dementia groups have a say in planning any future arrangements for implementing dementia policies and strategies.

## 7. North East Region wide information

There are three key sources of NE wide dementia information:

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

### 7.1 Available information

There are three key sources of information indicating where partners are in the NE in relation to implementation of the NDS. These set out the key areas which need to be considered, how localities propose to address gaps and a regional wide picture of community and personal support, outlining key recommendations.

### 7.2 Baseline assessment results from using the NE Mapping Tool

In June and July 2009, partnerships in each of the twelve localities in the NE carried out a self-assessment on how they were delivering 15 of the 17 NDS objectives. The objectives not included related to national activity: objective 16 to obtain a clear picture of research evidence and needs and objective 17 to ensure effective national and regional support for implementation of the strategy.

The self-assessment was developed in the NE as a result of a commission by the Mental Health CIT. The self-assessment was based on localities rating themselves either red, amber or green (RAG rating system). Partners were asked to include commentary and examples of good practice. The assessment levels were based around indicators relating to the detailed steps towards achieving each objective. Where localities rated themselves green this did not necessarily mean that they had achieved the delivery of the whole of that objective but they had achieved the green level relating to that indicator. The exercise was not carried out to measure performance but to form the basis on which to improve practice and inform the local and regional action planning process.

A summary of the results provides the most comprehensive position of where the region is in relation to implementing the NDS. Details can be found in “Readiness to Implement” - October 2009<sup>64</sup>. The objectives highlighted as needing greatest attention were:

- Raising awareness and improved information (across objectives 1 & 3)
- Good quality early diagnosis and intervention for all (objective 2)

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<sup>64</sup> Department of Health (2009) *National Dementia Strategy in The North East Readiness to Implement*. London: Department of Health

- Improved community personal support services (objective 6)
- Improved care for people with dementia in general hospitals (objective 8)
- Improved intermediate care (objective 9)
- Considering the potential for housing support, housing related services and telecare to support people with dementia and their carers (objective 10)
- Living well with dementia in care homes (objective 11)
- An informed and effective workforce (objective 13)

These findings are in excess of 18 months old but still remain pertinent.

### 7.3 Locality Action Plans

The locality plans outline how the twelve localities will deliver the NDS. These were developed after the baseline assessment exercise. The format was not prescribed but plans include objectives, activities and time frames. The plans have not been validated outside the relevant locality.

As mentioned in section 3.3, ten of the twelve NE locality plans can be found on the PHINE website (in the Social Care group) and seven can be found on the dementia information portal website (NE pages). There are two plans from the NE which are not yet available on these sites. The remaining localities are working on their plan but they are not sufficiently developed to be shared more widely at the time of this report being written.

Links to the plans are as follows:

<http://www.dementia.dh.gov.uk/inYourRegion/northEast/>

<http://www.phine.org.uk/group.php?gid=173&resources>

### 7.4 A Resource for Commissioners – Objective 6

The most detailed information collated in one place about services in the NE for people with dementia can be found in “Developing a comprehensive evidence base for the future commissioning of dementia services in the NE”<sup>65</sup>. This information was collected for a project on community and personal support. The report, its findings and recommendations are based on data provided by the NHS and local authorities in response to requests for information relating to objective 6 of the NDS.

The key issue to emerge was that, in view of the increase in the predicted prevalence of dementia across the NE, urgent action was needed to develop more cost effective services. It is possible that additional costs could be avoided, at least in part, by earlier diagnosis, personalised assessment on diagnosis and enhanced community services’ such as telecare and memory services, to support independent living. Savings could also be made by using acute liaison services and using the learning from the national report “Counting the Cost”<sup>66</sup> work in acute hospitals.

The predicted rise in the prevalence of dementia was the primary concern reported in terms of capacity to continue to deliver services. Many providers stated that they would struggle to deliver services if changes were not made; merely providing ‘more of the same’ to meet the growing demand is unlikely to be a viable option.

<sup>65</sup> Public Health Intelligence North East (2011) *Social Care North East* [Online] Available at : <http://www.phine.org.uk/group.php?gid=173&resources>

<sup>66</sup> Alzheimer’s Society (2009) *Counting the Cost – Caring for People with Dementia on Hospital Wards*. London: Alzheimer’s Society

The cost to PCTs of organic conditions (due to damage or deterioration of the brain tissue these include dementia but also include other conditions including brain trauma caused by injury), together with LA care home costs, was estimated to be £143m across the NE. If costs increase in proportion with the rise in prevalence, dementia care will cost an additional £70m by 2025. This is a conservative estimate of the potential extra costs if services are not remodelled.

Staff training and raising public awareness about dementia have been identified as major issues in feedback from LAs and their partners.

There are significant inconsistencies in the way each LA collects and presents its information and data on dementia. Dementia information is not collected separately from general older people's data, making it difficult to disaggregate and analyse information relating solely to dementia. This is seen as a barrier to effective delivery, and it is suggested that a consistent and comprehensive method of data collection for dementia services is developed in the future.

## 7.5 Summary

A baseline self-assessment was carried out in 2009 on progress towards implementing the NDS. This self-assessment showed that the NE had significant strengths and weaknesses in its ability to carry through the NDS. Action plans have been developed and are being implemented which build on the strengths and improve those areas where problems have been identified. Once the remaining action plans are shared further assessment of the regions capability to deliver can be made.

The commissioning information outlined in the 'Developing a Comprehensive Evidence Base' document provides some insight into service provision and spend, making some recommendations that can be taken forward.

One key issue, which needs addressing urgently, is whether current organisations will be able to continue to deliver the NDS as the NHS undertakes what may be the biggest re-organisation in its history. Localities should do another self-assessment to both assess progress and measure their capacity to deliver the NDS to meet the changes in NHS and local government introduced by the Coalition Government.

## 8. What the people of North East England said is important to them

- There are four key consultation exercises which outline stakeholders views. They cover primarily what people with dementia and their carers want and their experiences.
- These provide the views of in excess of 500 people.
- Three exercises are NE wide and one is subregional.
- One report specifically gives the views of people with a Learning Disability.
- Views are often repeated in the various reports and are echoed in later reports, despite exercises being carried out up to two years apart.
- There is little evidence in the reports that minority communities were consulted with.

### 8.1 The stakeholder information

The following section outlines key sources of information about the views of people with dementia and carers or those who have an interest in dementia. It highlights details of four major NE listening and engagement exercises which have been carried out to seek views and experiences of dementia care and how it should be delivered. It gives the views of in excess of 500 people. Three exercises covered the region whilst one covered 'North of Tyne'. The exercises took place between 2008 and 2010 but as illustrated by the findings of the 2010 event the findings still remain relevant.

### 8.2 "Listening to You – National Dementia Strategy – NE Listening and Engagement Events Feedback"

The first section of the 'Listening to You' report provides a NE summary of the views of a wide range of stakeholders who contributed to seven Listening and Engagement events which were held across the NE in February 2008. Of the 250 stakeholders who attended, 18 were people with dementia, 47 were carers of a person with dementia, 114 were staff from statutory agencies and 71 were staff from non-statutory agencies<sup>67</sup>. Two events were held specifically for the Chinese community in Newcastle.

The purpose of these events was to seek views as to what should be included in the NDS. At each of the events questions were asked based on three themes: raising awareness, early intervention and improving the care of people living with dementia. The views of attendees were collated into a NE report which was submitted to the Department of Health in March 2008. The issues raised were then analysed further to produce a second report "Listening to You – National Dementia Strategy – NE Key

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<sup>67</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* Alzheimer's Society:London pg 8

Priorities Identified from the Listening and Engagement Exercise”. This report was developed to help the stakeholder group to identify their work priorities.

There were a number of overarching recommendations:

- The need to remember that the person is a citizen first and a person with dementia second
- There needs to be an emphasis on individual needs assessment and person centred care
- Information and raising awareness needs to be tailored for specific groups including people from black and ethnic minority communities<sup>68</sup>

The most frequently raised issues across the consultations and themes were: providing training (particularly in relation to raising awareness); involvement of GPs and provision of information to aid raising awareness and to support early detection.

### **8.3 “National Dementia Strategy. A report of consultation with people with learning disabilities in the North East. What we think of the Government’s Plan”**

People with a learning disability (including Downs Syndrome) are more likely to be affected by dementia. Recognising this, Skills for People, a user led organisation for people with learning disabilities in Newcastle upon Tyne was commissioned to carry out a consultation which explained what people with a learning disability felt was important to include in the NDS. Three events were held, in Newcastle upon Tyne, North Tyneside and Middlesbrough during August 2008. A total of 76 people came to these events, of which 55 had learning disabilities. 21 professionals working to support the people with dementia also attended. At each session people were asked the same questions relating to housing support, care and health. A report was produced outlining the findings entitled, “National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think of the Government’s Plan” (August 2008)<sup>69</sup>.

### **8.4 “We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers NHS North of Tyne 2010”**

As part of the NHS North of Tyne service review and as a NE Department of Health early adopter site, the Alzheimer’s Society and Mental Health North East hosted a series of engagement events to obtain the views of people in Newcastle, North Tyneside and Northumberland who used mental health and social care services. The aim was to assess current service provision and compare this with the needs of people with dementia and their carers. The views of over 200 service users and carers were collected. The findings were used to shape service delivery and commissioning intentions of NHS North of Tyne.

For consistency and clarity each event utilised a template of prompts that reflected the first 15 objectives of the National Dementia Strategy. From the 15 objectives covered

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<sup>68</sup> Alzheimer’s Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* Alzheimer’s Society:London pg1.

<sup>69</sup> Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

throughout the events a number of themes emerged. Although a variety of points were raised at the meetings, a theme common to all of the events was that though there were examples of good practice in treatment, care and support there was a need to continue to develop and improve services.

### **8.5 “National Dementia Strategy: North East Experiences of Dementia Services 2010 – a Report on Focus Groups with Users and Carers”**

The North East Regional Stakeholder Group commissioned feedback from people with dementia and carers throughout the region on their experiences of the six NE priority strategy objectives<sup>70</sup> (reduction of the inappropriate use of antipsychotic medication was not included). The feedback obtained in 2010 by the Alzheimer’s Society used focus groups in Gateshead, Middlesbrough and Hexham. These groups considered questions relating to the six objectives. The numbers involved in the group meetings were small: 18 overall, but the results are consistent with those obtained in a feedback exercise undertaken in the North East in 2008, which had larger numbers (reported in ‘*Listening to You: National Dementia Strategy NE Listening and Engagement Events Feedback*’, 2008).

### **8.6 Summary**

Four major listening and engagement exercises have been carried out in the NE. Perhaps not surprisingly, the most common themes are around early diagnosis, training, awareness of dementia and appropriate person-centred care at all stages of their journey for the person with dementia and their carers. Most of these concerns are addressed by the NDS, but that should not lead to complacency that the strategy is being fully implemented, or that all concerns have been identified and dealt with.

For example, training and awareness are not things that can be fully implemented quickly, it takes time and effort over a long period before everyone involved in caring (in whatever environment) is fully sensitive to the needs of people with dementia and their carers. Even as training takes place in how to respond appropriately there is a need to be aware of new and improved ways of doing things. Staff turnover in the sector is high so there is a constant need to reinforce training and awareness of dementia.

Whilst three of the listening events were open to all (one was specifically for people with Learning Disabilities) it is unlikely that all people’s experiences of dementia have been captured. Responding appropriately to people with dementia and across all sectors of society is important. There is a need to identify the specific issues and needs of people with dementia from the following communities: Black Minority Ethnic (BME), faith-based, and Lesbian Gay Bisexual Transgender (LGBT). All members of society with dementia need to be included and none excluded as we plan and deliver services in the future.

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<sup>70</sup> For more information see section 3.1.3

## 9. Dementia Service Providers in the North East

In the NE the following providers and services are available for people with dementia and their carers:

- Four trusts provide secondary mental health services.
- Twelve local authorities provide both specialist and universal services which include assessment of need and service provision.
- Around 10 third sector organisations provide over 60 services.
- 'Not for profit' organisations are providing housing services.
- Significant 'for profit' organisations are providing care home and domiciliary services.
- One known user lead organisation has been developed.

### 9.1 Introduction

This section outlines who the key dementia service providers are and what services they provide in the NE. The section starts with details of the statutory sector, followed by the third sector, not for profit, commercial sector and user led organisations.

### 9.2 The Statutory Sector

#### 9.2.1 Specialist Mental Health Services

There are two dedicated NHS mental health providers in the NE. They are Tees, Esk and Wear Valleys Foundation Trust (TEWV) and Northumberland, Tyne and Wear NHS Foundation Trust (NTW). In addition, Northumbria Healthcare NHS Foundation Trust and Gateshead Health NHS Foundation Trust provide mental health services.

**The Tees, Esk and Wear Valleys NHS Trust (TEWV)** provides mental health services for older people. Working in partnership with local authority social care teams and the voluntary and independent service sectors, the Trust provides in-patient, day and out-patient assessment and treatment services (including acute, intensive care and rehabilitation services) and a wide range of community based services including in-reach care home teams and general in-reach hospital teams. The Trust also provides a young onset dementia service. The Trust covers County Durham and Tees Valley and some areas in North Yorkshire.

**The Northumberland, Tyne and Wear NHS Foundation Trust (NTW)** provides services to older people through their Older People's Directorate. The Trust provides assessment, treatment, rehabilitation and ongoing care to older people with organic and/or functional mental illness, this includes services for older people with complex mental health problems and/or challenging behaviour. Services are also provided to younger people with early onset dementia. The Trust also provides in-reach services to



other local NHS and independent providers when they require specialist mental health input or psychological therapies.

Services are provided within hospital and community settings as close to the individuals' home as possible. The Trust covers Northumberland, Newcastle, the Longbenton area of North Tyneside, South Tyneside and Sunderland.

**The Northumbria Healthcare NHS Foundation Trust** is a hospital trust providing secondary care services. However, they have a 'Psychiatry of Old Age' service that provides, to older people with mental health problems, early assessment, treatment and care within their home environment when that is their choice, thus reducing the need for hospitalisation. The Trust provides services for Gateshead and North Tyneside (excluding Longbenton).

**Gateshead Health NHS Foundation Trust** provides specialist Older Person's Mental Health services in Gateshead, at a number of sites and via outreach. They have an admission and assessment unit for older people with organic mental illness and two units for continuing care and palliative care services. They also provide outreach services for people requiring assessment and younger people with dementia, a 7-day nurse-led day hospital providing assessment, treatment, rehabilitation and monitoring of people over the age of 65 with organic and functional mental health problems and a Community Psychiatric Nursing Service visiting clients in their own home, as well as an anti-dementia team and Community Resource Team for Older People (CROP).

### 9.2.2 Local Authorities

There are 12 local authorities in the NE which provide assessment and support to people who have dementia and their carers. The most information collated in one place relating to dementia specific services in each locality can be found in the document "Developing a comprehensive evidence based for the future commissioning of dementia services in the NE". Some examples of services provided by the Local Authorities include assessment and information for the person with dementia and their carer, day services (such as day centres), home care and support and access to individual budgets and direct payments. Local authorities also provide a series of universal services which can be accessed by people with dementia such as adult education, leisure and housing.

