

## **Living well with Dementia:**

**Transforming the quality and experience  
of dementia care for the people of Norfolk**

**A joint commissioning strategy  
2009-2014**

# Contents

	Page
	3
	4
<b>1</b>	6
<b>2</b>	11
<b>3</b>	
1	20
2	25
3	32
4	41
5	44
6	47
7	53
8	57
9	62
10	66
11	70
12	74
13	76
14	81
<b>Appendices</b>	
<b>A</b>	85
<b>Supporting documents available on request/on the internet</b>	
Demographic Detail	
Extracts from the Mental health Needs of the Elderly Population in Norfolk	
What people with dementia and their carers have told us	
The Draft Norfolk Care Pathway	
<b>E</b>	Service mapping to current services

## **Foreword by Director of Norfolk Adult Social Services, NHS Norfolk Chief Executive and NHS Great Yarmouth and Waveney Chief Executive**

In developing Norfolk's response to the challenges of improving services for people with dementia, now and in the future, we have worked with a wide range of people. Most importantly, we have been able to draw on the views and experience of people with dementia and their carers

The challenges are many – including tackling the stigma that surrounds dementia and improving and joining up the wide range of services needed by people with dementia and their carers. With Norfolk's large and growing population of older people, dementia will affect more and more lives.

There is a need for both members of the public and professionals to have, understand, and appreciate the full facts about dementia and for more tailor made education and training for professionals.

By diagnosing people earlier and providing them with the support they need, we will ensure people will have more choice and control over how they live with dementia. This will also enable them to live life to the full.

Recognising that people with dementia are first and foremost individuals should mean that people are treated with respect and dignity. Services will therefore become 'person-centred'. Better training will therefore enable services to develop to meet people's needs.

We have identified key priorities for Norfolk over the next five years and the purpose of this consultation is to check these priorities and their related actions have wider support.

Chief Executive  
NHS Norfolk

Director of Adult Social Services

Chief Executive  
NHS Great Yarmouth & Waveney

Julie Garbutt

Harold Bodmer

Dr Sushil Jathanna

## Executive Summary

The term “dementia” is used to describe a number of illnesses or symptoms in which there is a progressive impact in a person’s ability to take part in day to day activities, including a memory loss, reasoning, communication skills and the ability to carry out daily activities. Alongside this, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering. The causes of these illnesses are not well understood. The greatest risk factor is age, although this can affect adults of working age.

This draft joint commissioning strategy is Norfolk’s plan for implementing the National Dementia Strategy. The five year National Dementia Strategy (NDS) was published in February 2009 following widespread public consultation. The National Dementia Strategy can be found at;  
[www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm](http://www.dh.gov.uk/en/socialcare/deliveringadultsocialcare/olderpeople/nationaldementiastrategy/index.htm)

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 NDS lists 17 Strategic Objectives, 12 of which relate to services that should be available locally to all people with dementia, and two underpinning local action on workforce development and joint commissioning between public sector organisations. We have used 14 objectives as the framework for Norfolk’s joint strategy in order to ensure that dementia services in the future are more ‘person-centred’.

There are currently estimated to be 700,000 people in the UK with dementia. Dementia is thought to cost the UK economy £17 billion a year. This is more than the combined similar costs associated with stroke, heart disease and cancer together. These costs are spread across health and care services, as well as individuals and their carers. The number of people with dementia is set to double in the next 30 years and the cost predicted to treble.

In 2008 the number of people aged 65 and over in Norfolk predicted to have dementia stood at 12,714. By 2025 this figure is predicted to rise to 20,312 – a 62% increase, compared with a predicted national increase of 51%.

There is national and local evidence that people with dementia experience:

- Under-diagnosis increased delayed discharges from acute and community hospitals and multiple re-admissions.
- Premature admissions to care homes, and
- A general lack of appropriate services.

The NDS suggests that local strategies should pay particular attention to;

- Early diagnosis and intervention - up to two-thirds of people with dementia never receive a formal diagnosis
- Workforce development, and

- Improving care in care homes, where a third of people with dementia live.

The priorities for Norfolk were developed with people who use services, their families, NHS and social care staff and key partners such as voluntary organisations and housing agencies. The priorities are:

- Early diagnosis and support - such as information and treatment
- Raising awareness and understanding amongst professionals working with older people, and the public, so that people come forward for earlier diagnosis
- Providing support and breaks for carers
- Improving the quality of care for people with dementia who live in care homes, and
- Improved quality of care for people in general hospitals.

The NDS looked at the financial benefits (and costs) of its proposals and highlighted that:

- The additional costs of early diagnosis and support would be offset by savings elsewhere, especially in social care, and reduced care home admissions
- The cost of people inappropriately being cared for in general hospitals – perhaps from ‘emergency’ or ‘crisis’ treatments especially where dementia is not diagnosed - is on average around £6m for each hospital annually, as well as leading to poorer outcomes for people with dementia, and
- Good quality care homes for people with dementia have the same unit costs as poor quality homes.

We will only improve the quality and range of services for people with dementia and their carers through strong partnerships working together to make changes. The development of the joint commissioning strategy with extensive stakeholder involvement underpins the partnership approach. This also includes working together to identify where savings can be made to invest in our priority for new or expanded services without losing current effective services. Overall, implementing the strategy we believe will enable people with dementia and their carers to live well with dementia.

## Introduction

Dementia is a term surrounded in stigma, often misunderstood and those with dementia are often not diagnosed quickly enough, leaving individuals with dementia, their families and carers in difficult circumstances.

It is predicted that the number of older people with dementia will rise in Norfolk from 12,714 in 2008 to 20,621 in 2025, an increase of 62% over this period (3.6% per annum). However dementia also affects people under 65 (an estimated 400 people plus 31 under 65s who have Down's syndrome and dementia).

In Norfolk we know that we are spending a significant sum of money across the agencies on people with dementia. It is difficult to produce an exact figure because a lot of people have multiple needs, and therefore many of their needs are met by a wide range of services.

It has been recognised nationally that dementia has not had the same high profile as other illnesses. A National Dementia Strategy (NDS) "Living well with dementia" was produced early in 2009.

Following the publication of the national strategy, Norfolk County Council, NHS Norfolk, and NHS Great Yarmouth and Waveney, worked with colleagues from primary care, Norfolk and Waveney Mental Health Partnership Foundation Trust (NWMHFT), Norfolk Local Involvement Network (Link), local voluntary sector organisations and carers to develop a local strategy for Norfolk.

To ensure full involvement in the design of the strategy a "Stakeholder" event was held to help us decide on the priorities for Norfolk. This included a wider range of partners such as people with dementia, their carers, housing and social care providers.

We have jointly developed and agreed this strategy to transform the quality and experience of dementia health and social care services for the people of Norfolk. It will be important for all those affected in Norfolk, whether it be those who develop dementia themselves, or family carers who do such a valiant job caring for and supporting loved ones.

The strategy is underpinned by the National Dementia Strategy, which focuses on three themes:

- Raised awareness and understanding of dementia
- Early diagnosis and support, and
- Giving people the ability to live well with dementia.

Our strategy has been divided into the same 14 objectives that are found in the national strategy. For each objective we have put together information about the current situation, recommendations for improvement and plans for the development of future services.

The project delivery team is also in the process of talking more extensively with people with a dementia diagnosis and their carers to ensure we take their views fully into account. The research is due to be completed by December 2009 and the results will be published in January 2010. NHS Norfolk, Norfolk County Council and NHS Great Yarmouth and Waveney have made a commitment to ensure that the results of the research will be reflected in the final joint commissioning strategy.

But this is only the beginning. What will be most important is how all the agencies and organisations in Norfolk will work together in a strong partnership to deliver the plans contained in the strategy over the next five years in line with the national strategy.

## **Dementia – key facts**

It is a little known fact that much can be done to delay the onset and progression of dementia. Lifestyle changes, such as cutting down on alcohol, having a good diet and not smoking, can reduce the risk of an individual developing dementia in the future.

Dementia can be caused by a number of illnesses in which there is progressive decline in memory, reasoning, communication skills and the ability to carry out daily activities. Changes in behaviour are not uncommon, such as depression, psychosis, aggression and wandering.

Dementia is a long term terminal condition that impacts on a person's health, social circumstances and family life and has accordingly been given specialist consideration in long-term commissioning strategies. Dementia accounts for more years of disability than almost any other condition, including stroke, cardiovascular disease and cancer. It accounts for 10 per cent of deaths in men over 65, and 15 per cent of deaths in women over 65.

The risk factors for dementia are complex and vary according to the type of dementia. However, there is a higher risk of dementia:

- With age - about one in 14 people over 65 and one in 6 people over 80 has some form of dementia
- In women - who are slightly more likely to develop dementia than men.
- In smokers
- In those who consume alcohol to excess
- With an unhealthy diet
- In obesity and in those who do little physical exercise, and
- If the mind is not kept active.

