



National Dementia Strategy Northern Housing Consortium Briefing

Purpose of paper

This briefing is intended to provide an overview of the Government's plans for a National Dementia Strategy in order to assist Consortium members to influence the strategy and promote the role that housing can play in improving provision and services for people living with this condition.

The Consortium will be attending a listening and engagement event on 19th February, held by the Care Services Improvement Partnership (CSIP), which will inform the content of the Strategy. In order to ensure we are able to represent our members effectively at this event, this briefing paper poses a series of questions about the role that the social housing sector can play in the Strategy. We are keen to hear member's opinions on this issue and about any examples of good practice in this area so that we can contribute to the development of the National Dementia Strategy.

It is also our intention to submit a full response to the consultation when the draft Strategy is published later this year using the comments and evidence we have gathered from members.

Scale of the problem

What is dementia?

Dementia is the term used to describe a collection of different brain disorders that trigger a loss of brain function. This includes a decline in memory, reasoning and communication skills, and a gradual loss of skills needed to carry out daily activities. Dementia is a progressive condition meaning that symptoms become more severe over time. It is also a terminal condition; there is no cure for dementia. The causes of dementia are not yet fully understood and there are over 100 different types.

Who is affected?

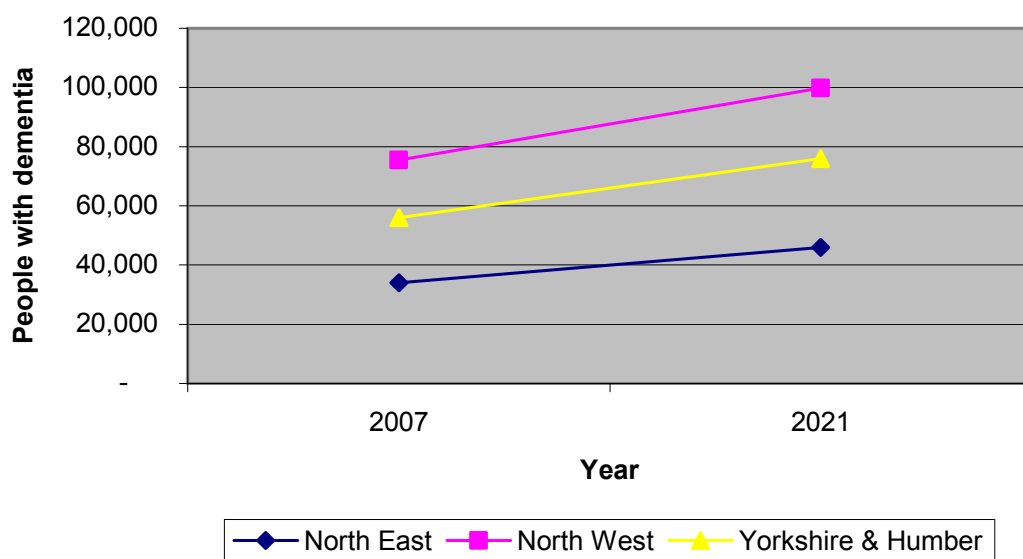
There are currently 700,000 people with dementia in the UK (575,000 in England); 62% of these people have Alzheimer's disease which is the most common type. Dementia is a disease typically associated with older age; one in five people over the age of 80 and one in 20 people over 65 has a form of dementia. However, dementia can affect people of any age and while early-onset dementia is comparatively rare, it is estimated that there are more than 15,000 people under the age of 65 with the disease. An article by the Financial Times in August 2006 estimated that a case of dementia is diagnosed every 3 minutes.

We know that the UK has an ageing population; by 2025, 20% of the population will be aged 65 or over. We also know that the prevalence of dementia increases with age and that dementia is one of the main causes of disability in later life. The total number of people with dementia in the UK is forecast to increase to over 1 million people by 2025 and 1.7 million by 2051.

At the moment, the majority of people (63.5%) with late-onset dementia live in private households, and 36.5% live in care homes. In terms of care for those people with dementia living in the community, the majority is informal, unpaid care provided by family and/or friends. Of all people living in care homes, 64% have a form of dementia.