### 9.3 The Third Sector

The third sector has developed a series of services for people with dementia and their carers and others which are universal and can be accessed by all. The DH Social Care Team in the NE and the Voluntary Organisations Network North East (VONNE) have produced a directory of services which are provided specifically for people with dementia and their carers by the third sector<sup>71</sup>. This has been developed from information submitted via questionnaire. Ten different third sector providers are listed, illustrating the breadth of providers and number of services (in excess of 60 different services). The directory is not comprehensive, for example Clevearc, a large provider in Stockton, has not been included.

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<sup>71</sup>Smith,D. (2011) *Third Sector Providers Supporting People with Dementia and their Carers in North East England Directory of Services* . Department of Health:London

The organisations listed provide information, support, respite, dementia cafes, arts projects and nursing home care. Some of these services are only provided in such a specialised way by the third sector e.g. arts work by Equal Arts<sup>72</sup>. Based on this directory of services the fewest services specifically provided by the third sector are in South Tyneside and Middlesbrough; whilst the greatest number of services are provided in Northumberland and Newcastle, followed by North Tyneside and Gateshead. The greatest number of services are provided by the Alzheimer's Society.

It is also worth noting that a considerable number of services provided by third sector organisations accessed by people with dementia and their carers, are common to other groups. One example of this is carers' services. A NE directory of support that is available to carers of people with dementia<sup>73</sup> includes details of other third sector organisations (for example, Darlington Disability Forum, Carers Together and Stockton Carers Support Group), which are not mentioned in Third Sector Providers directory. Equally, services provided by organisations such as Age UK will be used by people who have dementia and their carers even though they are not specifically for those groups.

#### 9.4 Not for profit

'Not for profit' organisations include organisations such as registered social landlords (RSLs) sometimes called housing associations. There are a number of RSLs in the NE who have developed facilities in partnership with local authorities to support people with dementia. These include Home Housing working with Durham County Council. There are a number of schemes which are either operational or under development but details of these are not collated in one central place.

#### 9.5 Commercial and 'for profit' organisations

The latest collated information in relation to care home provision is from 2009<sup>74</sup>.

Across the NE, there were 418 care homes registered with the then Commission for Social Care Inspection (CSCI), now superseded by the Care Quality Commission (CQC), in the categories of:

- Older People and mental ill health and or dementia
- People with mental ill health
- People with dementia
- People with dementia requiring nursing care

Of the 418 care homes, 139 are registered to provide nursing care.

Most of this provision is likely to be 'for profit'. If providers including organisations like Greatham Hospital of God, Clevearc and Anchor Trust are removed, the overall number of care homes owned by 'for profit' organisations is about 400. Up to 75% of residents in non-specialist care homes for older people have dementia<sup>75</sup> and the prevalence rises

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<sup>72</sup> Equal Arts (2011) [Online] Available at : [www.equalarts.org.uk](http://www.equalarts.org.uk) (Accessed 14 June 2011)

<sup>73</sup>Smith, D (2011) *Directory of North East Dementia Support Groups And Useful Organisations-Supporting Recognised, valued and supported: next steps for the Carers Strategy* London: Department of Health

<sup>74</sup> Amos,S (2009) *Baseline Analysis of North East Care Homes Providing Care For Older People Experiencing Mental Ill Health and Dementia*. London: Department of Health

<sup>75</sup>Macdonald AJ, Carpenter GI, Box O et al (2002).Cited in Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London 59

to between 90% and 95% in homes for the elderly mentally infirm<sup>76</sup>. In addition it is important to consider the care home provision registered with the CQC to provide services for older people as well as the categories listed above.

Other care providers include independent domiciliary support workers, personal assistants and day care. There is no comprehensive picture of what services are provided for people with dementia and their carers by this sector. The most detailed information held in one document is “Developing a comprehensive evidence base for the future commissioning of dementia services in the NE”. Section 3.2 lists the services commissioned by local authorities from the commercial and for profit sectors.

The only way to ascertain the number and type of providers would be to use data from the Care Quality Commission (CQC) about the number of registered providers. This would however still exclude Personal Assistants who are not required to be registered with the CQC.

### 9.6 User Led Organisations

There is one user led organisation in the NE that has been specifically developed for people with dementia and meets the Department of Health definition<sup>77</sup>. Set up in 2011 in Stockton, the organisation is linked to Fusion Café (which is a dementia café) and the memory service. It provides the opportunity for people with dementia and carers either together or as groups to meet and discuss issues that are important to them.

There are a number of groups in the NE that have been set up by people with dementia and their carers. For example Chrysalis in Hexham is an art club for people with dementia. Technically they do not meet the Department of Health’s definition of user led organisations but are equally important in providing help and support. An exact picture of these broader groups is unknown.

### 9.7 Summary

There are a number of service providers throughout the NE both in the statutory, ‘for profit’, third sector and operating as RSLs who provide services specifically for people with dementia and their carers. This provides a richness of service provision across the dementia pathway. Some detailed information is available as to the type and spread of the services. It will be important to ascertain across particular segments who and where the providers are, to be able to support them in the delivery of the NDS and identify where the gaps are. This is particularly important for care homes, domiciliary care and RSL services.

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<sup>76</sup>Margallo-Lana M, Swann A, O’Brien J et al (2001). Cited in Department of Health (2009) Living well with dementia: a National Dementia Strategy. Department of Health:London p59

<sup>77</sup> “one where the people the organisation represents, or provides a service to, have a majority on the Management Committee or Board and where there is clear accountability to members and/or service users.” Morris (2006) as cited in Department of Health (2009) *User-led Organisations Development Fund*. London: Department of Health

## 10. The Priority Objectives - Position against key National Dementia Strategy Objectives (Diagnosis, general hospital care, care homes and reducing the use of antipsychotic medication)

In the NE

- A memory service specification has been developed for use across the NE.
- GPs are seen as key to diagnosis – stakeholders report both positive and negative experiences.
- Pathways are being developed in relation to early diagnosis and general hospital care.
- In-reach services are available to some general hospitals and care homes – the coverage and quality is unknown.
- National audits will help to inform the regional position on memory services and general hospital care.
- There are some good examples of training and development to support early diagnosis, good quality hospital care and care homes. But there doesn't appear to be a strategic approach.
- Contracts and the development of quality standards are being used to drive up quality in care homes.
- Some detailed regional work has been carried out on how to implement the care home objective.
- A strategic approach to reducing inappropriate prescribing of antipsychotic medication is being led by the Mental Health Clinical Innovations Team.
- Baseline data on the number of people with dementia who are being prescribed antipsychotic medication is not currently available but the Mental Health CIT will be carrying out this work in Summer 2011.

### 10.1 Introduction

This section outlines what is happening in the NE in relation to the four national priority areas: good quality early diagnosis, improved quality of care for people with dementia in general hospitals, living well with dementia in care homes and reducing the inappropriate use of antipsychotic medication.

This section gives an outline of the objectives (diagnosis, general hospital care, care homes and reducing the use of antipsychotic medication), the views of stakeholders, the position of the localities, based on the 12 baseline assessments, what localities are

planning to do (as extracted from ten plans), the regional response and examples of local responses and good practice followed by a summary.

## 10.2. Good quality early diagnosis for all - objective 2

The objective states, "All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area".

### 10.2.1 What people in the NE told us about what they want in relation to objective 2

Good early diagnosis is essential so that people can access a variety of services and support to remain independent<sup>78</sup> and have the opportunity to plan<sup>79</sup>.

The view of people with learning disabilities was that those who are at risk of developing dementia should be offered regular assessment of their skills and abilities. This will help to ensure that any changes in the future, due to dementia, are not mistaken for part of a learning disability. There was the view that assessment materials should be made available which clearly define the differences between having a learning disability and dementia<sup>80</sup>.

Views from people with dementia and their carers indicate experience of diagnosis in the NE is quite mixed and it was not always at an early stage<sup>81 82</sup>. For most people, the initial point of contact with health services is their GP, emphasising the key role GPs play in early diagnosis and as "gatekeepers"<sup>83</sup> to wider health services. Satisfaction with GPs varied<sup>84</sup>. The main issue raised during the largest consultation in the NE relating to early diagnosis and intervention was the need for GPs to have sufficient training and knowledge of the early signs of dementia and a positive attitude towards early diagnosis. Where appropriate they should be referring to secondary services once dementia was suspected<sup>85 86 87</sup>.

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<sup>78</sup> Skills for People (2008) National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government's Plan Newcastle: Skills for People

<sup>79</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society pg 12

<sup>80</sup> Skills for People (2008) National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government's Plan

<sup>81</sup> NHS North of Tyne (2010) *We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers* Newcastle:NHS North of Tyne 2010

<sup>82</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

<sup>83</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>84</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group[Online] Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

<sup>85</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group[Online] Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

<sup>86</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

It was felt specialist memory assessment and treatment services should be funded and developed<sup>88</sup>. These should be part of interagency pathways which support consistent and effective service provision<sup>89</sup>. These services should be available as a “one stop shop”, delivered in a non-threatening environment. There was considerable support for the provision of these services in primary care settings<sup>90</sup>.

A number of people felt that following diagnosis they had to wait a long time for any follow-up<sup>91</sup>. Some people took the view that people with dementia and their carers should be offered the opportunity to have a discussion immediately after a diagnosis<sup>92</sup>. There was general agreement on the need to ensure that all people with dementia and their carers were systematically informed of what will happen next and what services are available.

### 10.2.2 The position based on the baseline assessment

The baseline assessment established whether a locality has a multi-stakeholder pathway for care for people with dementia within their locality that is inclusive of primary care and delivers objective 2 of the NDS.

One locality assessed itself as having an internal pathway between the Community Mental Health Team, Health and Social Care which had been signed off. However this had not yet been fully implemented.

Eleven of the twelve localities assessed themselves as being in the process of developing a multi-stakeholder agreed pathway. They stated they had a dementia pathway of some kind; with most localities saying that they have a single point of contact for their service. Seven Localities reported that they have a memory clinic, which either has had or is seeking accreditation by the Royal College of Psychiatrists. Many of the localities say their proposed pathways are multi-stakeholder, including primary care. Some report that there is inconsistency (unspecified) in the way primary care approached dementia, but generally, GPs seem to be aware of the dementia pathways and do use them. One locality reported that it has two providers, which has caused differences in the kind of services on offer to people in those areas. One area of concern expressed by a number of localities is capacity; with increased diagnosis of dementia and more demand for services the current provision might not be able to cope.

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<sup>87</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011)

<sup>88</sup>Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>89</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>90</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>91</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011)

<sup>92</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011)

It is worth noting that in May 2011 the Department of Health is to carry out a “National Audit of Dementia Services – Establishment of Memory Services”. Primary Care Trust’s will be asked whether they provide memory services, how much they spend, the range of services and whether the memory services are accredited by the Royal College of Psychiatrists.

### 10.2.3 What the locality action plans tell us

The published action plans show that three localities specifically say they are going to develop a pathway to promote early diagnosis (South Tyneside, Middlesbrough and Redcar & Cleveland).

Many of the twelve localities are looking at developing, or improving their memory services. Two localities are developing “one stop shops” (Middlesbrough and Darlington). Newcastle, Middlesbrough and Stockton have a particular focus on supporting people with young onset dementia. Middlesbrough and Stockton also have a focus on people with a learning disability.

One indication of the successful delivery of this objective is to have a high rate of diagnosis. No national or NE targets have been set. In the NE 44% or 14,034 of the 31,840 predicted people who have dementia have a diagnosis<sup>93</sup>, which is above the national average for England. Therefore some localities are looking at using the quality and outcomes framework data to establish a baseline of how many people have a diagnosis. Newcastle has set a target for the number of people who are assessed by memory services.

Once an individual has a diagnosis, action planning for their future can begin. In the NE plans are aiming to lead to the development of a wide range of services. This will include the use of non-traditional services and ensuring that people have access to psychological therapies and physical activities (as in Sunderland).

### 10.2.4 Regional activities to deliver the objective 2

The Mental Health Clinical Innovation Team (CIT) leads the improvements in good quality early diagnosis of dementia across the whole NE. This group includes clinicians, mental health providers and the Strategic Health Authority Lead for Dementia. A memory service specification has been developed by the CIT for use across the region. A gap analysis is being carried out by one of the mental health trusts to see how far it meets the specification; this will lead to improved standards of service in the NE.

Considerable work has been carried out in Sunderland on delirium. The findings are being considered by both the NE Dementia Oversight Board and the Mental Health CIT and will be key to ensuring that an accurate and timely diagnosis is made.

### 10.2.5 Known local examples of practice or activities

#### **A memory protection specification**

A memory protection specification has been developed by NHS South of Tyne and Wear; the service will be delivered as an intermediate service between primary and secondary care. It is anticipated the contracting process for the new service will be completed by June 2011.

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<sup>93</sup> Alzheimer's Society and Tesco (2011) *Mapping the Dementia Gap*. [Online] Available at <http://alzheimers.org.uk/dementiamap> (Accessed 13 June 2011)

### **Accredited memory services**

The Royal College of Psychiatrists have an accreditation programme for memory services. As of May 2011 there was one accredited memory service for older people in Newcastle. There were three services within the Northumberland, Tyne and Wear Foundation Trust and one service managed by Northumbria Healthcare NHS Foundation Trust which were in the review stage or were preparing to go through the accreditation process<sup>94</sup>.

### **Work with people with learning disabilities**

The Middlesbrough and Redcar and Cleveland “South Tees Dementia Development Report”<sup>95</sup> has highlighted in its section on objective 2 the issues for people with Learning Disabilities. It outlines stakeholder’s views, current practice, best practice across the country and recommendations.

#### **10.2.6 Summary**

Localities are developing multi-stakeholder pathways but, inevitably, this is taking time, with different localities adopting various approaches to suit their local circumstances. Key to all of this is the early diagnosis of dementia and emphasis is put on the ability of GPs to be able to recognise when an individual may have dementia and be able to refer with confidence to appropriate services. High quality training for clinicians in primary care is essential. The training should include awareness of risks associated with people who have learning disabilities so that dementia in people with learning disabilities can be diagnosed early.

Basic dementia specific services, such as memory services, need to be provided throughout the NE in non-threatening environments and at the same time information and advice should be readily available in a variety of formats.

### **10.3 Improved quality of care in general hospitals - objective 8**

The objective states, “Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people’s mental health teams to work in general hospitals”.

#### **10.3.1 What people in the NE told us about what they want in relation to objective 8**

Stakeholders felt that hospital admission should be avoided if at all possible as they said hospital stays de-skill people<sup>96</sup>.