## **Fundamental principles**

We believe that the principles that should underpin all services should be that they are:

- Integrated**
- The whole care system, health and social services, should be joined up to help people living with dementia and their carers.
- Patient/person-**
- The person with dementia and their carers should be the focal

<b>centred</b>	<p>point of commissioning</p> <ul style="list-style-type: none"> <li>• The care provided should be focused on the individual, not the environment in which it is provided</li> <li>• Promotes independence through the personalisation programme, assistive technology, housing and community based services.</li> </ul>
<b>Family-orientated</b>	<ul style="list-style-type: none"> <li>• An approach that works in partnership with, and takes account of, the needs of family members caring for loved ones.</li> </ul>
<b>Recognition for all services</b>	<ul style="list-style-type: none"> <li>• Full recognition given to the importance of third sector services. The people responsible for commissioning (buying) services will ensure that voluntary sector providers achieve full cost recovery for the services.</li> </ul>
<b>Housed well</b>	<ul style="list-style-type: none"> <li>• Housing options should be flexible and promote choice and independence, including care homes.</li> </ul>
<b>Offering help and prevention</b>	<ul style="list-style-type: none"> <li>• If there is a crisis, then services should be able to respond quickly and, where possible, prevent problems cropping up in the first place. This will reduce the likelihood of reoccurrence</li> </ul>
<b>Targeted</b>	<ul style="list-style-type: none"> <li>• Commissioners will ensure that services find and target populations with a higher prevalence of developing dementia, for example, coronary heart disease and alcohol related conditions, as well as specific communities with increased risks such as Black Minority and Ethnic Communities (BME).</li> </ul>
<b>Knowledgeable workers</b>	<ul style="list-style-type: none"> <li>• All areas of care and health should be aware of dementia. Specialist practitioners must be available with the skills to manage younger people with dementia and people with learning disabilities and dementia, and</li> <li>• The ‘specialist’, whether they are registered professionals or trained staff, must be able to provide suitable evidence of the knowledge they have in caring for people with a diagnosis of dementia. They may be employed by a variety of agencies but work together to form a specialist service within given geographical areas.</li> </ul>
<b>Enough workers</b>	<ul style="list-style-type: none"> <li>• Commissioners and providers need to make sure there are enough trained and experienced workers to meet demand</li> </ul>
<b>Equal</b>	<ul style="list-style-type: none"> <li>• Services should not discriminate on the grounds of age, race, gender, disability, culture, faith or sexual orientation. (Recording of age and ethnicity of service users should be emphasised as an inherent part of all quality monitoring systems)</li> <li>• Adherence to legislation on mental health, the Mental Health Act (2007), Mental Capacity Act (2005) and the Single Equality Act (2008), and</li> <li>• Providers need to demonstrate how all services treat people with equal dignity and respect.</li> </ul>
<b>Meets national standards</b>	<ul style="list-style-type: none"> <li>• Services must comply with national drivers.</li> </ul>

## Norfolk – current resources

As part of the preparation to inform this strategy, a mapping exercise was undertaken to find out what we have already in Norfolk. It is recognised that there are constant changes in the county and that we may have missed some services. We will build on this as we extend the work over the next five years. The mapping has proved to be difficult as many of the services provided to people with dementia do not specifically record dementia as part of the needs of the individual. Outline details of services are listed in a supporting document which is on the website or available on request; this information is also summarised under each objective in the full strategy document.

There is limited national funding for implementation and some of it is being used to pilot and evaluate new approaches. Norfolk for example was successful in obtaining funding to pilot the role of dementia advisor across Norfolk. The dementia adviser role is to provide ongoing information, advice and signposting support to people who are newly diagnosed with dementia.

The NDS impact assessment included information on the financial benefits (and costs) of its proposals. These highlighted that:

- The additional costs of early diagnosis and support would be offset by savings elsewhere, especially in social care. In addition there is evidence that such support, and early carer support, could reduce care home admissions by over a fifth
- The costs of people inappropriately being cared for in acute hospitals – perhaps from ‘emergency’ or ‘crisis’ treatments especially where dementia is not diagnosed - costs on average around £6m for each hospital annually, as well as leading to poorer outcomes for people with dementia, and
- Good quality care homes for people with dementia have the same costs as poor quality homes.

Whilst encouraging, this means that we will have to work together to significantly redesign services in order to realise savings to be reinvested for example in improved diagnosis and improved support services prioritised by Norfolk stakeholders.

Further work is being carried out to identify the financial implications of the Norfolk joint commissioning strategy using a Dementia Commissioning Toolkit (DCT). This tool provides the ability to better understand the health and care needs and services required for Norfolk. As well as supporting the development of care pathways for selected patients it outlines the financial and service implications of planned changes across health and social care.

The DCT will enable Adult Social Services and primary care trusts to better identify where additional resources are needed. We will also be able to see where savings can be made with no loss of service, to fund vital investments to implement the Norfolk Joint Commissioning Strategy.

In addition, many of the recommendations link to current plans for service development such as for carers’ services or end of life services. Work on these dementia objectives will be taken forward as a vital part of the carers and end of life strategies and plans.

Other benefits can be achieved by commissioning more training in staff skills and staff awareness – which was very clearly highlighted as a priority through the involvement events.

## 2 Pathways and Priorities

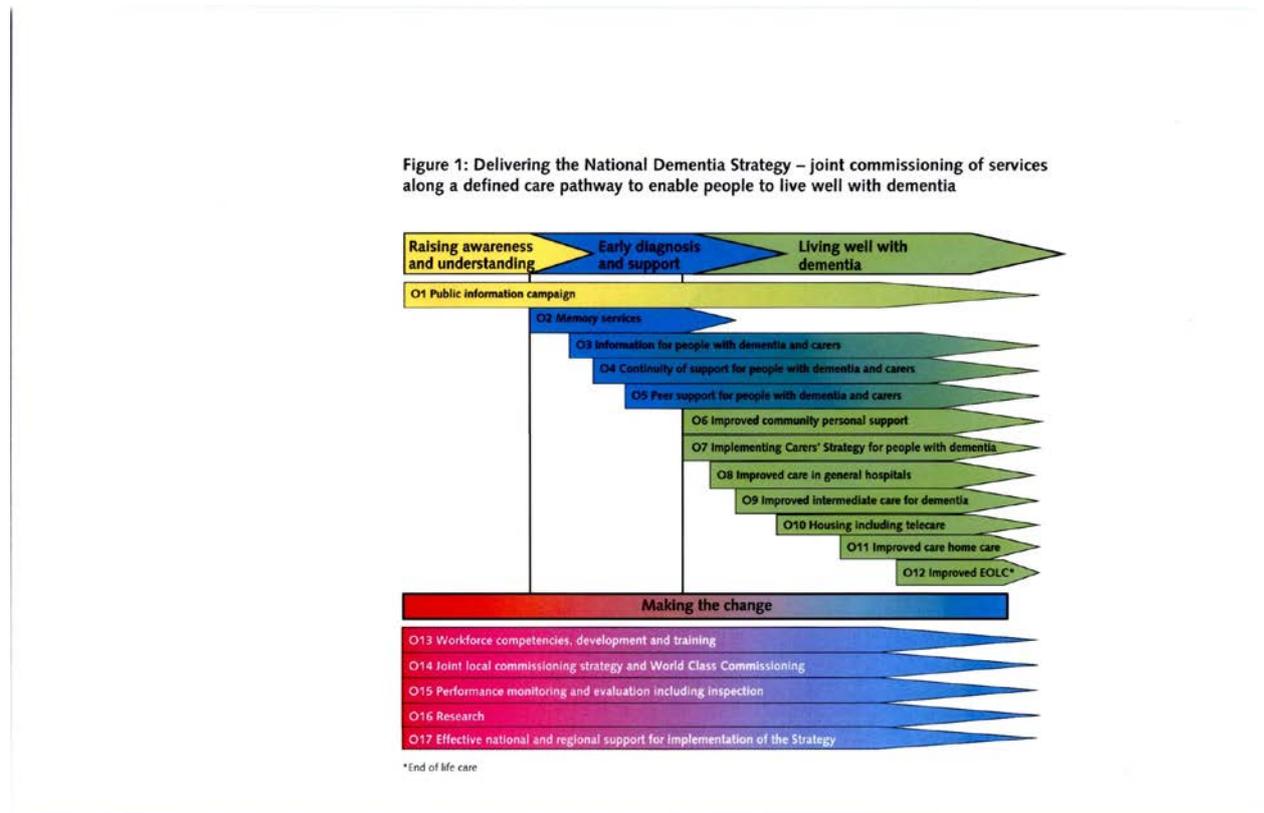
### National and local pathways

The National Dementia Strategy (NDS) sets out a three part framework to deliver the overall aim that all people diagnosed with dementia and their carers are helped to live well with dementia.

