

National Dementia Strategy for England update September 2008

This update is to inform Alzheimer's Society staff in England about work in progress on the Dementia Strategy. An Arena page on the NDSE is in development where this update and further information on the Strategy will be posted.

1. Publication date change

The publication date for the NDSE has been changed from October to mid-November. At this stage there is no specific publication date.

2. OMT sub group

A cross-directorate Operational Management Team (OMT) group has been set up to plan the Society's response to the NDSE on an ongoing basis. This group has met twice and will be meeting monthly for the foreseeable future. The purpose of the group is to ensure the Society is prepared to respond to the Strategy across the organisation.

Members of the group are Mary Garvey (Services), Linda Seaward (Marketing and Publishing), Louise Lakey (Policy), Phil Shoemith (Business Planning), Alison Watt (Fundraising), and Andrew Chidgey (Policy and Campaigns and chair of the group). Please contact any of them with questions you may have.

3. A reminder on what the draft Strategy proposes

The draft National Dementia Strategy for England describes a 5-year transformation plan for dementia in England. It has 15 recommendations.

1. Increased public and professional awareness of dementia through public awareness campaigns.
2. An informed and effective workforce through improved training.
3. Good quality early diagnosis through the development of more memory services which can diagnose and treat people with dementia.
4. Better access to information for people with dementia and their carers
5. Access to advice through a care adviser.
6. Better care in hospitals through older people's mental health liaison teams, clinical leads and developed care pathways.
7. Home care to be provided by a specialist dementia care service.
8. Improved access to short breaks/respite services.
9. NHS and local authorities to create joint dementia plans.
10. Improved access to intermediate care services where people are supported at home to keep them out of hospital, prepare them for hospital or to help them to recover from a hospital stay.
11. Better care in care homes through appointing dementia care leaders, specialist healthcare support and getting councils to ask for better standards in their contracts.
12. Change the system of registration for care homes so that all homes should be able to take people with dementia.

- 13.13. Make sure there is good information on the delivery of the Strategy in the future.
14. Create a research strategy on research that looks at how different research funders can collaborate to improve research efforts.
15. Support for implementation of the Strategy at a local and national level.

To see the full Strategy please go to www.dh.org.uk/dementia

4. Society consultation response

The Society has made a formal consultation response to the Department of Health on the draft Dementia Strategy consultation, drawing on the views of 300 carers, 50 people with dementia, and a variety of other staff and volunteers. In addition the Society continues to have discussions with the Care Services Minister and the civil servants working on the Strategy.

The main points of the submission were as follows:

- **This Strategy if implemented effectively within 5 years will make a significant difference** to quality of life for people with dementia.
- **The Strategy needs new money:** The Society estimates that the cost of implementing the Strategy will be £600 million per year. This would require initial funding of £160 million in year 1 and £260 million in year 2 in order to begin changing practice. Over time service redesign will deliver efficiencies, but in the short term new money will be required.
- **The vision of the Strategy:** Although there must be an emphasis on transforming care and support, it must not be forgotten that this Strategy is about transforming the experience and lives of people with dementia.
- **Awareness:** Before a large-scale public awareness campaign, there is a need for robust research at the outset to establish baseline measures of the current levels of awareness, knowledge and stigma and the exact form that this stigma takes.
- **Workforce development:** The Society believes that the Strategy must incorporate a much stronger workforce development plan, following the precedent set in the End of Life Care Strategy. Although the Department does not have the power to make training mandatory, it can ensure workforce development through providing strong leadership to drive the agenda forward, working with key organisations and through the regulation system.
- **Diagnosis:** The care and support needs of individuals who do not have a clear diagnosis and their potential carers must be outlined.
- **Early intervention:** Barriers to low-level interventions, such as the Fair Access to Care Services criteria, must be addressed. It is unacceptable to have a system that works against providing any help to people with lower level and moderate needs.
- **Access to dementia drug treatments:** The Strategy is undermined by the current NICE guidance, which restricts access to drugs for people in the early stages of the disease. The role of dementia drugs in supporting people with dementia to live independently for longer must be specified.
- **End of life care:** The recently published End of Life Care Strategy did not adequately address the specific needs of people with dementia. End of life

care for people with dementia has now fallen between the two strategies and must be urgently addressed.

- **Transport:** Consideration must be given to transport, which is a vital aspect of the infrastructure needed to support the care of people with dementia and carers.
- **The needs of individuals:** The Society welcomes the fact that the Strategy is an inclusive document, however, the importance of considering the unique needs of individuals must be highlighted where appropriate, for example younger people with dementia, people from black and minority ethnic groups and people with learning disabilities.

Key areas where extra detail is needed include:

- **The dementia adviser role:** To ensure that the role is provided consistently across England, it is vital that there is a clear job specification and an understanding of how it fits in with other roles such as outreach workers. The Society estimates with dementia care advisers acting to sign post people to services and a case load of 200 people, this would require between 650 and 950 dementia care advisers.
- **Home care support:** The Strategy should further emphasise some of the benefits of the different types of support discussed and encourage commissioners to support their development.
- **Regulation in care homes:** To ensure that care homes can deliver their primary role of providing care to people with dementia, it is vital that the new CQC registration requirements EXPLICITLY stipulate that all care homes can take people with dementia.
- **Care home capacity:** The absolute number of places needed will continue to rise and the Strategy must advise commissioners to acknowledge and address this issue.
- **Antipsychotic drugs:** The DH review must ensure that non-pharmacological alternatives to drugs are available and implemented.
- **Peer support networks:** The Strategy makes some reference to peer support networks where people with dementia and carers can support each other and learn how to live with dementia. These need increased emphasis in the Strategy.
- **Abuse:** The Strategy must put in place measures to prevent abuse, including adequate training, ongoing support and supervision, and legal protection.
- **Personalisation:** It is essential that personalisation is a strong thread throughout the Strategy, underpinning all the recommendations.
- **Ensuring implementation:** Delivering the Strategy will require cross-governmental working and the Strategy must give consideration to how this will be achieved. It is vital that progress is monitored on an annual basis, as has been committed to in the Stroke Strategy, with a benchmarking activity to lay out the current situation. Leadership at a national and regional level is vital for the Strategy's success.
- **Research:** Alzheimer's Society believes there should be prioritisation of funding for dementia research, for example by the Medical Research Council.