Many carers identified poor quality of care in general hospital care<sup>97</sup>. Training of medical and care staff was a strong, recurring theme. It was felt by many that the best quality care could only be delivered if those who cared for people with dementia and their carers were fully trained, not only in the medical aspects of dementia but in the

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<sup>94</sup>The Royal College of Psychiatrists (2011) *Accreditation* [Online] Available at: <http://www.rcpsych.ac.uk> (Accessed 15 June 2011)

<sup>95</sup> Baker, J (2010) *South Tees Learning Disability, Dementia Development Report Executive Summary* [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed 17 June 2011) p13-38

<sup>98-105</sup> Alzheimer’s Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer’s Society



social aspects as well<sup>98</sup>. Specialist training was particularly called for “regarding the management of behaviours that others on the ward perceive as challenging”<sup>99</sup>.

For general hospitals, specialist multi-disciplinary teams should be created who provide and supervise the care of people with dementia or their carers. This could be through the provision of specialist in-reach services<sup>100</sup>.

Special consideration needs to be given to the provision of ‘end of life’ care for people with dementia. Specialist combined care units that address both the mental and physical health needs of the person were recommended<sup>101</sup>.

Improved discharge planning was mentioned several times, and discharge planning should begin at admission<sup>102</sup>.

Carers also wanted to be supported “to challenge where [there are] concerns about care”<sup>103</sup>.

### 10.3.2 The position based on the baseline assessment

All localities reported that their local general hospitals had some kind of clearly identified individual or small team working in dementia care. Two localities reported that their general hospitals had care pathways for dementia patients; the other localities reported they either had no pathways or had pathways which were partial and underdeveloped.

All localities saw significant advantages in having specialist dementia care teams working in hospitals both to improve the quality of care for patients and materially assist hospitals in effectively managing their caseload. The general consensus seems to be that such teams need to be genuinely multidisciplinary, working with patients both before and after their hospital treatment. It was regarded as especially important for people with dementia that home care is put in place before discharge.

### 10.3.3 What the locality action plans tell us

The actions which are most reported are:

- The development or review of pathways for people with dementia (North Tyneside, Darlington, Middlesbrough and Newcastle)
- The development or improvement of liaison services (Darlington, Stockton and North Tyneside)
- Using contracts to improve standards (Stockton, South Tyneside, Gateshead and Redcar & Cleveland)
- Using audits to improve standards, for example the Royal College Psychiatrist’s audit (Darlington, Gateshead and North Tyneside) and audit of people with dementia in general hospitals with dementia (Newcastle)
- Ensuring timely discharge and audit delays (Newcastle).

There was, in some cases, a focus on flow of patients through the hospital. This included the need to review admissions (Stockton), reduce length of stay by ensuring people with dementia had access to intermediate care services (Redcar & Cleveland) and hospital staff had access to information e.g. "This is Me" (North Tyneside).

### 10.3.4 Regional activities to deliver objective 8

#### **Darlington Dementia Collaborative**

Improving hospital care and strengthening clinical leadership is a priority in the NE. Investment has been made in the Darlington Dementia Collaborative so that the results and learning from the project can be rolled out across the region using the Mental Health Clinical Innovation Team as the key leadership vehicle. The Darlington Dementia Collaborative is working to improve care for people with dementia admitted to an acute general hospital ward. They have used the NE Transformation System business improvement methodologies, which are based on the Toyota Lean principles.

The Collaborative has held a series of workshops which have generated new initiatives which have resulted in reduced average length of stay, introduced environmental changes to hospitals including signage and additional sitting areas for patients, as well as process changes including additional nurse led multidisciplinary ward meetings<sup>104</sup>. Workshops held in March 2011 focused on improving the experience of patients over 75 attending Darlington Memorial Hospital and reducing admissions via 999/111 services from care homes.

#### **NE Acute Care Pathway Group**

The NE Acute Care Pathway Group is developing acute care pathways for people with dementia. It is anticipated that these will be completed in Spring 2011.

#### **Royal College of Psychiatrists' National Audit of Dementia**

Fifteen (93%) of qualifying general hospitals in the NE carried out the Royal College of Psychiatrists' National Audit of Dementia. The audit considered whether a comprehensive assessment of need was carried out on people with dementia, what information is collected about people with dementia and policies to safeguard against longer admissions. The national results of this audit, published in December 2010<sup>105</sup>, were considered by the NE Stakeholder Group. Attempts are being made to collate the results from the NE general hospitals so that they can consider the strengths identified and define development areas for general hospitals in the NE.

### 10.3.5 Known local examples of practice or activities

#### **Dementia Care - Vocational Training Level Two**

To help address the issue of the increasing numbers of older people in hospital with depression, delirium or dementia James Cook University Hospital, Middlesbrough, have developed a level two vocational programme to support the care of older people with mental health problems and address their needs and management in an acute care setting<sup>106</sup>.

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<sup>104</sup> Darlington Dementia Collaborative (2010) *Transforming Services for Patients with Dementia*  
Darlington: Darlington Dementia Collaborative

<sup>105</sup> Royal College of Psychiatrists (2010) *National Audit of Dementia (Care in General Hospitals)* London:  
The Royal College of Psychiatrists

<sup>106</sup> South Tees NHS Foundation Trust (2010) *The James Cook University Hospital Quality Account 2009/10*. London :South Tees NHS Foundation Trust p25

## **Hospital Groups**

North Tees and Hartlepool NHS Foundation Trust have developed a hospital group to look at improving hospital care for people with dementia.

## **Liaison Team at Wansbeck**

Northumbria Healthcare NHS Trust has old age liaison services for Wansbeck General Hospital and the Community Hospitals. This consists of dedicated sessions by a Consultant Psychiatrist and three full time liaison nurses. The service aims to support staff working within a hospital environment with regards to mental health issues and also to educate and inform staff of good practice<sup>107</sup>.

## **“This is Me”**

“This is Me” is a leaflet which, when completed gives some basic details of the person with dementia and their preferences and can be given to staff in hospital when a person with dementia is admitted. It was developed initially by the partnership in Northumberland including the Alzheimer’s Society but has now been adopted nationally.

## **10.3.6 Summary**

NHS Acute Trusts have responded well to the comments from people with dementia and their carers. The Trusts have recognised that people with dementia do have particular needs. Policies, procedures and pathways are being amended and re-designed to reflect these needs.

Commissioners working with Trusts feel that one of the best ways for them to improve (and to continue to improve) their care to people with dementia is to introduce specialist multi-disciplinary in-reach dementia care teams. Throughout the region, Commissioners are planning how best to introduce these teams and to identify the optimum ways for those teams to work. Crucial to the success of those teams will be to ensure that they listen to the views of people with dementia and their carers. It is accepted that some will need support in having a voice, and develop their specialist teams accordingly.

## **10.4 Living well with dementia in care homes - objective 11**

The objective states, “leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams, and through inspection regimes”.

### **10.4.1 What people in NE told us about what they want in relation to objective 11**

There were mixed experiences of service quality in care homes reported throughout the findings from the consultation events<sup>108</sup>. Some participants had limited contact with care homes, for example through use for respite care. However, they expressed the view that, “care in care homes was reasonable, although somewhat ‘old style’ and not person-centred”<sup>109</sup>.

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<sup>107</sup> North Tyneside Council (2010) *Joint Action Plan for the Delivery of the National Dementia Strategy Update* North Tyneside: North Tyneside Council p 14

<sup>108</sup> NHS North of Tyne (2010) *We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers* Newcastle: NHS North of Tyne

<sup>109</sup> Alzheimer’s Society (2010) *National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.* [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed: 17 June 2011)

Overall multiple issues need to be addressed. It was felt care homes should be monitored and checked using mystery shoppers and carers as part of routine inspections to assess quality<sup>110</sup>. In addition regulation should be improved with more inspections and unannounced visits<sup>111</sup>. Views expressed included the need for better recruitment and retention of staff<sup>112</sup>. Staff should have minimum qualifications, knowledge and skills<sup>113</sup>. It was suggested that staff could be supported by care home liaison or in-reach services<sup>114</sup> including specialist mental health staff and that residents should have access to service such as dentists, chiropody and opticians<sup>115</sup>.

The physical environment was felt to be important but it was emphasised that quality of care in the homes needed to be measured by the level of care provided, and less by the appearance of the homes<sup>116</sup>. Stakeholders said that they would like small care homes designed by people who have had experience and understanding of dementia and the needs of people with dementia<sup>117</sup>.

When a person needed to have a care home placement it was felt to be essential that they should have the choice of home<sup>118</sup>. Whilst choosing, the person with dementia and their carers need appropriate information including ratings and an understanding of the criteria being used<sup>119</sup>.

Purposeful activities that mentally stimulate residents were also considered critical in the care home environment. This included recreating past environments<sup>120</sup>, rather than relying on general entertainment and group activities such as television<sup>121</sup>. The

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<sup>110</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society pg 11

<sup>111</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society pg 7 NHS North of Tyne (2010) *We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers* Newcastle:NHS North of Tyne pg 37

<sup>112</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society pg 7

<sup>113</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>114</sup> Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society pg 4

<sup>115</sup> Alzheimer's Society (2010) *National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group*. [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed: 17 June 2011) pg 11

<sup>116</sup> NHS North of Tyne (2010) *We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers* Newcastle:NHS North of Tyne

<sup>117</sup> Skills for People (2008) *National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government's Plan Newcastle: Skills for People*

<sup>118</sup> Skills for People (2008) *National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government's Plan Newcastle: Skills for People* pg 22

<sup>119</sup> Alzheimer's Society (2010) *National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group*. [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) (Accessed: 17 June 2011) pg 11

<sup>120</sup> Skills for People (2008) *National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government's Plan Newcastle: Skills for People and Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East* London: Alzheimer's Society

<sup>121</sup> NHS North of Tyne (2010) *We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers* Newcastle:NHS North of Tyne pg 46 Alzheimer's Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer's Society: pg 7

implemented philosophy of the home was important. One participant stated a good care home should be, *“where residents are involved in the day-to-day running and can go and make themselves something to eat or drink when they like”*<sup>122</sup>.

While living in a care home residents with dementia need to have regular assessments and reviews to take account of changing needs.

#### **10.4.2 The position based on the baseline assessment**

All twelve localities report that care quality standards and quality improvement are included in their contracts with care homes. Eight stated that they did not specify in their contract with homes for people with dementia the need for a senior staff member to take on quality improvement, four stated they included this in some, or all relevant contracts. Where they didn't have these contract arrangements they stated that they would address them during formal contract reviews or when contracts come up for renewal.

Localities assessed whether the care homes in their locality had access to a comprehensive specialist mental health in-reach service for older people. All localities stated they have some access to specialist mental health services for residents in care homes though in some localities the provision is 'limited' and in others 'comprehensive'. One locality stipulates in its quality standards that care homes need to provide evidence that residents have access to specialist mental health services. Others reported that they are reviewing this provision to see how it can be enhanced.

#### **10.4.3 What the locality action plans tell us**

One primary improvement method, within the action plans, was to provide, or to review the provision of, specialist mental health in-reach services and use them to train and support care home staff<sup>123</sup>. Not all the in-reach actions related solely to mental health, for example South of Tyne localities wanted to ensure all specialist support was reviewed. They also wanted to make sure appropriate support was provided to the residents and care home staff through e.g. dentistry, opticians, pharmacy, chiropody.

The development of contracts was seen as a way of driving up standards by two localities<sup>124</sup>. North Tyneside were proposing to carry out quality monitoring visits in relation to deprivation of liberty and to use the contract to specify that a senior member of staff would take on the lead for dementia quality improvement.

Leadership development in care homes was also seen as key in Gateshead and South Tyneside's action plans.

The South of Tyne localities wanted to ensure care home staffing requirements were part of the local workforce plan, while Darlington were keen to ensure care home staff received training on the GOLD standards end of life framework. The South of Tyne localities were also looking to review local capacity and demand for care homes, and work with regulators to identify developments. They were also looking to use national best practice in commissioning care home provision.

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<sup>122</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011) pg 11

<sup>123</sup> Stockton, Redcar & Cleveland and Darlington and Middlesbrough

<sup>124</sup> Redcar & Cleveland and North Tyneside

Sunderland and Gateshead are planning to take action to monitor and manage the prescribing of antipsychotic drugs.

#### 10.4.4 Regional activities to deliver the objective 11

##### Commissioning Standards

There has been a focus on care home improvements in the NE since the publication of the NDS. Strategic leadership for this objective sits with the Association of Directors of Adult Social Services (ADASS). The Regional Improvement and Efficiency Programme (RIEP) have developed commissioning standards which are inclusive and in many cases specific to people with dementia. ADASS are still considering how best to implement these standards.

##### A care home event and report

In March 2009 a care home event was held for stakeholders to identify how objective 11 could be implemented in practice and a summary report was produced, The examples of good practice identified during the event were:<sup>125</sup>

- PEARL – Four Seasons independently judged accreditation system for their care homes, which provide person centred care for people with dementia. This has resulted in increased training to staff and the use of Dementia Care Mapping.
- Care home liaison services in Stockton, Hartlepool, Darlington, Middlesbrough and Redcar & Cleveland who “in-reach” into care homes in these areas.
- Connect for Care and Life Story work – A project using multi-media to collect a person’s life story.

##### NE My Home Life Network

My Home Life aims to celebrate existing best practice in care homes and promote care homes as a positive option for older people. The NE My Home Life Network have held events and developed and tested practice such as the INTERACT<sup>126</sup> workbook. With funding from the DH North East Social Care Team, Northumbria University worked with the Network to develop a training guide and workbook on maintaining and developing social interaction in care homes<sup>127</sup>. Together the guide and workbook provide guidance to enhance social interaction in care homes and raise awareness of innovative ways of promoting social engagement. The activities are designed to encourage reflection on practice and to foster interaction that underpins positive social relationships. The development of this training guide and workbook followed on from the examination of two innovative technologies (Connect for Care<sup>128</sup> and Paro<sup>129</sup>) on social interaction in care homes.

The NE Network is currently operating as a virtual network and circulates documents from the national My Home Life programme including practice development

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<sup>125</sup> Department of Health (2009) Living Well With Dementia Views From the North East. North East Views On How To Implement Objective 11 of the National Dementia Strategy.[Online] Available at :[www.dhcarenetworks.org.uk](http://www.dhcarenetworks.org.uk) ( Accessed:17 June 2011)

<sup>126</sup> Cook,G et al (2009) Maintaining and developing social interaction in care homes: a workbook for care home, health and social care staff Northumbria University: Northumbria University

<sup>127</sup> Public Health Intelligence North East (2011) *Social Care North East* [Online] Available at : <http://www.phine.org.uk/>

<sup>128</sup> Connect for Care (2011) *Connect for Care* [Online] Available at: <http://www.connectfor care.co.uk> (Accessed:15 June 2011)

<sup>129</sup> PARO (2011) *Paro Therapeutic Robot* [Online] Available at: <http://www.parorobots.com> (Accessed:15 June 2011)

opportunities and invitations to participate in research. There are 115 NE care homes affiliated in the network.

The current focus is on enhancing the sensory environment in the care home to promote quality of life. This builds on the INTERACT work and addresses good communication and leads to positive impacts on quality of life.

The My Home Life team nationally provides a range of resources, events, practice development initiatives and other activities<sup>130 131</sup>.