The three parts are:

- Encourage people to seek help and for help to be offered earlier
- Make early diagnosis and treatment the rule rather than the exception, and
- Enable people with dementia and their carers to live well with dementia by providing good quality care from diagnosis to the end of life.

Figure 1 below shows how the national objectives fit within this framework.

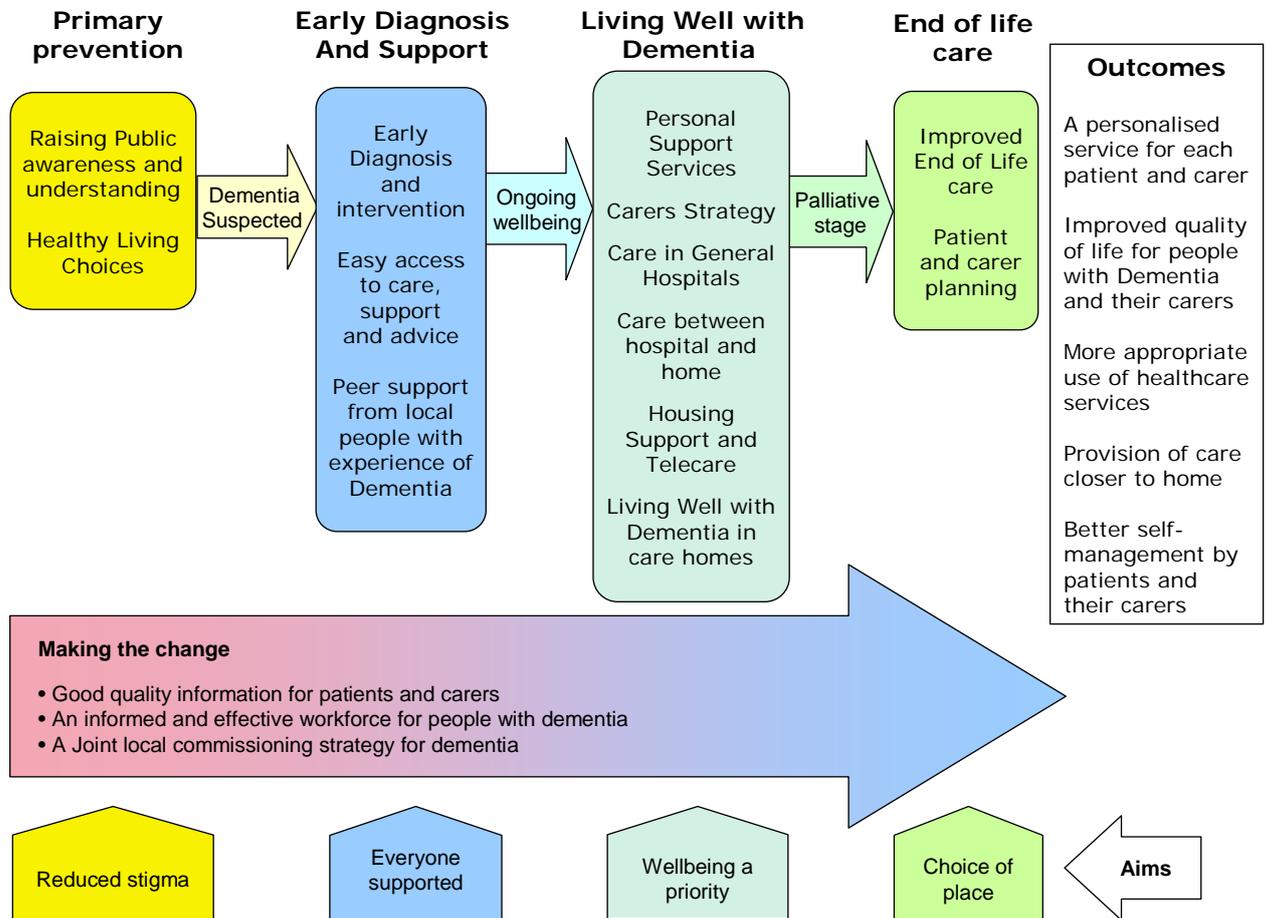


The work which has been undertaken in Norfolk has included developing a draft local care pathway and this is shown in Figure 2.

This is consistent with how we have developed pathways across Norfolk for other long term conditions, especially in NHS Norfolk. This means that we can join care pathways together, for example, where a person has both

dementia and diabetes. This should make care and treatment more person-centred.

**Figure 2**



## **Priorities for action**

The national strategy states that priorities for improvement should be decided locally, but suggests that particular attention should be paid to early diagnosis and intervention, workforce development, and improving care in care homes.

Norfolk's draft priorities have been developed through working with a wide range of people in public and third sector services who work with people with dementia and their carers in health, social care and housing.

The priorities have been shaped through more detailed discussions with people diagnosed with dementia and their carers. We have also drawn on public consultation and development work on carers' services, end of life services, housing options for older people, and day opportunities.

From all this work the Norfolk priorities for action from 2009 to 2012 have been identified as:

- Early diagnosis and support around information and treatment.

Improved services in these areas need to be in place before we move forward on a related priority:

- Raise awareness and understanding amongst professionals working with older people and the public so that people come forward for earlier diagnosis.

However the people who were involved in developing priorities are aware that they must not forget people who are already living with dementia.

As a result our other priorities are:

- Providing support and breaks for carers
- Improve the quality of care for the third of people with dementia who live in care homes, and
- Improve the quality of care for people in acute hospitals; this will also make better use of resources.

Underpinning these priorities are two key areas which will support improvement

- Workforce development, and
- Taking forward joint commissioning.

Members of the project group have linked into regional and national dementia work on workforce and joint commissioning issues.

In setting the priorities, the members of the project group have also taken into account that there are areas where Norfolk is already providing good services, for example, assistive technology, or where significant service development is planned. Examples of these include intermediate care to pro-actively avoid

acute hospital admissions, end of life care and carer strategy developments. We will make sure that the needs of people with dementia are fully integrated into these areas.

## Action plans

The following recommendations are aimed at making sure the Norfolk Joint Commissioning strategy deliver major improvements prioritised over the next two to three years (**Please note**, the numbering relates to the national objectives in the NDS.)

- Objective 1: Raise awareness and understanding amongst professionals and the public
- Objective 2: Good quality early diagnosis and intervention for all
- Objective 7: Providing support and breaks for carers
- Objective 8: Improved quality of care for people in acute hospitals
- Objective 11: Living well with dementia in care homes
- Objective 13: Workforce skills development; training around dementia issues, and
- Objective 14: A joint commissioning strategy for dementia.

The national strategy is designed around a five year plan. We will review Norfolk's priorities after two years and the delivery of plans annually. More detail can be found in the appendices on each Objective in the full strategy.

### Action 2009/2010

2.1 A protocol to be agreed and adopted for primary care services within Norfolk on the screening, early diagnosis and referral pathways for people with symptoms which may be mild, moderate or severe dementia. This will involve developing more effective screening tools for GPs, which also take account of people's diverse backgrounds.

2.4 We are currently checking on the numbers of clients currently being seen in Norfolk in memory clinics. This service can vary and there is a need to link with national and international developments to make be sure that memory clinics deliver the same services and standards across Norfolk in order to improve the rate at which people are diagnosed.

2.5 The 'best practice around delivering services recommended by the NDS is through a multi disciplinary team (MDT) working between primary care services and specialist older peoples mental health services. Further work will need to be undertaken to decide if this is the right model for Norfolk, building on existing services, and to agree roles, skill mix and staffing levels. This will link into investment plans.

7.2 Agree a joint health and social care model for day opportunities which will support joint commissioning and the expansion of services to meet needs of people within a person-centred approach and work towards commissioning more social care places.

8.4 Review the potential impact of specialist liaison older people's mental health staff in local acute hospitals and voluntary sector mental health staff. There is a need to look at national work to see if the nature or coverage of the

role needs to be extended, for example from medicine for older people into other 'specialist areas' and to provide support to patients and staff. We will also look at the training and education of health staff to make sure they involve family members more, for example when supporting the discharge process alongside social services staff.

8.5 Implement nutrition action plans in acute hospitals for people with dementia, where they are not already in place, including visible ways to ensure supported feeding always occurs.

11.1 Complete the review of the local anti-psychotic drug initiative, and share the learning on the management/ guidelines for the use of drugs and medication in the treatment of dementia with all care homes in Norfolk

11.3 Maximise the capacity to deliver in-reach services to care homes by NWMHFT to prevent crises and preventable hospital admissions.