The northern picture

In the North of England, the situation is very much the same as the national one. Currently, 29% of all people with dementia in England live in the North and this is expected to remain the case in 2021. The number of people with dementia in the North of England will increase by 35% between 2007 and 2021, which is in line with national trends. The chart below indicates how the problem is expected to grow within each of the northern regions.



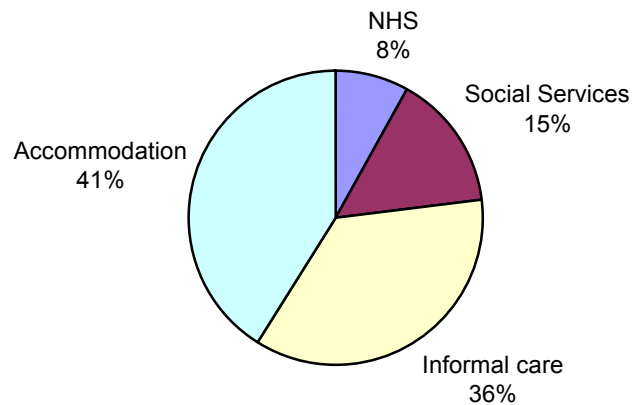
How much does it cost?

In February 2007, the Alzheimer’s Society published a major study on the social and economic impact of dementia in the UK. The ‘Dementia UK’ report shows that dementia costs the UK £17 billion a year, or £539 a second. This includes costs provided by formal care agencies and the financial value of unpaid informal care provided by family and friends.

The average cost per person with late-onset dementia is £25,472 a year but this changes depending on the residential setting and severity of the disease:-

- 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

The chart overleaf shows the breakdown of the costs associated with dementia. Accommodation accounted for the largest amount of the cost of dementia at 41% of the total and over a third (36%) was due to informal care inputs by family members and other unpaid carers. However, unpaid carers supporting someone with dementia also save the economy £6 billion a year.



In terms of benefit payments, people with dementia (along with some other mental health issues) accounted for the second highest number of recipients of disability living allowance in 2003 which represents a significant expense to the Government.

Policy context

“Services need to begin gearing up for the Strategy and its implementation. They should start thinking about how to shape themselves so they are better able to tackle the challenge of dementia and meet the needs of people with this devastating illness.”

Ivan Lewis MP, Parliamentary Under Secretary for Care Services
 Strengthening the Involvement of People with Dementia
 November 2007

On the 6th August 2007, Ivan Lewis, Parliamentary Under Secretary of State for Care Services, announced the development of the first ever National Dementia Strategy for England. The announcement followed a series of national reports about dementia care and signifies how serious the Government is taking the needs of people with this illness. David Nicholson, NHS Chief Executive, said that the UK was in the bottom third of Europe in delivering high quality dementia care and historically there has been a lack of attention from policy makers and service commissioners to the needs of people with dementia. The preparation of a national Strategy marks a real step forward in terms of policy and raising the standards of care for people with dementia.

There are going to be three key themes of the Strategy:

Improving awareness

There is currently a low level of public and professional understanding of dementia. Symptoms of dementia are often misattributed to “old age” and those suffering from dementia or their relatives can be reluctant to seek help because of this. There is also a social stigma and fear associated with dementia which can impact on timely diagnosis and access to care.

This part of the Strategy will focus on: developing a better understanding of dementia by the public and professionals, ensuring that better information is available on how

to seek help and the treatment available, and tackling the stigma and misunderstandings that surround this disease.

Early diagnosis and interventions

The nature of dementia makes it very difficult to formally diagnose and currently only a third of people with dementia receive a diagnosis at any time in their illness. Diagnoses are often made too late for those suffering from the illness to make choices or they are made at a time of crisis, which could probably have been avoided had a diagnosis been made earlier.

This part of the Strategy will focus on developing effective services for early diagnosis and intervention on a nationwide basis.