### **Baseline Analysis Of North East Care Homes Providing Care For Older People Experiencing Mental Ill Health and Dementia March 2009**

This report<sup>132</sup> provides a baseline analysis of care home provision in the NE based on inspections carried out by the Commission for Social Care Inspection (CSCI). The research used the star-rating framework used by the Commission at that time. The report covers the 418 care homes which were then registered to provide accommodation and care for older people in the 4 CSCI categories (ie people with mental ill health and/or dementia, people with mental ill health, people with dementia and people with dementia requiring nursing care).

The report shows that care home provision tends to follow the population figures for people with dementia, with Durham and Northumberland having the largest number of care homes. The report also shows that higher star-ratings awarded by CSCI are disproportionately achieved by small privately owned care homes.

#### **10.4.5 Known local examples of practice or activities**

##### **Sunderland Quality Standards**

The aim of the Sunderland Quality Standards is to create a reliable way to assess the quality of independent care homes for people aged 65 and over. They identify the homes that operate high standards, identify those whose standards of care require further development, and inform current and future residents and their carers of the quality of care provided in each home, measured against the standards.

The Sunderland Quality Standards include 86 additional standards to those of the Care Quality Commission Standards. They relate to social and personal care but they do not cover the quality of nursing care.

##### **Darlington contract compliance of care homes**

Darlington Borough Council uses older people to assess service quality in care homes, providing them with appropriate support and training.

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<sup>130</sup> My Home Life (2011) *My Home Life* [Online] Available at: <http://myhomelifemovement.org> (Accessed:16 June 2011)

<sup>131</sup> NE Network contact: Glenda Cook [glenda.cook@northumbria.ac.uk](mailto:glenda.cook@northumbria.ac.uk)

<sup>132</sup> Amos,S (2009) *Baseline Analysis Of North East Care Homes Providing Care For Older People Experiencing Mental Ill Health and Dementia* London:Department of Health

## 10.4.6 Summary

Overwhelmingly, people with dementia and their carers want to be offered the choice of a wide range of high quality care homes, with well trained staff, focusing on the best outcomes for each individual resident. A lot of work is going on in the NE to bring this about. Some of the work is regional (for example, the new enhanced quality standards for regulated and non-regulated care) and some is at the level of individual care homes (care home liaison services with local authorities). All of this work is helping care homes to focus their services around outcomes that really matter to people.

As with previous objectives, training is regarded as the key to success; staff in care homes need to be aware of the needs of people with dementia, which includes the necessity of providing events and activities that stimulate them. Care home staff also need support through specialist mental health in-reach services. These are available in some NE care homes but not all.

There is some evidence to suggest that smaller, privately run care homes provide a better service and we may need to research what would be the best model for care home provision.

## 10.5 Reduced use of antipsychotic medication

The reduction of inappropriate use of antipsychotic medication was not originally an objective within the NDS. However references were made to reducing inappropriate prescribing in the care homes section of the NDS<sup>133</sup> with one care home manager suggesting that 50% of people with dementia in care homes were in receipt of antipsychotic medication<sup>134</sup>.

The NDS highlighted as a concern the use of antipsychotic medication in care homes for the management of behavioural and psychological symptoms in those residents with dementia. The NDS identified serious risks from antipsychotic medication to people with dementia, most particularly an increased risk of stroke and early death. The NDS stated that “there is accumulating evidence that in care homes they [antipsychotic medicine regimes] are initiated too freely, they are not reviewed appropriately following initiation, and they are not withdrawn as quickly as they could be. However it is also the case that behavioural problems in people with dementia can be dangerous and disruptive, and in some cases medication is the least worst option”<sup>135</sup>. Improving the quality of care in care homes requires these issues to be addressed through:

- The formulation and deployment of non-pharmacological management strategies for behavioural disorder in dementia, so avoiding the initiation of antipsychotic medication<sup>136</sup>
- Specialist input into decision making concerning the initiation, review and cessation of antipsychotic medication for people with dementia<sup>137</sup>

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<sup>133</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London pg 57

<sup>134</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London pg 45

<sup>135</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London pg 59

<sup>136</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London pg 60

<sup>137</sup> Department of Health (2009) *Living well with dementia: a National Dementia Strategy*. Department of Health:London pg 60



- Rapid specialist review of all those with dementia initiated on antipsychotic medication<sup>138</sup>

The NDS call for action was followed by the publication of “Time for Action”<sup>139</sup> in November 2009; this document in effect made the need to reduce the over prescription of antipsychotic drugs into the 18<sup>th</sup> objective of the NDS.

### **Time for Action**

This report identifies limited benefits and significant harms in treating behavioural symptoms of people with dementia with antipsychotics. It estimates that there are 180,000 people with dementia treated with antipsychotic medication in England per year. Of these, up to 36,000 may derive some benefit from treatment but as a result of antipsychotic treatment, an additional 1,800 may die and 1,620 may suffer a cerebrovascular adverse event (around half of which may be severe) per year. The report suggests that if support was available to provide alternative methods of managing behavioural problems, prescribing of antipsychotics could be reduced by two-thirds in people with dementia.

The report includes a list of recommendations for prioritisation, improvements in leadership, audit, training of staff and improvements in the services offered to people with dementia. It is recommended that the NICE/SCIE dementia guideline for the management of non-cognitive symptoms and ‘behaviour that challenges’ are followed. This would reduce situations where it would be appropriate to prescribe.

All of these recommendations have been accepted by the Government and, if adopted, will facilitate a reduction in the unnecessary prescribing of antipsychotic drugs to people with dementia.

### **10.5.1 What people in NE told us about what they want in relation to the reduction of antipsychotic medication**

There is limited information about what people with dementia and carers have told us about what they want to see happen in relation to reducing the inappropriate prescribing of antipsychotic drugs, largely due to it not being a specific objective. However, as the majority of people with dementia on antipsychotic drugs live in care homes it is possible to adduce some views from other responses including:

- Need for staff to have the right knowledge and skills<sup>140</sup>.
- Homes should feel less institutional.
- Greater stimulation should be provided through meaningful activities indoors and in the garden<sup>141</sup>.

<sup>138</sup>Department of Health (2009) Living well with dementia: a National Dementia Strategy. Department of Health:London pg 60

<sup>139</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>140</sup> Alzheimer’s Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer’s Society pg 11

<sup>141</sup> Alzheimer’s Society & NE CSIP (2008) *Listening to You National Dementia Strategy North East* London: Alzheimer’s Society pg

- More specialist care home liaison services where individual assessment is provided and care home staff are trained.

### 10.5.2 The position based on the baseline assessment

As the requirement to reduce the inappropriate use of antipsychotic medication was not an objective in the NDS no specific questions were asked as part of the baseline assessment. There is, therefore, no reference to antipsychotic drugs in the “Readiness to Implement” summary.

### 10.5.3 What the locality action plans tell us

Of the ten published action plans, six have specific actions in relation to reducing the inappropriate prescribing of antipsychotic medication. Of these, two plans outlined the need to monitor the use of antipsychotic medication in specific settings e.g. general hospitals<sup>142</sup> and care homes<sup>143</sup> and one is to carry out an audit of antipsychotic medication<sup>144</sup>. The other three have further enabling actions including:

- Conduct an audit of antipsychotic medication.
- Implement the recommendations arising from any audit of antipsychotic medication<sup>145</sup>.

### 10.5.4 Regional activities to deliver a reduction in the use of antipsychotic medication

The reduction in the prescribing of antipsychotic drugs has become a priority in the NE following the publication of the priority objectives<sup>146</sup> in September 2010. With support from the DHNE Social Care Team and the Strategic Health Authority Lead, the Mental Health CIT took a lead and held a Fast Focus stakeholder event in March 2011 to develop a strategic approach for the NE. The event considered successful projects in the region and across the country, which had led to a reduction the prescription of this medication<sup>147</sup>. A considerable number of proposed activities have come from the event and they are currently being developed into an action plan.

### 10.5.5 Known examples of practice or activities

“Reducing the use of antipsychotics for people with dementia – Evidence of North East Practice”<sup>148</sup> summarises activities in the NE to reduce prescribing of antipsychotic medication. These include:

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<sup>142</sup>South Tyneside Council & NHS (2009) Living well with Dementia in South Tyneside A Joint Commissioning Framework 2009-2012 [Online] Available at : [www.phine.org.uk/](http://www.phine.org.uk/) (Accessed: 28 June 2011)pg 18

<sup>143</sup> National Dementia Baseline Assessment rating for Hartlepool [Online] Available at : [www.phine.org.uk/](http://www.phine.org.uk/) (Accessed: 28 June 2011 pg15

<sup>144</sup> Newcastle

<sup>145</sup>North Tyneside, Gateshead and Sunderland.

<sup>146</sup> Quality outcomes for people with dementia: building on the work of the National Dementia Strategy

<sup>147</sup>Smith,D (2011) *Reducing the use of antipsychotics for people with dementia - Evidence of NE Practice*. [Online] Available at:[www.phine.org.uk](http://www.phine.org.uk/) (Accessed: 16 June 2011)

<sup>148</sup>Smith,D (2011) *Reducing the use of antipsychotics for people with dementia - Evidence of NE Practice*. [Online] Available at:[www.phine.org.uk](http://www.phine.org.uk/) (Accessed: 16 June 2011)

### **Stockton care home project**

The aim of the project is to deliver a dementia awareness training programme (Awareness & Promotion) to staff in a care home in the Stockton locality. This will focus on enhancing both skills and knowledge in challenging areas of dementia care such as using a cognitive screening questionnaire and discussing the possibility of dementia as a diagnosis. It will also support the use of alternative, person centred approaches and therapies other than antipsychotic medication.

### **The Station Medical Group nursing home project**

This was a primary care initiative led by the Station Medical Group in Blyth. The work related to a nursing home registered for elderly mentally infirm residents many of who fitted the criteria for continuing care. Through medication reviews with the support of the community pharmacist and secondary care consultant (psycho-geriatrician) the prescribing of tranquillisers and antipsychotics was reduced. At the time of review of their 17 patients, 16 were not taking any sedative or antipsychotic medication; only one person was taking an antipsychotic that was deemed to be appropriate.

### **Specialist care development practitioner in Easington and Hartlepool**

This is a two year funded project from the NE Strategic Health Authority for two specialist practitioner posts. The practitioners are working with eleven nursing homes across Hartlepool and Easington localities which provide care for people who have mental health problems, primarily dementia. The practitioner has an educative role and does not carry a caseload, or take direct referrals. The overall aim is to increase use of non-pharmacological interventions in managing challenging behaviour in people with dementia, therefore decreasing the use of antipsychotic medications.

## **10.6 Summary**

The use and over use of antipsychotic medication can have serious adverse effects on the person with dementia as well as being distressing to their carers. Reducing the inappropriate use of antipsychotic drugs is now a major concern and has, in effect, been adopted as an objective of the NDS.

Some localities in the NE either have plans to review the use of antipsychotics or are taking steps to better understand the issue to be able to identify how best to approach this subject locally.

At the regional level there is a lack of basic prescribing data about antipsychotic drugs and people with dementia, making it difficult to assess the full scale of the problem. The mental health CIT are to commission activity which will produce information on prescribing. There is a need to build on the work of the Fast Focus event, reducing the inappropriate prescribing of antipsychotics. At the same time continued collation of results of various local initiatives should take place to provide an evidence base on what works.

## 11. The other objectives which make up the 7 NE regional priority objectives

This section outlines what is happening in the NE in relation to the three additional objectives that make up the seven NE priorities. They relate to housing and telecare, community and personal support and end of life care.

- Personalisation is seen as key to the implementation of good community and personal support.
- Provision of appropriate respite and domiciliary care is important to people with dementia and their carers.
- Community provision is seen as being sufficient by eleven localities.
- There are a number of Registered Social Landlords providing housing and support but a full regional picture is not known.
- Housing and housing support commissioning is based on evidence but localities don't have a way of keeping up to date with current research.
- Good end of life care is considered to be very important but having the conversations with someone with dementia is seen as being difficult.
- People with dementia are included in end of life initiatives in the region.
- People with dementia and their carers want more information on personal budgets, telecare and end of life care.
- Training in relation to personalisation, telecare and end of life care needs to be delivered well and consistently across the region.

### 11.1 Community and Personal Support - objective 6

The objective states:

“Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services”.

### 11.1.1 What people in the NE told us about what they want in relation to objective 6

People with dementia and their carers need good support to help them to stay in their own home and retain their independence<sup>149</sup>. They should be able to access high quality healthcare and support regardless of where they live<sup>150</sup>. Examples of good practice should be shared amongst service providers to stimulate all professionals and carers to provide the best possible care and support available<sup>151</sup>.

Presently care packages are seen as having little flexibility and, depending on the qualities and personality of the staff member, some services provided were better than others<sup>152</sup>.

Key to the provision of good quality care are good respite care services which are provided in a range of settings (including in the persons own home) both during daytime and overnight. Respite care needs to be provided regularly and be flexible to enable changing needs to be met<sup>153</sup>. Some consulted stakeholders stated that often people are told they are entitled to respite care when they actually found they weren't, due either to incorrect information being provided or services being unavailable<sup>154</sup>.

Specialist home care services should be delivered by staff trained to work with people with dementia, providing appropriate lengths of visit based on need<sup>155</sup>.

Alternative day services should be available which enable people with dementia to stay socially included within their communities and maintain engagement in their roles and interests<sup>156</sup>.

Direct payments through personal budgets were not used widely by the participants in the consultation<sup>157</sup>. Stakeholders mentioned that people need better information and support regarding direct payments and that they need to be used more often and more flexibly. Take up could be improved by more promotion of personal budgets and direct payments and consistent review and support arrangements for those in receipt of them<sup>158</sup>. To assist with this people need to be able to access commissioned

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<sup>149</sup> National Dementia Strategy. A report of consultation with people with learning disabilities in the North East What we think of the Government's Plan August 2008 pg 23

<sup>150</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 48

<sup>151</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 48

<sup>152</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 25

<sup>153</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 6

<sup>154</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 48

<sup>155</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 6

<sup>156</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society 2008 pg 6

<sup>157</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

<sup>158</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

independent person centred planning teams from the voluntary sector<sup>159</sup>. Carers highlighted the difficulty of recruiting suitable ‘personal assistant’ staff and not all carers welcomed the extra responsibility that comes with managing a direct payment<sup>160</sup>.

Part of retaining people in their own homes was to promote the use of assistive technology. More detail about the views on this topic can be seen in section 11.2.1.

### 11.1.2 Position based on the baseline assessment

There were three indicators linked to this objective against which the localities assessed themselves.

**Indicator 1** assessed whether localities provided a good comprehensive range of services to support people with dementia living at home and their carers and if they are “adequate to meet local needs”. Eleven localities assessed themselves as having a range of services to support people with dementia living at home and their carers as adequate or comprehensive in terms of meeting local needs. Two localities highlighted that they use Telecare where appropriate.