11.4 Continue to test the potential of telecare and assistive technology within the care home setting and consider the opportunities from award winning tele-health and tele-care services already operating across Norfolk.

14.1 Develop an agreed integrated pathway for dementia with new service models as required to underpin investment decisions.

14.2 Develop the use of the dementia commissioning tool (DCT) to support dementia services investment decisions.

14.3 Work with the NHS programme boards and clinical networks covering primary care, planned and unplanned acute care, long term conditions and end of life care so that they meet the needs of people with dementia and their families in their commissioning decisions. Make sure it is embedded in the performance management of providers.

14.4 Work with partners in the Local Area Agreement to ensure that mainstream services take full account of the needs of people with dementia and their carers.

14.5 Strengthen the locality focus on dementia by working innovatively with Practice Based Commissioners (PBC). Increase the participation of people with dementia, their carers and service providers in the Norfolk mental health locality groups. Use these groups to shape the potential future development of the dementia adviser service currently being piloted, and to coordinate with pilots of other 'navigator roles' for people diagnosed with a long term condition.

## **Action 2010/2011**

1.1 Undertake high profile media campaigns across Norfolk to back up the raised public awareness following the launch of the National Dementia Strategy. A campaign of this nature must have a phased approach, developing and continuing over time, this needs to be linked to the joint strategy.

1.2 Accurate, accessible, evidence based information will be made available to all people in Norfolk. This will be in a variety of formats through the INTRAN partnership and development of health and social care information networks. The information will meet the health and social care needs of individuals and their carers and be culturally sensitive.

1.3 Organisations will be encouraged to use existing networks to broaden the distribution of information relating to issues around dementia, diagnosis, help and the support available. Joint commissioning from the third sector should be expanded as a source of information. Commissioners will seek partner organisations to develop and to distribute information packs needed to inform the general public, individuals with dementia and their carers.

2.2 Monitoring will take place to ensure GP practices increasingly and routinely screen patients with known risk factors for dementia, such as coronary heart disease and stroke, during their annual review.

2.6 Work with Practice Based Commissioning to develop primary care services, for example through awareness skills training, GPs with special interest in dementia, older people's mental health services, and specialist nurses carrying out screening.

7.1 Information packs - these will be increasingly available for family carers.

7.3 Short-breaks. Improving the variety and flexibility of short break services available for families of people with dementia, both current bed-based within residential settings, and home based services and those developed in the future. This will utilise both social care and health funding and increasingly will be supported by the introduction of personal budgets and personal health budgets to offer greater flexibility and choices and innovative opportunities.

8.1 Each acute hospital should identify a senior clinician to lead a task force of staff for quality improvement in supporting those with dementia in hospital. This could be a shared appointment with for example NWMHFT.

8.2 Acute hospitals should develop an explicit care pathway for the management and care of people with dementia in hospital, from a task force of staff, possibly led by that senior clinician.

8.3 Extended assessment in acute hospitals to include specific information from both family carers and paid carers to better assist with the care of the person with dementia.

8.6 Develop awareness training for all hospital staff on the health and social care support needs and requirements of those with dementia and their carers. This could potentially include information displays throughout the hospital.

8.7 Implement training of hospital staff in order to better understand the needs of people with dementia. This will ensure positive outcomes from all around involvement with patients with dementia and their carers.

11.2 Establish a Norfolk Dementia Provider Forum, building on the existing Norfolk County Council Adult Social Services Dementia Provider Forum and other forums including Norfolk Mental Health Provider Forum. This will encourage leadership in each area, including in each care home, and act as a network to promote good practice

13.1 Develop a Norfolk workforce strategy through local networks, and linking with regional plans to take on board the implications of the dementia strategy. This will ensure a coordinated approach to staff training and development around dementia issues for all staff in health, social care and the housing sectors especially, who are in contact with people with dementia.

13.2 Commissioners, with input from people with dementia and their carers will specify the necessary potentially mandatory dementia training across the whole care pathway, including end of life for service providers. This will also cover training those who care for people with dementia, including family carers and services in the community.

13.3 Require all providers who support or care for people with dementia or their carers to have a baseline awareness of their current staff in relation to dementia, and to develop an action plan to reach the overall required standards.

### **Action 2011/2012**

2.3 Routine screening will be expanded, using a phased approach, to target the generic older population. Screening will be carried out by professionals such as practice nurses trained in a core set of competencies.

13.4 Influence training for staff in universal services for example, receptionists, help desk staff, porters, and clerical teams. This will ensure there are more skills and awareness training around dementia across the widest possible range of staff that may be in contact either directly or indirectly with people diagnosed with dementia or their carers.

## **Plans for other objectives**

The key plans for the remaining seven objectives are shown below. As with the NDS they are considered to be very important but have been seen by stakeholders as being as of lower priority than those focused upon already. Many of them are developments of existing work. More information on all the objectives, the current situation and local plans can be found in the full strategy which is available on the website: [www.yournorfolkyoursay.org](http://www.yournorfolkyoursay.org) You can also get a copy by phoning 01603 228847

3. Good quality information for people with dementia and their carers. We will improve the co-ordination and access to information about dementia and services for people with dementia and their carers, both at diagnosis and during their care.

4. Easy access to support and advice after diagnosis. We will pilot the dementia adviser role to provide information, support and advice and decide on its long term future.

5. Develop structured peer support and learning networks. We will develop existing services so that people with dementia and their carers will be able to get support from local people with experience of dementia and take an active role in developing local services.

6. Improve community personal support services for people living at home. We will develop flexible services to support people with dementia living at home and their carers. This will include crisis response services, day opportunities, advocacy services and domiciliary care.

9. Improve intermediate care for people with dementia. We will ensure that services designed to avoid hospital admissions and help people leave hospital quickly are able to meet the needs of people with dementia.

10. Consider how housing support, housing-related services, technology and telecare can help support people with dementia and their carers. Services will consider the needs of people with dementia and their carers when planning housing and housing services and try to help people to live in their own homes for longer.

12. Improve end of life care for people with dementia. We will consider the needs of people with dementia and their carers when planning local end of life services.

### **3 Where we are now and our plans for change against the National Dementia Strategy Objectives.**

#### **Where are we now and priorities for change?**

##### **National Dementia Strategy Objective 1: Improving public and professional awareness and the 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.

#### **Awareness raising**

Currently fewer than half of people with dementia will ever receive a diagnosis. People with dementia and their carers are prevented from accessing diagnosis, and hence services and treatment, through stigma which prevents discussion, a false belief that the symptoms are due to 'old age' and a false belief that nothing can be done. This results in activity in seeking help. There are similar factors operating within professional groups.

Improving awareness is needed to develop a better understanding of dementia by the public and professionals and to tackle stigma, backed by improved information on what help and treatment is available. The national strategy is planning an awareness strategy, an anti stigma campaign and better communication with the public and a wide range of professionals.

#### **Information to reduce risk factors**

Dementia accounts for 10 per cent of deaths in men over 65, and 15 per cent of deaths in women over 65. Delaying the onset of dementia by five years would halve the number of deaths in the UK due to dementia to 30,000 a year.

While there is no evidence of ways to prevent dementia, it is possible to reduce some of the risks associated with it. The most significant risk factor for Alzheimer's disease is increasing age, together with other factors which cannot be changed such as gender, genetics, having Down's syndrome and other medical conditions such as multiple sclerosis and Huntington's disease. The risk factors for vascular dementia include age, high blood pressure, obesity and stroke. Most of these are amenable to intervention.

A healthy lifestyle can help reduce the risk of developing vascular and other dementias. These include:

- Taking regular exercise

- Eating healthily
- Drinking in moderation
- Not smoking
- Having regular checks on blood pressure and cholesterol levels
- Maintaining interests and hobbies
- Maintaining an active social life
- Mental stimulation, through adult education, reading, crosswords etc

Population-level screening is not practicable but screening may be targeted at people who are at high risk of developing dementia, such as people with Down's syndrome. At a broader level, strong public health messages and education campaigns are needed.

### **The current situation in Norfolk**

Norfolk's 'Finding Your Way' booklet for the public, on older people's mental health issues, has been extensively distributed and encourages people to seek help early.

'Mind Your Memory' campaign has been run by Alzheimer's Society through e.g. GP practices in 2008. There will be awareness raising with Norfolk GPs in the autumn with regional support, encouraging them to run the Mind Your Memory campaign in surgeries

Memory Matters roadshows to inform the general public around dementia have been run in Norfolk in summer 2009 and more are planned

NCC Adult Social Services run a dementia forum that is open to anyone working in social care and includes staff from the NWMHFT. The aims are to improve quality of dementia care and share good practice.