Improving the quality of care

People with dementia, their families and carers require a lot of support and there is a need to enhance joint health and social care mental health teams in the community to provide this. There is also a need to improve intermediate care services so that alternatives to hospital admission are available and early discharge from acute and mental health hospitals is possible for people with dementia. In addition to this, there is a need for improved systems to manage people with dementia during emergency and acute care, as well as to prevent unnecessary admission to hospital because of a lack of alternatives.

This part of the Strategy will focus on: improving liaison services that can enable effective management in hospital and intermediate care, and building better skills and understanding of dementia in the health and social care workforce so that all those working with older people develop skills in this area.

Housing's contribution

Social housing providers have been playing an important role in supporting the needs of people suffering from dementia for many years and with the introduction of a National Strategy they will see this role emphasised and strengthened. The role that the social housing sector can play is wide ranging and comes in different forms; from the implementation of the Supporting People programme, to the work of Home Improvement Agencies, through to providing specialist housing like Extra Care schemes, or support in the home making use of assistive technology, and the latest Telecare, Telehealth and Telemedicine systems.

In terms of the plans for the National Dementia Strategy, the themes of *early diagnosis and interventions* and *improving the quality of care* apply to the social housing sector the most and are where we hope to see housing's contribution highlighted when the draft Strategy is published. The Strategy is expected to put a strong emphasis in enabling and supporting people with dementia to live independently in their own homes and this is where housing providers are able to make a difference.

In order to ensure that housing's role is accurately reflected in the Strategy, we would like to hear from our members in order to gather a comprehensive picture on the scale of the problem of dementia and the ways in which social housing providers can help to support and assist people with dementia to live independently in their own homes.

We would ask you to consider the following questions and send us your thoughts, comments and opinions by Friday 8th February to Sarah Taylor, Policy & Practice

Development Manager (sarah.taylor@northern-consortium.org.uk). Sarah will be attending a listening and engagement event on 19th February and intends to take information gathered from members to this event to inform the content of the Strategy.

What should the Strategy say about the role of housing?

What more can government do to support the sector?

What evidence do you have on the scale of the issue in your area?

What are the main strategic challenges for your organisation in supporting the needs of people with dementia?

What are your delivery challenges?

What barriers you experienced and how they have been overcome?

Do you have any good practice in the area which you would like to share?

Looking to the future what will be, or would you hope to be, your major accomplishments in this area?

What support do you require from the Northern Housing Consortium?

Next Steps

CSIP, in partnership with the Alzheimer's Society, are leading a series of engagement and listening exercises in each region in January and March. These will feed directly into the development and implementation of the Department of Health's (DH) National Dementia Strategy. The purpose of the engagement and listening exercises is to inform the content of the Strategy and help gain commitment to its implementation. The events will enable individuals and organisations at regional and local levels, including people with dementia and their carers, to engage with the Strategy and contribute to its development. Stakeholders in every region will be invited to submit their views on the three key themes.

There are events being held in every region including the following dates for the northern regions:

- February 8th – Alnwick
- February 19th – Billingham
- February 20th – Leeds
- February 21st – York
- February 22nd – Preston
- February 25th – Manchester
- February 26th – Runcorn
- February 27th – Sheffield
- February 29th – Newcastle upon Tyne

For more information on any of these events, alternative dates or booking please contact Karen.cardy@nimhenevh.nhs.uk by February 1st.

The draft Strategy is intended to be published in the early summer 2008 which will be followed by a formal consultation period. The final Strategy is intended to be published in October 2008. The Consortium intends to send comment to the Department of Health on the draft Strategy when it is published and we invite members to provide us with their comments and examples of good practice as early as possible so that we may respond to the consultation.

Useful resources

The Alzheimer's Society (<http://www.alzheimers.org.uk/>)

Dementia UK report

(http://www.alzheimers.org.uk/site/scripts/documents_info.php?categoryID=200120&documentID=342)

Care Services Improvement Partnership (CSIP) (<http://www.csip.org.uk/>)

Department of Health (<http://www.dh.gov.uk/>)

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