There was general agreement on the characteristics of a good home care service. Such a service had to be flexible, for example a home care worker might not be able to keep to a strict schedule of visits as they will need to respond to a client’s needs at the time of the visit. It was acknowledged that the “traditional home care model” might not be appropriate; people with Dementia can become distressed if new people turn up without warning and home care teams would also have to be multi-disciplinary. Finally, the care provided would have to be long term, possibly lifelong.

**Indicator 2** assessed how far localities had reached in implementing ‘Putting People First’ personalisation changes which are fully inclusive of people with dementia. Eleven localities stated they have a clear plan and have either begun or have implemented ‘Putting People First’ changes which are fully inclusive of people with dementia. Some of the delays in implementing this aspect of policy related to working out issues such as legal capacity.

**Indicator 3** identified that all localities had an evidence base for effective specialist commissioners to use to commission services to support people with dementia at home. Some localities suggest that their evidence base is not comprehensive and that more work is needed. However, localities reported that commissioners were clearly using the evidence they do have to review existing services and commission new ones. Most localities reported that a needs analysis for dementia had been carried out and the results were included in their local Joint Strategic Needs Assessment (JSNA).

### 11.1.3 What the locality action plans tell us

The development and use of individual budgets to support people with dementia is the most frequently mentioned action in the locality plans that will contribute to the delivery of the community and personal support objective. The implementation detail in the plans relates to skilling up staff, increasing capacity, developing support and brokerage.

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<sup>159</sup> Skills for People (2008) National Dementia Strategy. Report of consultation with people with learning disabilities in the North East What we think about the Government’s Plan Newcastle: Skills for People pg 32

<sup>160</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 7

Service development and retendering so that services can be provided to people with dementia, are key actions (Darlington) along with the need for sufficient day services (South Tyneside and Sunderland). Middlesbrough was keen for support services to be dementia friendly by providing input from a liaison team to service providers. Commissioning using evidence was seen as very important.

Staff training is a priority in many of the action plans. Newcastle emphasised that they wanted to ensure people are able to maintain their skills. Sunderland and Gateshead felt that they needed to ensure their safeguarding procedures were inclusive of people with dementia. Stockton has a particular action relating to a project which supports people with dementia to remain in their own homes. This is by training home care staff and using the research from Stirling University on the use of design and colour to maintain people in their own homes (see section 11.1.5).

#### **11.1.4 Regional activities to deliver objective 6**

##### **The Objective 6 Project**

The NE Joint Improvement Partnership (part of the RIEP) and DH Social Care jointly funded a community and personal support project. There are three legacy products:

- A “Comprehensive Evidence Base for Future Commissioning of Dementia Services in the NE”
- “Supporting the Implementation of Personalisation Changes in the North East that are fully Inclusive of People with Dementia and Their Carers”
- An online training resource about personalisation and dementia.

These resources are available to all interested stakeholders.

Three further projects were also commissioned as part of this work. Two projects are covered in the next section (11.1.5) and the third in section 3.2 (pg 21).

#### **11.1.5 Known examples of practice or activities**

##### **Smarter Homes for the Future**

This is a joint project between Stockton Borough Council, Brookleigh Caring Services (an independent home care provider), North Tees & Hartlepool NHS Foundation Trust Speech and Language Therapy Department and the Mental Health and Learning Disabilities Trust Tees, Esk & Wear Valleys NHS Foundation Trust. The project aims to improve the outcomes of people with dementia and their carers. This will be done by implementing the University of Stirling’s research into safe and well-designed living spaces in people’s own homes in order to help people with dementia and their carers in their day-to-day lives. The research will incorporate the key elements of contrast, colour and clarity in the person’s home environment and the use of assistive innovative “smart” technology, and other communication aids where necessary. This will be implemented through

- 1) Training provided to staff which will then be cascaded to people with dementia and their carers. This will be delivered using the University of Stirling’s training package in re-designing the living environment. Training will also be given on assistive technology (by the Community Safety Team) and communication aids (by Speech and Language Therapy). Support will continue to be provided from the training provider throughout the pilot.
- 2) Changes to the physical home environment (for example, colour contrasting walls, soft furnishings and everyday home equipment, and signage).

3) The provision of assistive technology equipment to improve health and safety, including medication compliance. Stockton Borough Council's Community Safety Control Centre will provide monitoring support for people using this equipment.

4) The provision of communication aids (talking mats) where necessary/appropriate<sup>161</sup>.

### **Lifestyle monitoring to support family carers of people with dementia**

This is a joint project being led by Middlesbrough Council with Gateshead Council, Carr Gomm Middlesbrough, Alzheimer Support Gateshead, Dementia Care Partnership, and Tynetec. The project will utilise lifestyle-monitoring technology to support people with dementia who live on their own and are supported by family carers. The technology will alert family members to occurrences outside the individual's normal lifestyle allowing them to intervene earlier. The technology will also allow family members to view online and understand the lifestyle of the person with dementia<sup>162</sup>.

### **Redcar & Cleveland Borough Council**

The RCBC Care at Home Service is a specialist service for people with dementia in Redcar and Cleveland<sup>163</sup>.

### **Dementia is everybody's business**

The "Dementia is Everybody's Business" project is a partnership project between the Dementia Care Partnership<sup>164</sup>, Newcastle Carers Centre and Newcastle Adult Services. The project is testing and piloting pathways, putting people with dementia and their carers in the lead, to maximise efficiencies without compromising quality and to achieve positive outcomes<sup>165</sup>. Funding comes from the RIEP JIP provider development fund. This project started in 2009 and will end in 2011.

#### **11.1.6 Summary**

People with dementia and their carers raised access to respite as an issue. They acknowledged that personalisation, including the use of personal budgets, could be useful to them, but they requested more information and support to ensure that it can be made to work for them. It is critical that staff employed by statutory agencies listen and respond appropriately to this request as many localities are planning to use personal budgets as a key element in the implementation of the community and personal support objective.

Both the stakeholder consultation events and the locality baseline assessments acknowledged that domiciliary support and provision had to have certain service elements to enable the service to deliver suitable outcomes to people with dementia.

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<sup>161</sup> Contact: Peter Smith (Personalisation Manager) 01642 528446 [p.smith@stockton.gov.uk](mailto:p.smith@stockton.gov.uk)

For more details see <http://www.northeastiep.gov.uk/adult/DementiaFundProjects.htm>

<sup>162</sup> Project Lead Contact: Polly Wright, Service Development Officer Middlesbrough Council Tel: 01642 728823 e-mail: [polly\\_wright@middlesbrough.gov.uk](mailto:polly_wright@middlesbrough.gov.uk)

For more details see <http://www.northeastiep.gov.uk/adult/DementiaFundProjects.htm>

<sup>163</sup> Redcar and Cleveland Borough Council (2011) *Care at Home Specialist Dementia Service*. [Online] Available at: [www.redcar-cleveland.gov.uk](http://www.redcar-cleveland.gov.uk) (Accessed: 16 June 2011)

<sup>164</sup> Dementia Care Partnership (2011) *Dementia Care Partnership*. [Online] Available at: [www.dementiacare.org.uk](http://www.dementiacare.org.uk) (Accessed: 16 June 2011)

<sup>165</sup> North East Improvement and Efficiency Partnership (2011) *Provider Development - Innovation Fund* [Online] Available at: [www.northeastiep.gov.uk](http://www.northeastiep.gov.uk) (Accessed: 16 June 2011)



Of the twelve localities, eleven felt that they had “adequate” community services to support people with dementia and their carers and that they had personalisation plans, which were inclusive of people with dementia. The suitability of services needs to be evaluated from a user and carers perspective now that personalisation has been more fully implemented.

A NE wide project has developed a training resource on personalisation and dementia, a commissioning resource and series of locality based projects. The recommendations from the objective 6 project reports (11.1.4) need to be considered and implemented where appropriate.

## **11.2 Housing and telecare: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers – objective 10**

The objective states, “The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services”.

### **11.2.1 What people in the NE told us about what they want in relation to objective 10**

People with dementia and their carers expressed a desire to continue to live in their own homes and neighbourhoods for as long as possible<sup>166</sup>. Assistive technologies were welcomed to help people to stay independent<sup>167</sup> and, when combined with specialist care, to stay in their own homes longer<sup>168</sup>. The provision of this equipment was seen by some as part of “good care at home”<sup>169</sup>. However not many participants in the Alzheimer’s Society led consultation were aware of what assistive technology was<sup>170</sup>. A few people were aware of low-level support devices and once assistive technology was explained they knew where they would obtain it. To get maximum benefit, individually planned care packages were regarded as essential as not all telecare kit is appropriate for everyone<sup>171</sup>. It was also felt important that personal support aids should not replace personal contact<sup>172</sup>. Some participants mentioned

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<sup>166</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34 and Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011) pg 10

<sup>167</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34 and 35

<sup>168</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 7

<sup>169</sup> National Dementia Strategy. A report of consultation with people with learning disabilities in the North East What we think of the Government’s Plan August 2008 pg 25

<sup>170</sup> Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011) pg 10

<sup>171</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34

<sup>172</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34

other “low tech” solutions that can help to retain people in their own homes, for example walk in showers and handrails<sup>173</sup>.

Where a person with dementia had to move to alternative accommodation or supported housing schemes it is critical that considerable planning is undertaken to ensure their future home is suitable for them<sup>174</sup>. “Extra support” and independent living bungalows were considered to be excellent ideas to help maintain independence<sup>175</sup>. Some preferred smaller scale assisted living within the community<sup>176</sup>, whilst some felt a housing scheme should include a warden because they felt they could provide useful back up<sup>177</sup>.

### 11.2.2 Position based on baseline assessment

Three indicators were developed for localities to assess progress in relation to housing and telecare<sup>178</sup>.

Indicator 1 assessed whether localities currently considered all of the following for people with dementia and their carers:

- i. Housing support
- ii. Housing related services
- iii. Housing options
- iv. Assistive technology/Telecare

One out of 12 localities stated they consider people with dementia and their carers when developing all four services. Eleven stated that they considered at least one but not all of them. In terms of the detail, the area for greatest development would appear to be sheltered housing which has dedicated independent supported living tenancies for older people with dementia (and people with young onset dementia).

#### (i) Housing Support

All localities stated they provided housing support to vulnerable people, that is, the housing design allows people with dementia to live as independently as possible and the full range of this type of support is open to people with dementia. A couple of localities report that they are completely reviewing the housing needs and provision for people with mental health problems, including dementia.

#### (ii) Housing Related Services

All localities report that they offer a full range of housing support (for example handyman services, community alarm services) to all, including people with dementia. In addition, localities offer specific dementia related services, for example housing

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<sup>173</sup> Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:www.phine.org.uk (Accessed:17 June 2011) pg 10

<sup>174</sup>Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>175</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34

<sup>176</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34

<sup>177</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 34

<sup>178</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pgs 26-31

advisers to help people with dementia to retain their tenancies, or access to a community psychiatric nurse or other health care professional.

### (iii) Housing Options

Most localities report that they have a range of housing options from sheltered housing to dedicated independent supported living tenancies for older people with dementia (and people with young onset dementia).

### (iv) Assistive technology/telecare

All localities report that they use assistive technology and telecare where and when it is appropriate, for example monitoring when people with dementia leave their homes or providing gas sensors and other alert systems. In all localities adaptations are available to all who need them, including people with dementia.

Indicator 2 assessed whether localities systematically support staff working within housing and housing-related services, by providing training. This training is to develop specific skills needed to provide the best quality care and support for people with dementia in the roles and settings where they work.

Three localities assessed themselves as not currently providing training and nine stated they provided some training to staff working within housing and housing-related services. Of the nine who provided some training, most report that it is not systematic and is not delivered to all staff working within housing and housing support. All localities stated that they needed to review and expand this training.

Indicator 3 asked whether commissioners systematically use research on assistive technology and telecare to support the needs of people with dementia and their carers. Nine stated commissioners look at research when developing services but do not have a system to remain in touch with new research that considers the provision of options to prolong independent living and delay reliance on more intensive services. Three stated that commissioners systematically use research on assistive technology and telecare to support the needs of people with dementia and their carers.

Whilst some localities reported that commissioners use research on assistive technology; two localities have dedicated officers whose job is to evaluate new assistive technology. Two localities report that assistive technology research is used but not as widely as it might be. They are working to develop this function more fully.

### **11.2.3 What the locality action plans tell us**

There is growing use of assistive technology in a number of localities, and actions identified to increase use of telecare and assistive technology for people with dementia. Telecare is part of the action plans in a number of localities, with specific references to support for people with dementia. Some localities are developing joint telecare / telehealth strategies whilst others are examining processes to help people with low and moderate needs to have access to telecare and telehealth.

A number of localities are looking to incorporate specific references to dementia into their housing policies and practices.

### 11.2.4 Regional activities to deliver objective 10

ADASS have a strategic lead for this objective.

#### **Purposeful Walking Project**

The Joint Improvement Partnership has completed a project using assistive technology Global Positioning System (GPS) to support people with dementia and their carers. The use of the equipment has led to reports of improved outcomes for people with dementia and significant improvements for carers. Savings resulting from the pilot were approximately £160k per annum based on care home fees alone<sup>179</sup>.

#### **Developing a comprehensive evidence base for the future commissioning of dementia services in the NE.**

The Purposeful Walking pilot evaluation report estimated that the potential savings for the NE from the use of telecare for people with dementia could be up to £10.7 million. This is based conservatively on benchmarked results from pilots in the NE and elsewhere and assumes that 10% of the current cohort of people diagnosed with dementia benefit from telecare. The savings would be more with wider implementation and as the prevalence of dementia spreads, further costs of traditional care will be avoided.<sup>180</sup>

### 11.2.5 Known local examples of practice or activities

**Moordale Court** is an extra care scheme due to open in the summer of 2011 in Redcar and Cleveland. It will be built and managed by Guinness Northern Counties. It is designed to be dementia friendly and will welcome people with mild and moderate dementia. It will offer 37 two bedroomed units.

**Appleton Lodge** is an extra care scheme for people with memory problems in Spennymoor. It has been developed in partnership between Home Group and Durham County Council. The facility has been designed to meet the needs of older people with memory problems who require more care and support than other sheltered housing would provide. This will enable them to live as independently as possible in their own home within their own community. It consists of 21 flats - 16 one-bedroom units and five two-bedroom units. There is on-site care available 24-hours a day to meet both planned and any unplanned care and support requirements.

### 11.2.6 Summary

Most people with dementia and their carers indicated that they would like to remain living in their own home for as long as possible; this not only has benefits for the individuals but also helps reduce the need for more costly stays in hospital or care homes. Often the provision of low level telecare (assistive technology) or adaptations to homes will help the person with dementia and their carer to live independently for longer. But carers and people with dementia don't always know what is available and how it can be used.

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<sup>179</sup> Martin Wood (2010) Peace of Mind: The Purposeful Walking Pilot Evaluation [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) ( Accessed 20 June 2011)

<sup>180</sup> Martin Wood (2010) Peace of Mind: The Purposeful Walking Pilot Evaluation [Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) ( Accessed 20 June 2011)

Most localities said that they considered at least one form of housing assistance (for example, telecare or housing support) for people with dementia. Most localities said they provided some training to housing staff to help them support people with dementia and all localities said that their commissioners use research into telecare to help them when commissioning telecare services for people with dementia and their carers. NE based projects indicate the use of telecare could lead to significant savings. It makes sense to give this serious consideration.