UEA have undertaken an extensive study into initiatives to support carers

### **Norfolk priorities for action**

- Developing and delivering a local general public information campaign to complement national campaigns and meet local needs.
- Targeted campaigns for other specific groups (e.g. utilities, public-facing service employees, schools and cultural and religious organisations, ethnic minority groups, people with disabilities).
- Commission the 'Memory Matters Roadshows' that aims to de-stigmatise dementia. The roadshows to bring together a variety of providers from the statutory and non-statutory sectors to offer advice and referral.
- To ensure that all public and health professionals have the knowledge to recognise dementia symptoms and to signpost people to appropriate services
- Introduce children to issues around dementia through interactive work e.g. citizenship teaching, health and social care

- Inclusion of the strong prevention message that ‘what’s good for your heart is good for your head’ e.g. healthy eating (5-a-day etc, tackling obesity, exercise, smoking cessation)
- Run a public awareness campaign that highlights the role of smoking in increasing dementia risk and encourages/ signposts people to sources of support to help them quit smoking.
- To include in the Local Area Agreement target on exercise/ physical activity a sub-target for older people – this will involve a wide range of partners
- Target specific areas through information on different socio-economic groups and lifestyles
- All information to be available in easy to read format

**Objective 1: Improving public and professional awareness and the understanding of dementia**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
1.1	Undertake high profile media campaigns across Norfolk to back up the raised public awareness following the launch of the National Dementia Strategy. A campaign of this nature must have a phased approach, developing and continuing over time, this needs to be linked to the joint strategy.	To run a media campaign aimed at the wider general public encouraging them to take steps to reduce their risk factors. The campaign to be based on a 'what's good for your heart is good for your head' approach.		PCTs	Increased awareness of lifestyle factors that increase the risk of dementia and lifestyle changes to reduce risk factors
1.2	Accurate, accessible, evidence based information will be made available to all people in Norfolk. This will be in a variety of formats through the INTRAN partnership and development of health and social care information networks. The information will meet the health and social care needs of individuals and their carers and be culturally sensitive.	Review of information provided by Heron with public/patient/carers. Accurate, up-to-date information to be available in a variety of accessible formats at GP surgeries, voluntary organisations, cultural and religious groups, libraries, Citizens Advice Bureaux, housing offices, community centres, solicitors offices etc.		PCTs and ASSD	

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
1.3	Organisations will be encouraged to use existing networks to broaden the distribution of information relating to issues around dementia, diagnosis, help and the support available. Joint commissioning from the third sector should be expanded as a source of information. Commissioners will seek partner organisations to develop and to distribute information packs needed to inform the general public, individuals with dementia and their carers.	To develop a local Dementia Network to facilitate the sharing of good practice, information and to cascade training. To identify and compile a register of all service providers and potential service providers. To work with 3 <sup>rd</sup> sector providers to developed a standardised information pack for service users and carers.			

**Potential Quality Indicators (EOE guidance)**

- User and family carer survey on satisfaction with the source, access, accuracy, timeliness and quality of the information provided, to include point of referral
- % of clinics, day centres, care homes, libraries, NHS Trusts, Local authority offices ,GP practices and online resources providing access to specialist information on dementia and uptake of that information
- Numbers attending dementia support services within the voluntary sector and numbers of new attendee's
- Numbers of people referred for information prescriptions (recorded by referrer)
- Numbers of people presenting with information prescriptions and numbers of visits required to get the information needed

## Where are we now and priorities for change

### **National Dementia Strategy 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.

Commissioners of Dementia Services (health and social care) are being recommended by the National Dementia Strategy (NDS) to work closely with primary care commissioners and practice-based commissioners to improve the quality of referral and diagnosis and increase the numbers of people who receive a formal diagnosis.

Currently between half and two thirds of people with dementia never have a confirmed diagnosis (Alzheimer's Society, 2007). Often it is at a time of crisis that a person is diagnosed and by then it is very late for them to be able to make choices. A core aspect of the NDS is to ensure that effective services for early diagnosis and intervention are available for all.

The NDS included the clinical and health economic case for early diagnosis and intervention services for people with dementia. The economic case demonstrates how, over 10 years, reductions can be made in admissions to long-term institutional care thus releasing revenue to invest in prevention and early intervention. Early intervention also improves the quality of life and wellbeing for people with dementia and their carers.

### **The current situation in Norfolk**

The Alzheimer's Society report on 'Dementia – what every commissioner needs to know' stated that, on average, 40% of the predicted population with dementia are on GP dementia registers. The percentage on GP registers for 2006/07 was 37.1% in NHS Norfolk and 49.9% in NHS Great Yarmouth and Waveney.

NHS Norfolk's 2009 Mental Health Needs Assessment of Older People in Norfolk found that barriers to access for assessment by specialist mental health services included denial by older people (blaming their age for reducing memory and not seeking help for symptoms) and lack of recognition of symptoms by GPs. NWMHFT reported increased referrals from GPs for specialist assessments e.g. between 2007 and 2008 the demand had grown by 17% in southern locality and 23% in northern locality.

NWMHFT is piloting a Dementia Worker role in early diagnosis and signposting attached to GP practices (currently one in south Norfolk. Pilot for Norwich due October/November 09)

The current PCT Referral Guidelines for GPs on Suspected Dementia are due for review.

## **The current situation in Norfolk continued**

Norfolk was a part of the Partnership for Older People Pilots (POPPs) programme established by the Department of Health to develop the evidence base for benefits of early intervention. Norfolk evidenced significant improvements in outcomes for people using POPPs services. Users reported that their health-related quality of life improved in five key domains – mobility, washing/dressing, usual daily activities, pain and anxiety. Financial evidence is also encouraging. For every £1 spent on POPPs, 73 pence will be saved on the cost per month of emergency bed days, assuming the cost of bed days to be £120.

A review of the evidence confirms that there is a marked reluctance on the part of primary care to be directly involved in the diagnosis of dementia. Reasons include risk avoidance, concerns about competency and available resources in the Practice and to support those diagnosed. The National Strategy recognises that these are reasonable concerns and that the role of primary care should be that of identifying those with symptoms, excluding any other explanatory disorder and referring on to a specialist service for the patient to receive a definitive diagnosis, not only of dementia but also of the sub-type of dementia.

The NDS recommends that referrals should be made from primary care to a specialist service for early diagnosis and intervention. Such services would need to provide a simple single focus for referrals from primary care and would work locally to stimulate understanding of dementia and referral to the service. The primary care role following diagnosis can therefore be informed as to whether or not that person has dementia and of what sub-type, and treatment and support modified accordingly.

Commissioners are working on maximising the opportunities for screening for physical risk factors such as coronary heart disease, stroke (which are associated with vascular dementia) during a patient's annual review. Some basic cognitive screening questions, to be locally agreed between primary and secondary care, could be added to this review. If a patient answers positively to agreed questions then referral to a memory assessment service (MAS) is required. Using evidence based assessment tools, the initial memory assessment can be undertaken by specially trained primary care nurses (Practice Nurses, District Nurses, Health Visitors or Mental Health link workers).

Commissioners are also being recommended to model the impact of early diagnosis on other services. People diagnosed early are likely to receive pharmaceutical and therapeutic interventions that will help them to live active lives for longer. Commissioning services, particularly early diagnosis and support, must therefore be set within the context of whole pathways of services and support for the person diagnosed and their family/supporters.

There are close LINK between early diagnosis and

- Good quality information for those with diagnosed dementia and their carers (Objective 3)
- Enabling easy direct access to a contact who can signpost and facilitate health and social care input (Objective 4)
- Peer support and learning networks for people with dementia and their carers (Objective 5)

### **Norfolk priorities for action**

- To commission a good quality service for early diagnosis and intervention in dementia, available locally, which has the capacity to assess and support all new cases occurring in that area.
- To agree a core set of consistent screening and assessment tools and paperwork. To reviewing existing systems in agreeing this.
- To agree referral routes to early diagnosis services e.g. through primary care, social care, voluntary sector or 'open' for the public.

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

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>2.1</b>	A protocol to be agreed and adopted for primary care services within Norfolk on the screening, early diagnosis and referral pathways for people with symptoms which may be mild, moderate or severe dementia. This will involve developing more effective screening tools for GPs, which also take account of people's diverse backgrounds.	The current PCT Referral Guidelines for GPs on Suspected Dementia are due for review			
<b>2.2</b>	Monitoring will take place to ensure GP practices increasingly and routinely screen patients with known risk factors for dementia, such as coronary heart disease and stroke, during their annual review.				
<b>2.3</b>	Routine screening will be expanded, using a phased approach, to target the generic older population. Screening will be carried out by professionals such as practice nurses trained in a core set of competencies.				

