Suffolk
County Council

NHS

Living well with dementia

Transforming the quality and experience of dementia care for the people of Suffolk

A collaboration between Suffolk County Council, NHS Suffolk and Great Yarmouth & Waveney

leading health in Suffolk

Executive summary

The aim of the Strategy

The aim of the Strategy 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 identifies 17 key objectives which, when implemented, largely at a local level, 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. This Strategy should be a catalyst for a change in the way that people with dementia are viewed and cared for throughout England.

The issue

Recent reports and research have highlighted the shortcomings in the current provision of dementia services in the UK. Dementia presents a huge challenge to society, both now and increasingly in the future. There are currently 700,000 people in the UK with dementia, of whom approximately 570,000 live in England. Dementia costs the UK economy £17 billion a year and, in the next 30 years, the number of people with dementia in the UK will double to 1.4 million, with the costs trebling to over £50 billion a year.

While the numbers and the costs are daunting, the impact on those with the illness and on their families is also profound. Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills and the skills needed to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which complicate care and can occur at any stage of the illness. Family carers of people with dementia are often old and frail themselves, with high levels of depression and physical illness, and a diminished quality of life. Dementia is a terminal condition but people can live with it for 7–12 years after diagnosis.

The context

The size of the population affected by dementia and the pervasiveness of the condition mean that the development of policy and services for people with dementia and their families is also affected by the wider policy context. This currently includes initiatives, guidance and policy statements such as Our NHS, Our Future, Putting People First: A shared vision and commitment to the transformation of adult social care, the current public debate on the future of the care and support system, the National Institute for Health and Clinical Excellence (NICE) commissioning guide on memory assessment services, the Carers' Strategy (Carers at the heart of 21st century families and communities) and the National End of Life Care Strategy. Getting services right for people with dementia will make a positive contribution to all of these.

The consultation

Over 50 stakeholder events were held throughout the country as part of the consultation exercise, attended by over 4,000 individuals, and approximately 600 responses to the consultation document were received. The draft strategy was very well received by the public and professionals alike, and the recommendations it set out were seen as being the right ones if dementia services are to fully meet the needs of people with dementia and their carers. Areas where changes have been made are: provision for people with learning disabilities; the need for better peer support networks; improved end of life care; housing for people with dementia; and the particular needs of people with early-onset dementia (people under 65 years of age). In general, however, the draft strategy recommendations were acknowledged as the right ones and welcomed. A detailed response to the consultation has been published separately.

The Strategy objectives

The key objectives of the Strategy, addressed in more detail in the full document, are as follows below:

- **Objective 1:**
  Improving public and professional awareness and understanding of dementia.
  Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

- **Objective 2:**
  Good-quality early diagnosis and intervention for all.
  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.

- **Objective 3:**
  Good-quality information for those with diagnosed dementia and their carers.
  Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

- **Objective 4:**
  Enabling easy access to care, support and advice following diagnosis.
  A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

- **Objective 5:**
  Development of structured peer support and learning networks.
  The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

- **Objective 6:**
  Improved community personal support services.
  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. Services 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.

- **Objective 7:**
  Implementing the Carers' Strategy.
  Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

- **Objective 8:**
  Improved quality of care for people with dementia in general hospitals.
  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.

- **Objective 9:**
  Improved intermediate care for people with dementia.
  Intermediate care which is accessible to all people with dementia and which meets their needs.

- **Objective 10:**
  Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers.
  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.

- **Objective 11:**
  Living well with dementia in care homes.
  Improved quality of care for people with dementia in care homes by the development of explicit 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.

- **Objective 12:**
  Improved end of life care for people with dementia.
  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.

- **Objective 13:**
  An informed and effective workforce for people with dementia.
  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.

- **Objective 14:**
  A joint commissioning strategy for dementia. 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 and set out in Annex 1.

- **Objective 15:**
  mproved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.
  Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

- **Objective 16:**
  A clear picture of research evidence and needs.
  Evidence to be available on the existing research base on dementia in the UK and gaps that need to be filled.

- **Objective 17:**
  Effective national and regional support for implementation of the Strategy.
  Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

Implementation

7. The implementation plan for the Strategy can be found on the Department's dementia website at: www.dh.gov.uk/dementia. The Strategy's economic impact assessment (also available on the dementia website) is modelled over five years. However, the pace of implementation will inevitably vary, depending on local circumstances and the level and development of services within each NHS and local authority area. Decisions on funding for subsequent years will only be made once we have had the opportunity to consider the results from the initial demonstrator sites and evaluation work. There is no expectation therefore that all areas will necessarily be able to implement the Strategy within five years.

8. The Department will provide support for all those involved in implementing the strategy locally to ensure its delivery, particularly for those areas where services are less developed. Support will be provided at a national, regional and local level. The regional teams will work with localities within the region to help implement the Strategy. A national team will co-ordinate the programme and oversee production of materials to support implementation, using web-based materials and networks as well as running workshops and conferences.

What will the National Dementia Strategy mean for people with dementia and their carers?

9. Full implementation of the Strategy will mean that all people with dementia and those who care for them would have the best possible healthcare and support. We know that early diagnosis, effective intervention and support from diagnosis through the course of the illness can enable people to live well with dementia. We also know that improving health and social care outcomes in dementia in the short and medium term can have significant benefits for society both now and in the future.

10. Our vision is for the positive transformation of dementia services. It would be a system where all people with dementia have access to the care and support they need. It would be a system where the public and professionals alike are well informed; where the fear and stigma associated with dementia have been allayed; and where the false beliefs that dementia is a normal part of ageing and nothing can be done have been corrected. It would be a system where families affected by dementia know where to go for help, what services to expect, and where the quality of care is high and equal wherever they might live.


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A collaboration between Suffolk County Council, NHS Suffolk and Great Yarmouth & Waveney

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