The results of the baseline survey show a clear need to develop more options for housing for people with dementia and to provide better training on the options and possibilities of telecare, telehealth and assistive technology to commissioners and housing staff.

### 11.3 End of Life Care – objective 12

**The objective states** “People with dementia and their carers to be involved in planning ‘end of life’ care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia”.

The Department of Health, in conjunction with the National End of Life Care Programme, is working with and supporting key partners such as the National Council for Palliative Care and national dementia charities to help improve ‘end of life’ care for all adults, including those with dementia.

#### 11.3.1 What people in the NE told us they want in relation to objective 12

The “Listening to You” events highlighted that, “special consideration needs to be given to the provision of ‘end of life’ care for people with dementia”<sup>181</sup>. Planning for ‘end of life’ care was seen as very important by carers and people with dementia. It requires consideration both at diagnosis and in the future to allow appropriate time to clarify what people’s preferences and wishes are whilst they maintain sufficient mental capacity<sup>182</sup>. It was, however, seen as being a difficult subject to raise with someone you cared for<sup>183</sup>. Carers felt that they needed support and sometimes peers or professionals could provide that<sup>184</sup>.

This highlighted the need to have the correct mechanisms in place to allow conversations and planning for ‘end of life’ care to occur<sup>185</sup>. Carers and people with dementia weren’t always aware of what was and wasn’t available to support them and an example of where a hospice was not accessible to people with dementia was

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<sup>181</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 7

<sup>182</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

<sup>183</sup> Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group[Online] Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011) pg 11

<sup>184</sup> Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group[Online] Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011) pg 11 and 12

<sup>185</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

cited<sup>186</sup>. There was, therefore, a call for information on what was available for people with dementia and their carers<sup>187</sup>. Examples of good practice were highlighted where social workers were very supportive and when there was adequate planning to ensure the privacy and dignity of the person with dementia<sup>188</sup>. It was also thought that carers should be provided with support following bereavement<sup>189</sup>. No views about 'end of life' care for people with dementia came from the Skills for People consultation<sup>190</sup>.

### 11.3.2 The position based on the baseline assessment

The indicator for this objective in the baseline assessment asked whether localities have a local 'end of life' care strategy which makes reference to dementia care. At the time of assessment six localities stated they did not have a local 'end of life' care strategy that included reference to dementia care, whilst six did. Where strategies were developed, there was recognition that having the strategy is the first step and a lot of work was required to ensure that it was implemented.

### 11.3.3 What the locality action plans tell us

In their action plans, three localities state that they have an 'end of life' strategy which is inclusive of people with dementia, or that they will be including dementia as part of their strategy for the 'end of life' pathway

There are a number of actions which link with existing work around 'end of life' care. The three South of Tyne localities outline that they will be part of the delivery of the 'NE choices' programme which is a major palliative care programme enabling people to die in a place of their choice. Redcar and Cleveland and Stockton plans state they will use e-learning training to improve 'end of life' care. Four localities make specific references to ensuring that people with dementia have opportunities to undertake advanced care planning or develop advanced directives (Darlington, Durham, Gateshead, North Tyneside and Newcastle). Other actions include commissioning services from for example, Marie Curie (South of Tyne), reviewing provision (three South of Tyne localities), the use of an 'end of life' champion in Tees, Esk and Wear Valley Foundation Trust (Hartlepool) and provision of training (Newcastle).

### 11.3.4 Regional activities to deliver objective 12

#### Compassion at end of life

"A North East Charter for a Good Death – Compassion at End of Life" has been published following extensive consultation in 2009. It is based on the principles that all of us should have the right at the end of life to experience a good death and that family, partners or other carers deserve support and compassion at this time. Sensitive and appropriate 'end of life' support should begin at the time illness is identified and continue throughout ill health, during death and in bereavement. It should be available

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<sup>186</sup> Alzheimer's Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.

[Online] Available at: [www.phine.org.uk](http://www.phine.org.uk) ( Accessed:17 June 2011) pg 11

<sup>187</sup> National Dementia Strategy: NE experiences of dementia services 2010 – a Report on Focus Groups with Users and Carers

<sup>188</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

<sup>189</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

<sup>190</sup> Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011

to people coming to the end of life at any age and from any condition so it is inclusive of people with dementia.

### **11.3.5 Know local examples of practice or activities**

#### **Darlington**

Darlington is investing in the implementation of the Gold Standard Framework (GSF). Sixteen GPs signed up to it, which will be implemented in the patch.

There is also an initiative in Darlington where 12 domiciliary care providers are rolling out an End of Life Care and Dementia initiative.

### **11.3.6 Summary**

Stakeholders acknowledge that careful planning and good 'end of life' care is important. The difficulty highlighted was how to start a conversation about 'end of life' with a person who has dementia, and having information on what support is available. At the time of the baseline assessment, half the localities didn't have an 'end of life' care strategy, or if they did it didn't make reference to people with dementia.

Many of the locality plans highlight that improvements to 'end of life' care will be made through the implementation of generic end of life initiatives. Regionally, some excellent work has been carried out developing a charter for good 'end of life' care. If it is fully implemented this could lead to significant improvements in 'end of life' care for people with dementia.

## 12 Remaining NDS areas where there can be significant local and regional impact <sup>191</sup>

In the NE:

- Some public and professional awareness initiatives are being undertaken but they need to be stepped up.
  - People with dementia and their carers want information to be timely and accessible.
  - Access to information and guidance provided 'face to face' is desirable.
  - Carers want to be listened to as a partner in the support and care of the person with dementia.
  - Carers are supported through generic carers initiatives and a number of services specifically for carers of people with dementia.
  - Structured learning networks for people with dementia and their carers are thought to be available in 50% of the region.
  - Admission of people with dementia to hospitals needs to be avoided when at all possible.
  - Good hospital discharge planning is essential for people with dementia.
  - Many intermediate care (IC) services acknowledge they don't fully meet the needs of people with dementia.
  - Many IC services are being reviewed to ensure they are inclusive of people with dementia.
  - The need for staff training and development about dementia is a strong and recurring theme.
  - Training should be made available to all people who come into contact with people with dementia across professions and the pathway.
  - Some carers would like to be involved in developing and delivering training.
  - There is little evidence of a strategic approach to workforce development for staff working with people with dementia.
  - A NE dementia learning and development pathway is being developed
  - Stakeholders want to have a single system of care and support along the whole pathway for people with dementia.
- 
- Joint locality dementia action plans have been developed and published by ten of the twelve localities.



This chapter considers the remaining seven objectives that need to be implemented by the 12 localities across the NE region. The first section brings together five interrelated objectives which group together under the themes of support and information for people with dementia (objectives 1,3,4,5,7). This is followed by sections on intermediate care (objective 9) and the workforce (objective 13).

## 12.1 Support and information for people with dementia and their carers

This section considers what is happening in the NE in relation to providing support and information to people with dementia and their carers both before and following diagnosis. It relates to delivery of the following NDS objectives:

- Improving public and professional awareness and understanding of dementia (objective 1)
- Good quality information for those with diagnosed dementia and their carers (objective 3)
- Enabling easy access to care, support and advice following diagnosis (objective 4)
- Development of structures, peer support and learning networks (objective 5)
- Implementing the carers strategy (objective 7)

### 12.1.1 What people in the NE told us about what they want in relation to support and information for people with dementia and their carers

**Awareness:** It was felt that there is a lack of awareness amongst the general public about dementia<sup>192</sup>. It was thought that general public awareness about dementia would be a good thing in its own right and would also reduce any stigma associated with dementia<sup>193</sup>. One approach suggested was to carry out awareness raising and training with school children<sup>194 195</sup>. Information about, and explanations of, dementia should be provided to the public and particularly where older people meet; in GP surgeries; and at the point of referral for screening for dementia as well as at the point of diagnosis<sup>196</sup>.

**Information:** Lack of appropriate and timely information appeared to be a concern for most who took part in the North of Tyne consultation. "It was suggested that information needs to be available in multiple formats, at the appropriate time during the patient and carer's journey so as not to overload individuals"<sup>197</sup>. This point was developed further during the "Listening to You" consultation events. Participants stated that information and communication needs to "take into account factors such as social deprivation, rural isolation, and ethnic background. Access to effective interpreters is critical in order for information to be tailored for BME groups. Other groups who need tailored information include people with learning disabilities and their families, care staff and younger people

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<sup>192</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 4

<sup>193</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 48

<sup>194</sup>Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>195</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 4

<sup>196</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 4

<sup>197</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 48

who develop dementia before the age of 65 years”<sup>198</sup>. The idea of having a central person who is available for face-to-face meetings to provide information and guidance was well received by “Listening to You” participants. Increased knowledge for professionals on where to signpost people was seen as an area for improvement”<sup>199</sup>. The media were seen as having a key role in raising awareness through television and radio documentaries, drama and “soaps”, and through newspaper and magazine articles and live theatre<sup>200</sup>. People with dementia and carers benefit from mutual support and information sharing with other people with dementia and their families. Signposting to day care, dementia cafés and respite services is required in the early part of the journey. There was a focus on better signposting to a range of support services before a crisis occurs<sup>201</sup>.

**Carers:** “Carers are a major resource in the *treatment* of dementia and, as such, services and respite need to be in place to accommodate their needs. Carers should be able to have confidence that when others look after a person with dementia they will be looked after well. In addition meaningful engagement with carers should occur and should form an integral part of planning services or packages of care.”<sup>202</sup> “Carers need to play an active part in the assessment process and want to be listened to actively”<sup>203</sup>. “Carers need to have their own needs identified and supported. It should be recognised that carers’ needs change as the dementia progresses and needs should be monitored over time”<sup>204</sup>.

Respite care was a high priority and this need was raised by carers and staff from statutory and non-statutory organisations<sup>205</sup>. “Services and support that people with dementia and their carers are entitled to needs to be consistent”<sup>206</sup>. The caring role for a person supporting someone with dementia is particularly complex as it often includes supporting a person who has both physical and mental health needs.

### 12.1.2 The position based on baseline assessment

**Improving public and professional awareness (objective 1).** Whilst all of the localities reported that there was considerable partnership working and co-operation around ensuring people with dementia and their carers had good quality information (for example, there was extensive use of Alzheimer’s Society publications) none of them had worked with Public Health to draw up an action plan on awareness raising.

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<sup>198</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 5

<sup>199</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

<sup>200</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 4

<sup>201</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 6

<sup>202</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 46

<sup>203</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 5

<sup>204</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 6

<sup>205</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 7

<sup>206</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 46

However some localities reported that they had begun discussions with their local Public Health teams. Localities felt that they had a lot of good quality information but that they had not reviewed it to ensure it was up to date and in line with current policy<sup>207</sup>.

**Good quality information for those diagnosed with dementia (objective 3).** The indicator for this objective assessed whether localities had conducted a review of existing relevant local information sets for people with dementia and their carers and had implemented any identified action. Five localities stated they have conducted a review of which one had also implemented an action plan. Seven stated they now planned to conduct a review of existing relevant local information.

**Enabling easy access to care, support and advice following diagnosis (objective 4).** Eleven of the twelve localities stated that the dementia advisor role was being considered or was already part of the dementia care pathway<sup>208</sup>.

**Development of structures, peer support and learning networks (objective 5).** An assessment was conducted of how far localities had reached in developing local peer support and learning networks for people with dementia and their carers. They assessed how effective the networks were in providing practical and emotional support, reducing social isolation and promoting self-care, whilst also providing a source of information about local need to inform commissioning decisions. One locality had no plans to develop these, six had plans and five stated they had developed such support mechanisms<sup>209</sup>.

**Implementing the carers strategy (objective 7).** Localities were asked if they ascertained the support given to carers of people living with dementia by an assessment of their needs (if the carers chose to take the opportunity) and if carers are always supported through an agreed plan to support them in their role. Four localities stated they supported carers and eight stated they aim to support carers<sup>210</sup>. Participants were asked whether localities have a comprehensive range of short break opportunities adequate to meet local need which are responsive and flexible, including the use of direct payments to benefit people with dementia as well as their carers. Five stated they had a comprehensive range of services whilst seven stated they had some services<sup>211</sup>.

### 12.1.3 What the locality action plans tell us

#### Awareness and information

The action plans outline a series of ways in which the localities have or are going to raise awareness. These include the development of public and professional awareness campaigns (Gateshead, Sunderland, South Tyneside and Newcastle), the use of social marketing (South of Tyne).and development of a draft mental health promotion strategy

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<sup>207</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 9 - 10

<sup>208</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 13-14

<sup>209</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 15-16

<sup>210</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 20

<sup>211</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 21

that is ready for consultation (Stockton). Targeted approaches for GPs include using “Time Out” and “Lunch and Learn” Sessions (Hartlepool and Stockton) to raise awareness, by sending letters from the commissioners to GPs about the e-learning resource for GPs (North Tyneside)<sup>212</sup>. Other targeted groups referenced include the BME community (South Tyneside), whilst Stockton has appointed a BME worker employed by the Alzheimer’s Society.

Key partners in implementing awareness and information plans are the Third Sector. The South of Tyne plans have actions to commission the third sector to carry out a review of information. Hartlepool and Redcar & Cleveland want to review the information they have and develop an information pack. Stockton already has an information pack. Whilst North Tyneside said anyone coming into contact with the dementia advisor services receives a tailor made information pack. The service proposes to evaluate the effectiveness of these packs.

Another key way of sharing information is by using a Dementia Advisor. These are commissioned in the two demonstrator site areas (Redcar & Cleveland and North Tyneside)<sup>213</sup> and in Middlesbrough. Other localities are considering commissioning this service<sup>214</sup> and another is awaiting the results of the demonstrator pilot and will also carry out a needs assessment before they decide whether to develop the service. Newcastle is also developing a business case for ‘admiral nurses’.

Actions relating to peer support include Stockton’s promotion of a user led organisation, which enables people with dementia to share experiences and learn from each other.

Use of existing structures is central to many of the actions. For example Middlesbrough see that it is key to engage with public health. Redcar & Cleveland want to include information about older peoples mental health issues in any generic public health material produced.

Carers of people with dementia are receiving support through the Carers’ Strategy and some localities are using this support to enhance provision to carers of people with dementia by, for example, the development of carers health checks, the use of carers grant<sup>215</sup>, use of the carers centre to provide carers assessments, carers cards, and the use of direct payments for short breaks<sup>216</sup>. Sunderland and Gateshead feel that they need to review their services for carers and then establish if any specific services need to be commissioned.

#### **12.1.4 Regional activities to deliver support and information for people with dementia and their carers**

##### **A North East Directory of Services for People Caring for someone with Dementia**

“Directory of North East Dementia Support Groups and Useful Organisations. Supporting recognised, valued and supported: next steps for the carers strategy” was published in March 2011. This is a directory of known carers services that has been specifically developed for those caring for people with dementia.