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>2.4</b>	We are currently checking on the numbers of clients currently being seen in Norfolk in memory clinics. This service can vary and there is a need to link with national and international developments to make be sure that memory clinics deliver the same services and standards across Norfolk in order to improve the rate at which people are diagnosed.				
<b>2.5</b>	The 'best practice around delivering services recommended by the NDS is through a multi disciplinary team (MDT) working between primary care services and specialist older peoples mental health services. Further work will need to be undertaken to decide if this is the right model for Norfolk, building on existing services, and to agree roles, skill mix and staffing levels. This will link into investment plans.	IPSOS Mori are undertaking work with people with dementia and carers which will help inform this work. The consultation on the draft joint strategy will be used to develop service models and pathways in workshops	To be completed in October 2009  To be completed by February 2010	Commissioners	

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>2.6</b>	Work with Practice Based Commissioning to develop primary care services, for example through awareness skills training, GPs with special interest in dementia, older people's mental health services, and specialist nurses carrying out screening.				

**Potential Quality Indicators (EOE guidance )**

- READ coding for recording screening at CHD annual review, and outcome of screening, should be agreed and implemented
- PCTs to work with their GP practices to have a dementia protocol and pathway in place
- Time of waiting after referral to specialist treatment should initially not be longer than 18 weeks\_which includes time to assess and confirm diagnosis. This is in accordance with the National Standards on access
- Date of referral to memory assessment service and date seen to be recorded
- Date of referral from memory assessment service to date seen by specialist (where indicated) to be recorded
- Rates of detection in primary care monitored (targets for %age of expected cases identified)
- Record number of people referred (by GPs) to Memory Assessment Services that have had a medical review, urinalysis and routine blood investigations. Commissioners should aim to achieve a 100% of all referrals by a date to be set
- Providers to record the source of referrals (possibly including self-referral) to memory assessment services
- Numbers and throughput to Memory Assessment Services recorded
- Questionnaire on person's experience and Action plan to respond to outcomes
- Record date of first appointment with integrated team. Time of referral to specialist treatment should not be longer than 18 weeks, including time to assess and confirm diagnosis. This is in accordance with the National Standards on access

- Record % of people seen who have a follow up appointment arranged
- Record levels of prescribing of cholinesterase inhibitors

## Where are we now and priorities for change

### **National Dementia Strategy 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.

Accessible, evidence based information needs to be available in a timely manner, both at diagnosis and as the condition progresses. Information and information support services are required by those diagnosed with dementia, their families and carers (see also objective 7) about a range of issues, including:

- Information on the illness, coping techniques, financial and legal issues, services available and planning ahead
- Details about how to access advocacy support to assist with the accessing of services
- Information about the availability of rehabilitative approaches to managing memory loss, disorientation or difficulties with daily living skills.
- How to access support including one-to-one support and support groups.
- Information about how to access financial support to offset income loss for younger people with dementia or relatives who have to give up work to care for the person with dementia.

Individuals will require different levels of information at various stages, dependent on their individual needs and situations:

"...not to have too much all at once as it's overwhelming." (Suffolk)

'They didn't give me enough information. I came away thinking, "What do we do now, where do we go from here?" ' (NDS)

'Most important of all to be given all the information they need: not about what's just happened but about what is likely to happen and where you can go for assistance.' (NDS)

A coordinated approach will be taken to the provision of information across Norfolk, for patients, carers and health professionals. When assessing the quality and appropriateness of resources, account will be taken of both the work of the national information stakeholder group<sup>1</sup> and local needs.

---

<sup>1</sup> Living Well With Dementia: A National Dementia Strategy – Implementation Plan. P26: A national Information stakeholder group is being established to:

- Gather evidence of the information needs of people with dementia, carers, family and public
- Measure effectiveness of existing information (content and media)
- Complete review of existing information sets

Information needs to be culturally sensitive and available in a range of formats in order to cater for the diverse populations affected by dementia, e.g. different language needs, minority ethnic groups, people with learning disabilities, and those with early-onset dementia.

In order to reach all audience, information needs to be available in both formal and informal settings, e.g. GP practices and other health, social care and voluntary sector locations, and also via social and leisure locations such as libraries, community and shopping centres.

Information should not just be in the form of traditional literature, but also be shared via peer support networks (for more information see objective 5), social and training events, and in the form of different media, e.g. websites, web discussion groups, telephone help lines and audio-visual materials.

The availability of information and information services should be promoted via campaigns (see objective 1), and made more accessible via information support services such as Dementia Advisors (for more details see objective 4), other voluntary sector information and advice services, and signposting websites.

### **The current situation in Norfolk**

The Mental Health Assessment for Older People raised the issue that both the public and health professionals had a:

- Lack of recognition of dementia symptoms
- Lack of awareness of 3<sup>rd</sup> sector/agency services

In order to highlight the availability of dementia related services, a service mapping exercise was undertaken, which identified a number of services not already listed on the Heron website, and others that need their profiles raised. The process of gathering and promoting service information will continue via joint working with the Dementia Advisors and other information support services, and through the development of a website to support those with long term conditions.

The Alzheimer's Society and other organisations provide great deal of tried and tested information resources, including fact sheets, a discussion forum and telephone helpline.

However, a review of existing resources has identified a limited availability of information in different languages and alternative formats. Ongoing review will be undertaken in light of local requirements, and relevant translation and adaptation undertaken if required.

---

• Submit recommendations for information guidance, tools and packages at national, regional and local levels  
See: <http://www.dementia.dh.gov.uk/>

In Norfolk the following initiatives are contributing towards meeting this objective:

- Norfolk is one of the areas piloting a Dementia Adviser service, which will provide information and advice to patients and their carers, and signpost them to additional help and support (see objective 4 for more details). However, the Advisers will also work jointly with local information and knowledge services to assist the population and maintenance of the Heron service and support groups database, and the planned long term conditions website.
- A Primary care Dementia Worker is currently being piloted at Paston Surgery.
- A Crisis Intervention Worker service is currently being piloted at the Wensum Valley Medical Practice
- Personal Health Plans (PHP) will be a requirement for all Dementia patients by September 2010. In order to realise the benefits of PHP, patients and carer require clear support, guidance and high quality information. Therefore access to appropriate information sources is a pre-requisite for implementing personal health plans.
- The self care model of choice is a project that aims to provide access to self management options to people suffering from long term conditions. The options might include: exercise programmes, structured education, access to approved information, assistive technology, coaching, telephone review and Dementia Advisors. There are plans for a patient friendly web resource to assist with the dissemination and promotion of information and of patient / carer involvement.
- Upgrading and development of the Heron and Patient Information databases (available via the Heron and Knowledge Norfolk websites) will extend the facilities to integrate service / support group and condition related information into specialist resources aimed at specific user groups and situations.
- Health and social care are working on a joint Child and Family Services directory, which provides a simple search interface to search across various local services/support group databases, including Heron, County Council, Icon, Connexions etc. Once this is launched, work will begin on the interface to search across Adult services.

**Norfolk's priorities for action are:**

- A coordinated approach to the provision of information across Norfolk, for patients, carers and health professionals.
- Distribute and promote good quality national information resources, at diagnosis and throughout the course of the condition.
- Providing access to information via a wide variety of locations and methods to cater for the needs of different individuals
- Information packs to include outlines and signposting to local services and support groups, and resources in other media/languages where appropriate.
- Maintain and make accessible information about local services and support groups, and encourage information services and support groups to provide feedback on new or changed information to the Heron database.
- Complement the roles of Dementia Advisors and other services providing access to information with a user friendly 'long term conditions' website.
- Utilise the Knowledge Norfolk website to provide a single point of access to dementia information and guidance for professionals across Norfolk.