The full submission is on the Society website under consultation responses.
<http://www.alzheimers.org.uk/site/scripts/documents.php?categoryID=200168>

Please contact Louise Lakey louise.lakey@alzheimers.org.uk, 0207 423 3581 or Alice Jarratt alice.jarratt@alzheimers.org.uk, 0207 423 3580 for more information.

5. Political influencing update

Thank you to all branches who have been in contact with their MPs to ask them to press the Government for financial commitment to the Strategy. Some branches have been able to meet their MP, while others have written. If you have not done so, please write to your MPs asking them to press Ivan Lewis, Care Services Minister for funding.

Central office is building on this work by lobbying target MPs and Peers and at the party political conferences. All MPs in England have been contacted.

This week the Society is releasing opinion poll evidence which shows that amongst the over 55 year olds (the age group most likely to vote), dementia is feared more than cancer, heart disease or stroke. In addition three quarters of people cannot explain which political party has the best policies for older people. For further details please see the website.

In the October edition of Living with Dementia magazine members of the Society in England will be asked to send their MP a 'Fund the Dementia Strategy' postcard. Branches will be sent a further batch of postcards to distribute.

Please contact Sarah Thomas sarah.thomas@alzheimers.org.uk, 0204 423 3585 or Vicki Combe vicki.combe@alzheimers.org.uk, 0207 423 3584 for more details.

6. Regional seminars

The next round of area forums (October/November) will be provided with updates for discussion and possible action.

A series of regional seminars is being arranged for the end of October/early November to ensure that staff and volunteers who are in contact with local NHS and social care commissioners are in a position to put the case both for the Dementia Strategy and for the role of the Society in responding to it. Area managers are nominating staff and volunteers to attend these initial events which will also put attendees in a position to be able to advise others.

7. Commissioning tool kit

A tool kit folder for staff and volunteers in contact with health and social care commissioners is being created. This will have a booklet setting out the case for dementia which will arm our staff with information so they are better placed to persuade commissioners about the case for Dementia Strategy implementation and will also act as information to leave with commissioners. In addition there will be information leaflets about the different aspects of the

service offer that the Society can provide (e.g. Dementia care adviser, training...). This information will be available in digital form on Arena by the end of October followed as quickly as possible by printed materials.

Please contact Andrew Chidgey for more information
achidgey@alzheimers.org.uk, 0207 423 3583.

8. Service offer update

Many staff have asked for advice on what they should be saying to commissioners in their discussions about new services. Because we do not yet have a National Dementia Strategy, and cannot be sure exactly what will be in it, it is hard to be exact about our contribution to its implementation. In this interim period we need to continue to promote our organisation and its services, being positive about our intention to contribute fully to the implementation of the new strategy.

- The Society strongly welcomes the focus in the draft Strategy on the need for better information services, proposals for dementia adviser role and the need for an informed and effective workforce.
- There now needs to be much greater clarity in the final Strategy document about the role of dementia adviser and how it is envisaged it will fit with other existing services.
- The Society believes that the third sector is well placed to provide the new dementia adviser service. We want to be involved, and have begun work on developing the dementia adviser service, drawing on our vast experience of delivering information and support services to people with dementia and their carers.
- We are developing our information services so that they better meet individual needs. We will develop tools to enable better access to information about local services for people with dementia.
- We will establish demonstration sites around England for the new services, where rigorous evaluation will provide evidence of the impact of the service on the quality of life of people with dementia.
- We already have a track record in the delivery of training, and we intend to build on this.
- We are unlikely to publish externally the details of our proposed new dementia adviser role and other services until after the launch of the National Dementia Strategy in November.

Further information

An information challenge project group has been established, chaired by Mary Garvey. This group will

- Develop our information tools and technologies.
- Develop the role of dementia adviser.
- Develop demonstration sites that will be fully funded and fully evaluated.
- Communicate about this work.

Work has begun on all the above. A group of staff from across services will work on the development of the dementia adviser role. At the time of the

launch of the National Dementia Strategy, we will be ready to share publicly the details of our new dementia adviser service.

New services will have some features in common with our existing services. There is no intention that they replace these services. We want more services for people with dementia. In time, particularly when the learning from the evaluation becomes available, some of our existing services may adopt some of the methodologies and tools of dementia advisers. Any changes resulting from the launch of new services will happen in a planned way.

Please contact Mary Garvey mgarvey@alzheimers.org.uk, 0207 423 3531 for more details.

9. PCT letter

Given that the Dementia Strategy publication date has moved to November this will be well after the planning round for the financial year 2009/10 has started. The Society will be writing to all PCT Chief Executives in England explaining the priorities identified in the Strategy in the next week. If there are any Chief Executives who branches or area teams would not like us to write to because there is already close contact on this please contact Alice Jarratt by emailing alice.jarratt@alzheimers.org.uk or calling 0207 423 3580.

10. External messages

The communications plan for the National Dementia Strategy for England is being reviewed in light of the close of the consultation. An update will be posted on Arena including our revised key messages. Meanwhile if you are asked for an media interview on the strategy please contact your Regional Campaigns and Media Officer or Gayle Wing, head of media relations on 0207 423 3595 gwing@alzheimers.org.uk for a briefing.