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<sup>212</sup> e-Learning for Healthcare (2011) *e-Learning for General Practice* [Online] Available at: [www.e-lfh.org.uk](http://www.e-lfh.org.uk) (Accessed: 17 June 2011)

<sup>213</sup> Redcar and Cleveland and North Tyneside

<sup>214</sup> Sunderland, South Tyneside and Newcastle

<sup>215</sup> South Tyneside and Newcastle

<sup>216</sup> Hartlepool and Newcastle

## **Later Life Regional Advisory Group**

The Later Life Regional Advisory Group is the group who influence the implementation of the Later Life section of the NE Better Health, Fairer Health Strategy (the NE Health and Wellbeing Strategy). As one of their key themes, they have adopted 'raising awareness of dementia'. The initial stage has been to develop a module for an e-learning public health training pack to be used across the NE.

### **12.1.5 Known examples of practice or activities**

#### **Dementia Advisor Demonstrator Sites**

In Redcar and Cleveland<sup>217 218</sup> and North Tyneside the two NE Department of Health dementia advisor demonstrator sites have delivered successful outcomes for over 300 people during the period of their operation<sup>219</sup>. End of year reports (February 2011) outline significant benefits including engagement, education and service integration. In view of the success of the demonstrator sites, work is being undertaken to secure funding for the financial year 2011-2012.

#### **Courses for people with dementia and carers**

A course is available for people with dementia and their carers in Durham and Chester-le-Street to provide support and information about dementia. Places can be obtained via a GP referral<sup>220</sup>. Other training programmes and routes to training on dementia are available via the Dementia Care Partnership<sup>221</sup> and Carers Together<sup>222</sup> through the dementia advisor project.

#### **Stockton training**

Stockton provides an ongoing programme of information delivered by a partnership of agencies to support families and friends who care for someone with a dementia. The programme is free of charge and covers a wide range of topics such as benefits, carers' rights and carers' health and well-being. The programme runs for six weeks and each session lasts two hours. Carers can attend the whole programme or single sessions that are of particular interest to them. The programme is run on a 'rolling' basis so if topics of interest are missed then there are other opportunities to attend at a later date.

#### **Support to carers at Sunderland Royal Hospital**

Action on Dementia Sunderland (a third sector organisation) have obtain funding through the Department of Health's "reaching out to carers innovation fund". The aim of the project is to identify and support carers of people with dementia. The project started in Spring 2011.

Dementia frequently becomes highlighted and subsequently diagnosed when a person is admitted to a general hospital for a physical health reason. Carers may experience shock and fear following a potential or actual diagnosis. Identified carers will be provided with support and information and as part of giving information, links will be provided to local services and networks.

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<sup>217</sup> <http://www.dementia.dh.gov.uk/inYourRegion/northEast/> Learning from Redcar and Cleveland Dementia Advisor Site February 2011

<sup>218</sup> <http://home.btconnect.com/carerstogether-rc.org.uk/dementia.html>

<sup>219</sup> [http://www.dementia.dh.gov.uk/objectivesAndResources/Easy\\_access\\_to\\_care/National\\_Dementia\\_Strategy/](http://www.dementia.dh.gov.uk/objectivesAndResources/Easy_access_to_care/National_Dementia_Strategy/)

<sup>220</sup> Directory of North East Dementia Support Groups and Useful Organisations Supporting Recognised, valued and supported: next steps for the Carers Strategy was published in March 2011 pg

<sup>221</sup> <http://www.dementiacare.org.uk/>

<sup>222</sup> <http://home.btconnect.com/carerstogether-rc.org.uk/>

## Dementia Cafes

A number of dementia cafés operate throughout the NE. These provide support and information in an informal environment, to people with dementia and their carers. Some examples include:

- Fusion Café<sup>223</sup> Stockton meets on the last Friday of the month.
- Sweet Charity Café - Stockton is run by the Alzheimer's Society<sup>224</sup>
- Drop in Café Scotswood, Newcastle is run by the Alzheimer's Society. The Alzheimer's Society also run cafes in South Tyneside and Sunderland.
- Wellbeing Cafés in the Newcastle area are run by Dementia Care Partnership<sup>225</sup>
- D-Café Redcar and Cleveland is run by Carers Together<sup>226</sup>
- Memory Café Sunderland is run by Action on Dementia.

### 12.1.6 Summary

Stakeholders state that awareness about dementia needs to be improved. The localities have suggested in their action plans that public and professional awareness campaigns will be undertaken, including using social marketing. Information about dementia will be included in mainstream public health awareness raising campaigns. There is some NE wide commitment to raising awareness in the form of the Later Life Regional Advisory Group who want to do some co-ordinated work. Some targeted work with GPs is ongoing in the South of Tyne and North of Tees areas.

Tailored, timely information is critical for people with dementia and their carers. This need is met in some areas by the dementia advisor service, which is available in at least a quarter of localities. Others are considering commissioning the service. Many localities have not reviewed the information they provide about dementia. Some will use the information they have and develop information packs whilst some already have packs available. Six localities said they had plans to develop peer support and learning networks. There are already a series of dementia cafés across the region but the full coverage is not known. Some courses have been developed for people with dementia and their carers.

Carers are critical to supporting people with dementia and need to be involved and supported by the provision of high quality responsive respite services. The caring role for a person supporting someone with dementia is particularly complex as it often includes supporting a person who has both physical and mental health needs. Five localities said they had a comprehensive range of short break opportunities for people with dementia whilst seven stated they had some services. Carers also need to have their own needs identified and supported. In the action plans there is little direct reference given to how carers are to be involved in the development of support for the person with dementia. It is suggested that generic services for carers should be inclusive of people with dementia.

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<sup>223</sup> [http://clevearc.com/index.php?option=com\\_content&view=article&id=9&Itemid=28](http://clevearc.com/index.php?option=com_content&view=article&id=9&Itemid=28)

<sup>224</sup> [http://alzheimers.org.uk/site/custom\\_scripts/branch.php?branch=true&branchCode=12454](http://alzheimers.org.uk/site/custom_scripts/branch.php?branch=true&branchCode=12454)

<sup>225</sup> Dementia Care Partnership (2011) Dementia Care Partnership. [Online] Available at: [www.dementiacare.org.uk](http://www.dementiacare.org.uk) (Accessed: 16 June 2011)

<sup>226</sup> Carers Together in Redcar & Cleveland (2011) *Dementia Advisor Service* [Online] Available at <http://home.btconnect.com/carers-together-rc.org.uk/dementia.html> (Accessed: 17 June 2011)

## 12.2 Improved Intermediate Care for people with dementia - objective 9

The objective states, “Intermediate care which is accessible to people with dementia and which meets their needs”.

### 12.2.1 What the people in the NE told us about what they want in relation to objective 9

Stakeholders felt that hospital admissions should be avoided where possible as hospital stays de-skill people<sup>227</sup>. To avoid admissions “People need good support to help them to stay in their own home and retain their independence”<sup>228</sup>. When the person is ready to leave hospital, good planning is needed<sup>229</sup>. Experience of stakeholders suggests that there could be improvements made to the discharge process<sup>230</sup>. These improvements could include the provision of post discharge intermediate care.

Little direct feedback is available from NE stakeholders specifically in relation to intermediate care. Where the concept was explained there was a request to make things understandable to those who may be accessing the service, “Why don't they say ‘short term care’, not ‘intermediate care’?”<sup>231</sup>

In the North of Tyne consultation only a small number of participants had experienced intermediate care. “Those who were able to share their experiences often portrayed a negative image. Some described centres and clinics that were accessed as ‘awful’ and ‘not too good’, and said that more training for staff was required”<sup>232</sup>. Carers who had not experienced intermediate care services stated that staff in these settings should have specialist training in dementia and there should also be sufficient staff to patient ratios<sup>233</sup>.

There was a call for sufficient capital and revenue funding to be made available for more specialist, innovative services including intermediate care services<sup>234</sup>.

### 12.2.2 The position based on baseline assessment

The indicator for this objective asked if localities had intermediate care services which are accessible to people with dementia and asked for them to assess if they are being used by people with dementia and whether the service fully meets their needs. Nine localities stated that they had intermediate care services that are accessible to people with dementia. People with dementia were using these services but it was not clear if the service fully met people’s needs. The remaining three localities stated that they

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<sup>227</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society

<sup>228</sup> N Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East. [Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>229</sup> Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>230</sup> Alzheimer’s Society (2010) National Dementia Strategy: North East Experiences of Dementia Services 2010 Presentation of findings and recommendations to the North East Regional Stakeholder Group.[Online]Available at:[www.phine.org.uk](http://www.phine.org.uk) (Accessed:17 June 2011)

<sup>231</sup> National Dementia Strategy. A report of consultation with people with learning disabilities in the North East What we think of the Government’s Plan August 2008 pg 42

<sup>232</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 33

<sup>233</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 33.

<sup>234</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 6

currently had intermediate care services that are accessible to people with dementia and are being used by people with dementia and which fully meet their needs<sup>235</sup>.

### 12.2.3 What the locality action plans tell us

Of the ten locality plans published, eight had clear action points to review the intermediate care services and ensure the service was inclusive of people with dementia<sup>236</sup>. Of the other two, Redcar and Cleveland were going to raise awareness of the intermediate care service and were implementing a specific project to support the management of people with dementia across South of Tees and North Tyneside were monitoring how many people with dementia accessed the intermediate care service.

Three localities were not reviewing their intermediate care services. These were Darlington, who were considering the development of intensive home care treatment support by the mental health trust, and Stockton and Newcastle who were looking at the provision of training based on need in the intermediate care staff team.

### 12.2.4 Regional activities to deliver objective 9

A regional event was held in summer 2010 to look at the intermediate care guidance "Half Way Home"<sup>237</sup>. This allowed stakeholders to consider the elements in the guidance which builds on the intermediate care guidance of 2001 and states that intermediate care services should be inclusive of people with dementia or people with mental health needs.

### 12.2.5 Known local examples of practice or activities

#### County Durham

County Durham has developed a Joint Commissioning Strategy for Intermediate Care in March 2010<sup>238</sup>. This strategy includes action to ensure intermediate care services are inclusive of people with dementia.

#### Sunderland Intermediate Care Services

Sunderland has run an intermediate service which is inclusive of people with dementia at Farmborough Court Intermediate Care Centre since 2003. They have a dedicated unit for people with dementia with up to 26 residential places.

People with dementia have access to all services according to individual needs, (including Nurse Practitioner, GP, Occupational Therapy, Physiotherapy and Mental Health professionals) within the Centre. They can also receive services from outreach RMNs to follow them home or ease transition into permanent residential care.

In 2010 the average length of stay in the intermediate care service for people with a diagnosis of dementia was 25 days. 74% of these were not admitted to permanent care

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<sup>235</sup> Department of Health (2009) National Dementia Strategy in The North East Readiness to Implement. London: Department of Health pg 25

<sup>236</sup> South Tyneside, Sunderland, Redcar and Cleveland, Gateshead, Middlesbrough, Hartlepool & North Tyneside.

<sup>237</sup> Department of Health (2009) Intermediate Care – Halfway Home Updated Guidance for the NHS and Local Authorities. London: Department of Health

<sup>238</sup> NHS (2010) DCC Adults, *Wellbeing and Health*, and *NHS County Durham and Darlington, Joint Commissioning Strategy for Intermediate Care*. London:NHS



within 6 months of discharge. 2,400 patient days were 'saved' in the hospital trust during the 12 month period 2009-10.

### 12.2.6 Summary

Stakeholders say they would like to prevent people with dementia from being admitted to hospital unless it is absolutely necessary. As part of the baseline assessment nine localities stated that they had intermediate care services which are accessible to people with dementia, whilst three localities stated their intermediate care services fully meet the needs of people with dementia. Seven locality plans indicated they were reviewing intermediate care services and would ensure the services are inclusive of people with dementia.

Stakeholders also state they want improved discharge planning. This may be addressed to some extent through the provision of step down intermediate care. However there are no particular actions relating to discharge planning in the implementation plans.

There is a need to provide improved training for intermediate care staff especially in dementia care. However, only one locality action plan indicates that they are to look to provide training on dementia to intermediate care staff.

### 12.3 Informed and effective workforce for people with dementia - objective 13

The objective states, "Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia".

#### 12.3.1 What the people in the NE told us about what they want in relation to objective 13

Training of medical and social care staff was a strong, recurring theme throughout the four engagement events. It was felt by many that the best quality care could only be delivered if those who cared for people with dementia and their carers were fully trained. This training should not only consider the medical aspects of different types of dementia but also the social aspects of communication and the impact on families and carers<sup>239</sup>.

Specialist training in all aspects of dementia needed to be provided to everyone who could reasonably be expected to come into contact with people with dementia and their carers. This included the call for more training for people who could be identifying people with a possible dementia and signposting them for assessment<sup>240</sup>.

Specialist training for GPs would enable them to more quickly and confidently diagnose dementia and refer the person and their carer to appropriate services. The training for GPs should include information on how they can diagnose dementia in people with

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<sup>239</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne National Dementia Strategy. A report of consultation with people with learning disabilities in the North East What we think of the Government's Plan August 2008

<sup>240</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 4

learning disabilities<sup>241</sup>. In specific health and care settings, particularly hospitals, specialist multi-disciplinary teams should be created who provide and supervise the care of people with dementia or their carers. This could be through in-reach teams. People with dementia and their carers should be involved in designing and delivering the training, acting as expert trainers using their personal experiences<sup>242</sup>.

Workforce stability was seen as a particular problem that affected quality of care delivery. Contributing to this lack of stability were issues of low pay and how staff are valued by management<sup>243</sup>.

### **12.3.2 The position based on baseline assessment**

The indicator for this objective assessed to what extent contracts with service providers included specific requirements for staff to be provided with basic training and professional and vocational development in dementia care. One locality stated that all contracts with service providers included specific requirements for staff to be provided with basic training and professional and vocational development in dementia care. Nine stated some contracts required basic training to be provided and one stated no contracts included a specific requirements for staff to be provided with basic training in dementia care.

### **12.3.3 What the locality action plans tell us**

A partnership approach between commissioners and providers to workforce development has been undertaken in some localities. For example this partnership approach is demonstrated by the South of Tyne localities who want to carry out an audit of the workforce and then take appropriate action whereas Middlesbrough want to assess need and develop generic training. Sunderland specifically mention that they would like to use the Tyne and Wear Care Alliance to carry out a review and make recommendations as to what should be included in their workforce and training plan. Redcar and Cleveland plan to provide training to support staff when they have clients with behaviour that challenges and the Hartlepool plan highlights that they will use a care home project to support staff.

South Tyneside stated that in 2009 all new council contracts required providers to train staff to provide care that is, “appropriate to the service user including people with dementia”. Newcastle also state contracts have specific requirements for dementia training to be provided to staff.

The greatest numbers of service specific actions relate to care homes and the use of contract compliance to ensure staff have the correct level of training<sup>244</sup>.