**Objective 3: Good quality information for those with diagnosed dementia and their carers**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>3.1</b>	Coordinate the approach to information	Joint working across health, social care, voluntary sector and libraries			
<b>3.2</b>	At diagnosis and throughout the course of the condition distribute and promote good quality resources	<ul style="list-style-type: none"> <li>• Make use of national information resources wherever possible.</li> <li>• Information to be available in all locally required languages and formats. Where national materials do not cater for local language / format needs, these may be translated and adapted where required</li> </ul>			
<b>3.3</b>	Access and signposting to dementia information via a variety of methods and locations.	<ul style="list-style-type: none"> <li>• Dementia 'early diagnosis' diagnosis services.</li> <li>• Dementia Advisers</li> <li>• Information and signposting to be available via locations such as GP surgeries, health and social care services, residential and</li> </ul>			

Recommendation	Planned developments	Timing	Lead agency	Outcomes
<p><b>3.4</b> Supplement document based information with information and signposting to local services and support groups, information in other formats</p>	<p>nursing homes, voluntary sector organisation and meetings; and social meeting places, Libraries, shops and supermarkets</p> <ul style="list-style-type: none"> <li>• Updated and reprinted “Finding your way booklet”</li> <li>• An alternative signposting publication for those with early onset dementia</li> <li>• Heron website of services and support groups and tailored printouts</li> <li>• Audio-visual material and books on loan from libraries</li> <li>• Web-based resources and social networking tools</li> </ul>			
<p><b>3.5</b> Maintain and provide access to information about local services and support groups.</p>	<ul style="list-style-type: none"> <li>• Continue to collate health related services and support group via the Heron database.</li> </ul>			

Recommendation	Planned developments	Timing	Lead agency	Outcomes
<p><b>3.6</b> To complement other information support services, all information provided to patients/carers to be accessible/signposted via the planned patient friendly 'long term conditions' website</p>	<p>Those participating in information support services will be encouraged to utilise this resource and provide feedback on new services and changes</p> <ul style="list-style-type: none"> <li>• information from the Heron database to feed into the planned 'long term conditions' website; and the planned health and social care cross database search facility on the County Council website</li> <li>• website to provide access to the same information as available in print format, plus other electronic sources where appropriate.</li> <li>• access to information in other languages via language specific pages</li> <li>• Integration of data about local service info/support groups from the Heron</li> </ul>			

Recommendation	Planned developments	Timing	Lead agency	Outcomes
<p><b>3.7</b> Access to information for health professionals to continue to be provided via the Knowledge Norfolk website.</p>	<p>database</p> <ul style="list-style-type: none"> <li>• promotion of local courses and events, interactive peer support activities such as face to face and electronic forums and networks</li> <li>• GP practice websites to link to this site.</li> <li>• A dementia specific index will be established to highlight services and support groups, plus information for patients</li> <li>• The upgrade to the content management system will provide easier navigation and search facilities.</li> </ul>			

### **Potential Quality indicators (EOE guidance)**

- User and carer survey on satisfaction with the source, access, accuracy, timeliness and quality of the information provided, to include point of referral
- Information resources available in locally required languages and formats – compared with local demographic data
- % of clinics, day centres, care homes, libraries, NHS Trusts, Local authority offices, GP practices and online resources providing access to specialist information on dementia and uptake of that information
- Numbers attending dementia support services within the voluntary sector and numbers of new attendee's
- Numbers of people referred for information prescriptions (recorded by referrer)
- Numbers of people presenting with information prescriptions and numbers of visits required to get the information needed
- Providers to record the source of referrals
- Number of patients offered and number of patients using personal health plans with dementia (EoE SHA monitoring)

## Where are we now and priorities for change

**National Dementia Strategy Objective 4: Enabling Easy Direct Access to a Contact Who Can Signpost and Facilitate Health and Social Care Input following diagnosis.** A dementia adviser to facilitate on an on-going basis easy access to appropriate information, care, support and advice for those diagnosed with dementia and their carers.

The current practice across health and social care is to discharge the patient once they are stable and a care package is in place. The result is that care consists of a number of quite expensive individual episodes, separated in time, provided by different people who do not necessarily have an on-going relationship and often triggered as a result of a crisis.

The NDS consultation had a clear message from people with dementia and their carers that they would like to have access to someone whom they can approach for help and advice at any stage in the illness. The research for the carer's strategy in Norfolk has also consistently highlighted the need by carers to have a person who can "navigate" the system for them and ensure that they and the person they care for are given appropriate support. The suggestion is that this support needs to be additional to current health and social care support and to complement other elements of the care pathway, – the 'dementia adviser'.

### **The current situation in Norfolk**

There is a shortfall in the provision of a formal diagnosis for people with dementia – of the estimated 12,310 people in Norfolk with dementia only 4,918 were listed on the GP Dementia Registers in 2007.

A recent survey (May 2009) focusing on the mental health needs of older people in Norfolk highlighted a significant number of individuals who felt unable to navigate the "system" or felt let down by the "system".

In a Norfolk carer's survey conducted in 2008, 42% of those caring for someone with dementia felt they lacked emotional support.

A "Primary Care Dementia Worker" linked to four southern Norfolk GP Practices is currently being piloted by the Norfolk & Waveney Mental Health Trust. The role includes "signposting" so has common elements with that of the Dementia Adviser.

Norfolk has been successful in bidding for the funds to run a demonstration site to test the Dementia Adviser role. Work is progressing to have a part-time Adviser in each of the five localities in Norfolk by early 2010.

There is also a proposal by NHS Norfolk/ASSD to pilot a Health/Social Care "Navigator". This remains at an early stage of development.

The dementia adviser is a new idea, so there is no evidence base as to its effectiveness. The DoH have allocated funds to run a number of “demonstration” sites to test out what impact such extra advisers might have in changing the quality of life of people with dementia (and their carers) or the use of services. The dementia adviser service will provide a point of contact for all those with dementia and their carers following diagnosis. They will provide information and advice about dementia, and on an ongoing basis help to signpost them to additional help and support. The adviser will not duplicate existing ‘hands-on’ case management or care.

In Norfolk the following initiatives are contributing towards meeting this objective:

- The running of a Primary Care Dementia Worker pilot to test some of the elements of the Dementia Adviser role
- Successfully bidding for funding from the Department of Health of “demonstration site” status to test the “Dementia Adviser” model. The funding, including PCT funding, is for £238,000 in 2009-2011.
- Partnership working between the Alzheimer’s Society, Age Concern Norfolk, NHS Norfolk, NHS Great Yarmouth & Waveney, Norfolk and Waveney Mental Health Foundation Trust and Norfolk Adult Social Services to pilot the adviser role across the county

**Norfolk Priorities for action:**

- Implement the Dementia Adviser pilot and test the value of such a service to people in Norfolk newly diagnosed with dementia
- Assess the Dementia Adviser role against the Primary Care Dementia Worker pilot and the proposed NHS Norfolk/Norfolk Adult Social Services project to develop a “Health/Social Care Navigator “ for people with long term/complex conditions.

**Objective 4: Enabling easy access to care, support and advice following diagnosis**

<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>4.1.</b> To run a demonstration site across Norfolk to test the Dementia Adviser role	5 x part-time Dementia Adviser posts across the county	Sept 2009 to March 2011	Alzheimer’s Society (oversight by a multi-agency Project Management Group - Adult Social Services, PCTs, NWMHFT Trust, Age Concern Norfolk Commissioners within the Project Management Group	Evidence of effectiveness of role.
<b>4.2</b> To contribute to the national evaluation of the concept and to a decision whether to recommend the allocation of longer-term funding to dementia advisors within Norfolk	Data collection to reach an evidence-based decision	2010 - 2011	Commissioners within the Project Management Group	Decision on longer-term funding

**Potential Quality indicators (EOE guidance)**

- % of patients diagnosed with dementia having contact with a Dementia Adviser
- Number of people initiating repeat contacts as % of initial contacts
- A reported decrease in anxiety following 2 or more contacts with a Dementia Adviser
- % of people in contact with a Dementia Adviser who have prepared a personal dementia information plan
- An enhanced feeling of control following contact with a Dementia Adviser

## Where are we now and priorities for change

### **National Dementia Strategy Objective 5: Development of structured peer support and learning networks for people with dementia and their carers.**

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.

People draw significant benefit from being able to share experiences, to exchange practical advice and emotional support. Peer support networks are really valued by people with dementia, carers and relatives. They are established networks which can be further developed to provide wider geographical coverage. If the strategy succeeds in ensuring that early diagnosis of dementia becomes the norm, then this opens up the possibility for much greater levels of peer support and interaction. This is a way of empowering and enabling people to support each other in a safe way. In accordance with NDS, peer support groups should be designed according to user preference and local requirements. They should provide opportunities for people with dementia and carers to meet regularly with their peers and people with dementia and their carers to jointly meet on a regular basis.

The NDS highlights the need for learning opportunities in an informal environment to deliver information about dementia and practical tips about coping with dementia.

### **The current situation in Norfolk**

There are several good examples across the county of carer and cared for support groups mainly supported by the third sector. Several are funded through the Carers Grant or through one off funding. Some have statutory sector staff support.

Age Concern Norfolk run Pabulum cafés (reminiscence based activity for people with dementia and their carers) in Costessey and Diss. The monthly Pabulum group offers monthly musical reminiscence for people with dementia and carers.