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<sup>241</sup> Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East. [Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>242</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne

<sup>243</sup> Alzheimer’s Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer’s Society pg 7 and NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 41

<sup>244</sup> Redcar and Cleveland, Stockton

### 12.3.4 Regional activities to deliver objective 13

#### Learning and development pathway

A regional workforce development group known as NERDs group are producing a learning and development pathway for staff working with people with dementia. It is anticipated this will be ready in Summer 2011.

#### Community and Personal Support Services for People with Dementia, A guide for front line professional staff

As part of the regional work on community and personal support (objective 6) an e-learning resource was developed. This is freely available to all interested stakeholders on the social care section of the PHINE web site ([www.phine.org.uk](http://www.phine.org.uk)). The learning resource includes details of the definitions of dementia and information about personalisation (including personal budgets) and describes how personal budgets could be used to support people with dementia.

#### Developing an Adult Social Care Workforce Strategy for the North East

An analysis of the Social Care Workforce was commissioned by the Joint Improvement Partnership<sup>245</sup>. This highlighted the increasing pressures on the workforce to support people with dementia as a result of the demographic changes and the need to implement the NDS.

### 12.3.5 Known local examples of practice or activities

#### Dementia e-learning for GPs

Professor Louise Robinson, RCGP Clinical Champion for Ageing and Older People from the NE and Dr Emma Vardy, from Manchester University, have produced two e-learning modules on dementia, which are aimed at helping GPs develop knowledge and skills<sup>246</sup>.

#### Tees Valley Care Alliance

The Tees Valley Care Alliance has received funding from the Strategic Health Authority to develop 'end of life' care, which is inclusive of caring for people with dementia.

### 12.3.6 Summary

The engagement activities repeatedly made reference to the need for people working with dementia to have the right knowledge and skills to support people with dementia along the whole pathway. In health care this not only related to the knowledge of health needs but an understanding of social aspects including communication and the impact on families and carers.

Most localities reported that they had some contracts requiring providers to train their staff in dementia care. Four localities want to take a more strategic approach to workforce development. In addition there are a number of workforce initiatives going on

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<sup>245</sup> Peter Fletcher Associates Ltd & BV Hudson Consulting Ltd (2009) *Developing an Adult Social Care Workforce Strategy for the North East: A Vision and First Steps Forward Final Report* [Online] Available at: [www.northeastiep.gov.uk](http://www.northeastiep.gov.uk) (Accessed:17 June 2011)

<sup>246</sup> The modules can be found at [www.e-lfh.org.uk/projects/egp/index.html](http://www.e-lfh.org.uk/projects/egp/index.html) Anyone with an NHS email address can access the training information following registration. The training is supported by two associated factsheets, one on early diagnosis, the other on primary care of people with dementia.

across the region. However there does not appear to be a single strategic approach to skill up the workforce in dementia care across the NE.

#### **12.4 A joint commissioning strategy for dementia - objective 14**

The objective states, "Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy".

##### **12.4.1 What people in the NE told us they want in relation to objective 14**

Little is written about what stakeholders want in relation to a joint commissioning strategy. What has been expressed however is the desire for support and care for people with dementia to be joined up; "a single system we all know about, all the way through would be helpful, but I understand this is difficult with different budgets and systems"<sup>247</sup>. One way to achieve this is through "joined up commissioning and funding arrangements between health and social care."<sup>248</sup> There was also a plea for the use of terms, which could be understood by all<sup>249</sup>.

##### **12.4.2 The position based on the baseline assessment**

The indicator for this objective assessed how far localities had reached in developing a joint commissioning strategy which takes account of the needs of people with dementia for both mainstream and specialist services. Four localities stated they had a joint commissioning strategy which takes account of the needs of people with dementia for both mainstream and specialist services. Seven localities stated they are developing a strategy and one stated they are not.

##### **12.4.3 What the locality action plans tell us**

Three of the ten published locality action plans do not have any specific actions relating to objective 14. The remaining six localities state that they have a joint plan and some form of identified joint group accountable for implementation of the NDS. For these localities, the action plans are the defined joint commissioning strategies.

##### **12.4.4 Regional activities to deliver objective 14**

###### **Sharing plans**

The Dementia Leads Group was used to share early drafts of locality action plans both in terms of content and format. From the summer of 2010 the localities have been offered the opportunity to share their plans on the dementia information portal <sup>250</sup> and latterly the Social Care pages of the PHINE website.

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<sup>247</sup> NHS North of Tyne (2010) We Share, We Laugh, We Cry. An Engagement with people with dementia and their carers Newcastle:NHS North of Tyne pg 43

<sup>248</sup> Alzheimer's Society & NE CSIP (2008) Listening to You National Dementia Strategy North East London: Alzheimer's Society pg 5

<sup>249</sup> Skills for People (2008) National Dementia Strategy report of consultation with people with learning disabilities in the North East.[Online] Available at : <http://www.phine.org.uk> (Accessed:17 June 2011)

<sup>250</sup>Department of Health (2011) Dementia Information Portal [Online] Available at <http://www.dementia.dh.gov.uk> (Accessed: 14 June 2011)

### 12.4.5 Known local examples of practice or activities

#### **Durham Strategy**

County Durham has produced a “Joint Commissioning Strategy for older people with mental health conditions 2009 to 2013”<sup>251</sup>. This is inclusive of dementia<sup>252</sup>.

#### **The ten published dementia plans**

The ten published plans allude to being joint commissioning strategies. For example Sunderland and Gateshead named their dementia plan a “Joint Commissioning Strategy”. South Tyneside called their plan a “Joint Commissioning Plan”. The other three localities called theirs either joint action plans or implementation plans.

### 12.4.6 Summary

Stakeholders say they want a single system for care and support for people with dementia, which is understood throughout the whole pathway. One way to achieve this is by localities having joint commissioning plans. Ten joint locality plans have been published. The quality and effectiveness of these plans has not been evaluated.

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<sup>251</sup> Durham County Council ( 2011) Joint Commissioning Strategy for older people with mental health conditions [Online] available at:[www.durham.gov.uk/](http://www.durham.gov.uk/) (Accessed: 17 June 2011)

<sup>252</sup> Durham County Council ( 2011) Joint Commissioning Strategy for older people with mental health conditions [Online] available at:[www.durham.gov.uk/](http://www.durham.gov.uk/) (Accessed: 17 June 2011)

## 13. Objectives where there is less influence to be exerted by localities and the region

- There are three NDS objectives which are led nationally.
- These relate to service regulation, research and resources to support implementation of the NDS.
- NE responses include:
  - Development of quality standards for regulated providers.
  - Research that will fill dementia research gaps by universities in the NE.
  - Provision of a senior support manager for the implementation of the NDS until May 2012.

### 13.1 Introduction

There are three objectives which are listed in the NDS under the section “Delivering the NDS”. These are:

- Improved assessment and regulation of health and care services (objective 15),
- A clear picture of research needs (objective 16); and
- Effective support for the implementation of the NDS (objective 17).

The leadership for these objectives is at national level. However this section outlines any relevant factors in the NE.

#### 13.1.1 Improved assessment and regulation of health and care services (objective 15)

This objective relates to better regimes for care homes and other services that better assure the quality of dementia care provided. This particularly relates to the national regulation of services by the Care Quality Commission.

In the NE work has been carried out to develop quality service standards, some of which relate to care homes (for more details see section 10). In the NE the CQC have agreed to be part of the North East Dementia Alliance.

#### 13.1.2 A clear picture of research evidence and needs (objective 16)

This objective relates to evidence available on the existing research based on dementia in the UK and gaps that need to be filled.

In the NE considerable research relating to dementia is undertaken and will contribute to the national evidence base. (For more details see section 5)

#### 13.1.3 Effective national and regional support for implementation of the strategy (objective 17)

This objective relates to appropriate national and regional support being available to advise and assist in local implementation of the strategy. The Department of Health provided funding for regional support in the NE up to March 2011. The resource was used to fund a senior manager to support implementation of the NDS and related projects. Additional non-DH funding has been found to fund a senior manager to work

across the NE from May 2011 to April 2012. The Deputy Director of Social Care will continue to chair the NE Oversight Board.

### **13.2 Summary**

There are three nationally led supporting objectives that support the delivery of the NDS. Therefore direct activity in the NE is understandably relatively low key. However whilst improved regulation in objective 15 relates particularly to the role of CQC there are regional moves to develop enhanced quality standards. The leadership for assessing gaps in research is being provided nationally, whilst universities in the NE are some of the key research institutions in the country. Department of Health resource had been provided to support to the NDS implementation until March 2011, however this direct programme funding has now ceased. Further funding for a senior manager's post to support implementation has been found for one further year (until April 2012). There continues to be support from the Deputy Regional Director of Social Care.

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## Appendix A

### **Activity in the North East Under the Relevant objective (with examples)**

Throughout the report examples have been given of activity which has been undertaken to deliver each of the NDS objectives. Some of the activities deliver more than one objective for example dementia cafes deliver good quality information for those with diagnosis of dementia and their carers (objective 3), enabling easy access to care, support and advice following diagnosis (objective 4), development of structures, peer support and learning networks (objective 5) and an informed and effective workforce for people with dementia (objective 13). This section provide a reference of activity for each objective.

### **Improving public and professional awareness and understanding of dementia (objective 1)**

Diagnosis Rates 2.2.7

Helping GPs 3.5

Later Life Regional Advisory Group 12.1.4

### **Good quality early diagnosis and intervention for all (objective 2)**

Memory protection specification 10.2.5

Accredited memory services 10.2.5

Work with people with learning disabilities 10.2.5

### **Good quality information for those with diagnosis of dementia and their carers (objective 3)**

North East Directory of Service for people Caring for someone with dementia 12.1.4

Dementia Advisor Demonstrator Sites 12.1.5

Courses for people with dementia and carers 12.1.5

Stockton Training 12.1.5

Dementia Cafes 12.1.5

### **Enabling easy access to care, support and advice following diagnosis (objective 4)**

Dementia Advisor Demonstrator Sites 12.1.5

Courses for people with dementia and carers 12.1.5

Stockton Training 12.1.5

Dementia Cafes 12.1.5

### **Development of structures, peer support and learning networks (objective 5)**

Dementia Advisor Demonstrator Sites 12.1.5

Courses for people with dementia and carers 12.1.5

Stockton Training 12.1.5

Dementia Cafes 12.1.5

### **Improved community and personal support services (objective 6)**

Personalisation and objective 6 3.2

Resource for Commissioners 7.4

Commissioning Standards 10.4.4

Smarter Homes for the Future 11.1.5

Redcar and Cleveland Borough Council 11.1.5

Dementia is Everybody's Business 11.1.5

Community and personal support services for people with dementia: A guide for front line professional staff 12.3.4

### **Implementing the carers strategy (objective 7)**

North East Directory of Service for people Caring for someone with dementia 12.1.4

### **Improved quality of care for people with dementia in general hospitals (objective 8)**

Foundation Trust Status 3.5

Reduction cost in general hospital care in the NE (Darlington Dementia Collaborative) – 4.2, 10.3.4

NE Acute Care Pathway Group 10.3.4

Royal College of Psychiatrists' National Audit of dementia 10.3.4

Dementia care – Vocational Training Level Two 10.3.4

Hospital Groups 10.3.4

Liaison Team at Wansbeck 10.3.4

"This is Me" 10.3.4

### **Improved intermediate care for people with dementia (objective 9)**

County Durham 12.2.5

Sunderland Intermediate Care Services 12.2.5

### **Considering the potential for housing, support, housing-related services and telecare to support people with dementia and their carers (objective 10)**

Dementia is Everybody's Business 11.1.5

Purposeful Walking Project 11.2.4

Developing a Comprehensive evidence base for the future commissioning of dementia services in the North East 11.2.4

Moordale Court 11.2.5

Appleton Lodge 11.2.5

### **Living Well with dementia in care homes (objective 11)**

Commissioning Standards 10.4.4

Care Home Event and Report 10.4.4

NE My home Life Network 10.4.4

Baseline analysis of North East Care Homes providing care for older people experiencing mental ill health and dementia March 2009 10.4.4

Sunderland Quality Standards 10.4.5

Darlington contract compliance of care homes 10.4.5

### **Improved end of life care (objective 12)**

Compassion at end of life 11.3.4

Darlington Gold Standard Framework 11.3.5

Tees Valley Care Alliance 12.3.5

### **An informed and effective workforce for people with dementia (objective 13)**

Helping GPs 3.5

Research in the North East 5.1.1 to 5.1.3

Commissioning toolkit section 5.1.1

Dementia care – Vocational Training Level Two 10.3.4  
Smarter Homes for the Future 11.1.5  
Darlington Gold Standard Framework 11.3.5  
Courses for people with dementia and carers 12.1.5  
Stockton Training 12.1.5  
Dementia Cafes 12.1.5  
Learning and Development pathway 12.3.4  
Community and personal support services for people with dementia: A guide for front line professional staff 12.3.4  
Dementia E-learning for GPs 12.3.5  
Tees Valley Care Alliance 12.3.5

**A joint commissioning strategy for dementia (objective 14)**

Sharing Plans 12.4.4  
Durham Strategy 12.4.5  
The Ten published plans 13.4.5

**Improved assessment and regulation of health and care services (objective 15)**

Commissioning Standards 10.4.4  
Sunderland Quality Standards 10.4.5  
Darlington contract compliance of care homes 10.4.5

**A clear picture of research needs (objective 16)**

Research in the North East 5.1.1 to 5.1.3

**Effective support for the implementation of the NDS (objective 17)**

Effective national and regional support for the implementation of the NDS 13.1.3

**Reducing the inappropriate prescribing of antipsychotic medication**

Stockton care home project 10.5.5  
The Station Medical Group nursing home project 10.5.5  
Specialist care development practitioner in Easington and Hartlepool 10.5.5

**Cross cutting activities**

Outcomes project – Gateshead section 3.2  
North East Locality Dementia Action Plans – 3.2 and 7.3  
GP Consortia in the North East – 3.5  
Impact of the current economic climate on the third sector in the North East – 4.2  
Regional, sub regional and locality groups 6.1-6.4  
Baseline assessments 7.2  
Information from NE stakeholders 8.1 to 8.6  
Dementia Service Providers 9.1 to 9.7

## Appendix B

### The report structure

#### Section 10

Good quality early diagnosis	2
Improved quality of care in general hospitals	8
Living well with dementia in care homes	11
Reducing the Inappropriate use of antipsychotic	

#### Section 11

Improved community and personal support services	6
Considering the Potential for Housing Support, housing-related services and telecare to support people with dementia and their carers	10
Improved end of life support for people with dementia	12

#### Section 12

Improving Public and professional awareness and understanding of dementia	1
Good-quality information for those with diagnosed dementia and their carers	3
Enabling easy access to care, support and advice following diagnosis	4
Development of structured peer support and learning networks	5
Implementing the carers strategy	7
An informed and effective workforce for people with dementia	13
A joint commissioning strategy for dementia	14

#### Section 13

Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers	15
A clear picture of research evidence and needs	16
Effective national and regional support for implementation of the Strategy	17

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