Alzheimer's Society. All branches offer carers groups. Monthly Lunch groups and pub lunches at a variety of venues provide social opportunities and mutual support for carers and people with dementia. Singing for the Brain, a weekly interactive musical activity in Norwich, enables people with dementia and their carers to engage in the benefits of structured community singing. Activity groups aimed at people with dementia are offered throughout the County, often running concurrently with carers groups. Interactive participation is encouraged through a variety of media e.g. art, reminiscence, quizzes. Two groups in Norwich are specially targeted for younger people with dementia. The Alzheimer's Society and NWMHFT offer carers a set of six weekly/ fortnightly sessions with speakers on e.g. driving, benefits. These are held annually or six monthly at a variety of venues throughout the County. Norfolk Library services is currently running monthly carers cafes in Gorleston, Hellesdon and Fakenham.

## **Norfolk's priorities for action**

- Build on the current good practice already established in parts of Norfolk, working with the third sector and other partners, to develop local peer support and learning networks for people with dementia and their carers that provide practical and emotional support, reduce social isolation and promote self-care, while also providing a source of information about local needs to inform commissioning decisions.
- Support to third sector services commissioned by health and social care
- Use the national demonstrator sites and evaluation to identify models of good practice to inform future commissioning decisions from 2011 onwards.

**Objective 5: Development of structured peer support and learning networks**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>5.1</b>	Build on the current good practice already established in parts of Norfolk, working with the third sector and other partners, to ensure that there is a peer group set up in all major market towns which is well supported by transport systems, statutory services and meets the needs of the carer and cared for. Encourage the establishment of mutual support systems amongst carers e.g. buddy systems, informal groups, shared holidays	Peer support to carers and people with dementia in Southern Norfolk through a variety of social and support groups	August 09 onwards	Alzheimers Society	People with dementia offered access to a peer support network after diagnosis Carers are offered a peer support network. People with dementia receive practical tips/ information about living with dementia. Less social isolation
<b>5.2</b>	Review the experience of the national demonstrator sites to identify the most effective ways to provide this service		April 2011		

**Potential Quality indicators (EOE guidance)**

- Record numbers carers and people with dementia attending dementia support services within the voluntary sector and numbers of new attendees
- Annual satisfaction questionnaire for people with dementia and carers on accessibility, quality of service provided, detailing an action plan for improvement
- Record of numbers attending carer information/training sessions, record of types of information provided
- Carers feedback on quality of training and information received, relevance to caring role

## Where are we now and priorities for change

**National Dementia Strategy Objective 6: Improved community personal support** 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, people who pay for their care privately, through personal budgets, or through local authority arranged services.

Two thirds of people with dementia live in their own homes in the community and many of these live alone. Services need to support people from the early stages of their illness right through to the end of their lives. This section focuses on services for people in the community which are not covered under other objectives, and in particular home care, day opportunities, crisis response and advocacy. Increasingly such services will need to be personalised, offering choice, control and flexibility and reflect Norfolk's increasing diversity. The NDS reports increasing evidence that specialist dementia domiciliary care shows greater benefits to people with dementia and their carers than standard home care.

The National Audit Office (2007) says that an acute mental health service making full use of Crisis Response and Home Treatment (CHRT) services costs approximately £600 less per crisis episode than one in which CRHT is not available. If this applies to people with dementia, it is possible that sufficiently resourced CRHT services for older people with mental health needs will have a significant impact on reducing unnecessary admissions to hospital and reducing lengths of stay in hospital, as well as improving outcomes for people with dementia and their carers. In addition, earlier support is needed to prevent crises.

In September 2008, the Directors of Adult Social Services (ADASS) and the East Of England NHS produced 'Commissioning dementia services - an integrated commissioning strategy'. This emphasises the value of specialist integrated health and social care teams focused on coordinating and delivering the care of people with dementia within a specified locality. Such teams would play a key role in co-ordinating services, and work closely with general health and social care colleagues, the independent sector and voluntary organisations. They would liaise and refer people with dementia to specialist support services and contribute to multi-disciplinary assessments and assessments for continuing health care. Suffolk's strategy proposes the creation of the Dementia Support Worker in such teams, a hybrid, generic, multi-skilled worker who provides practical support and advice.

The NDS highlighted that people with dementia are an 'at risk' group in terms of abuse, particularly through financial exploitation, fraud and theft.

Safeguarding - both prevention and dealing with abuse – should be integral to any service for people with dementia.

### **The current situation in Norfolk**

**Domiciliary care.** ASSD's Norfolk First Support provides a 6 weeks re-ablement home based service which is flexible and responsive for people with dementia. Long term domiciliary care supports people with dementia but there is no specialist service for them.

Dementia social care **day opportunities** are provided by ASSD and contracted from the voluntary and independent sector. Many day centres for older people integrate people with dementia into the service. Adult Education provide activities in day services, such as reminiscence, gentle exercise and crafts. NWMHFT provides centre based day treatment sessions. In central Norfolk it is redesigning its day treatment services to provide more treatment at home or through outreach and to form part of crisis response.

NWMHFT's community mental health teams offer assessment and diagnosis of dementia state and treatment of associated behavioural or other mental health conditions, often in people's own homes. These teams include specialist social workers.

Specialist **crisis response services** include the NWMHFT Crisis Response and Home Treatment service in Great Yarmouth and the Intensive Support Teams in west and central Norfolk. The latter is being redesigned to improve support to people with dementia. The western service is not 24/7.

An Out of hours dementia service attached to ASSD's Emergency Duty Team provides help and advice out-of-hours in people's homes or over the telephone and has reduces Mental Health Act assessments.

Rethink is commissioned to provide an Independent Mental Capacity Act (IMCA) **advocacy** service for people lacking mental capacity who require someone to act on their behalf in specified circumstances in health and social care. Money Matters provides support with financial affairs to people referred through ASSD

### **Norfolk priorities for action**

- Ensure people with dementia are able to benefit from personalisation through implementation of personal budgets and personal health plans and specialist advocacy support
- Take account of the needs of people with dementia in other work to transform services e.g. Integrated Care Organisations
- Review and develop options for improved service integration and new roles as part of the planned integrated care pathway. To include improved LINK between the range of health and social care providers.
- Review the NDS evidence-base for effective specialist services to support people with dementia at home, including to inform the development and commissioning of domiciliary care
- Improve community based crisis response services specifically for older people with mental health problems, including dementia, including

stronger integration with universal crisis response and out of hours services such as Emergency Duty team, Night Owls, Swifts and rapid response

- Agree a joint health and social care model for more flexible day opportunities which will support joint commissioning and the expansion of services to meet needs. This would include befriending and peer support services
- Continue to work with partners, paid carers and the public to raise awareness of safeguarding issues, to reduce incidents of abuse and ensure that safeguarding arrangements work well.
- Ensure that care staff and others providing community services have appropriate training and awareness raising in the needs of people with dementia, including cultural and religious awareness

See also objectives 3 (information), 7 (carers), 9 (intermediate care), 10 (housing and assistive technology) and 13 (workforce development), 14 (joint commissioning).

**Objective 6: Improved community personal support services**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>6.1</b>	<b>Enhanced domiciliary care</b> – Commissioners will assess the evidence of national initiatives on specialisation to review the model of domiciliary care in the county, to shape future commissioning.		2010	ASSD	
<b>6.2</b>	Improve <b>community based crisis response services</b> specifically for older people with mental health problems, including dementia, including stronger integration with universal crisis response and out of hours services, to provide a 24/7 service with jointly developed, negotiated and agreed comprehensive local protocols for mental health referrals	Review of models for CRHT including IST in Central Norfolk  Work on integrating health and social care out of hours services		Commissioner and NWMHFT  Commissioners	
<b>6.3</b>	As part of the planned work on the integrated pathway explore options for closer <b>integration</b> between specialist health and social care services and new roles	Workshops on developing pathways and service models during consultation period	Initially complete by February 2010	Commissioners	

	<b>Recommendation</b>	Planned developments	Timing	Lead agency	<b>Outcomes</b>
<b>6.4</b>	<b>Day opportunities</b> Agree a joint health and social care model for more flexible day opportunities which will support joint commissioning and the expansion of services to meet needs.	Development of model of day opportunities/day treatment, new specification for dementia day care	2009/10	ASSD and both PCTS	
<b>6.5</b>	<b>Advocacy services</b> – We will develop an advocacy strategy that takes account of the gaps in current provision, and also takes account of the enhanced awareness and rights arising from the Mental Capacity Act	Joint commissioning of IMCA and IMHA service	End of March 2010	ASSD with both PCTs	

**Potential Quality indicators (EOE guidance)**

- Record numbers of people using day services
- Record numbers of new referrals to day services
- Record numbers of people accessing day treatment and associated services during crisis
- CSC Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement
- Annual report to commissioning organisations of the numbers of complaints and SUIs received, detailing an action plan for service improvement
- Target date for CRHT to be available to anyone over the age of 18 years.
- Reduction in overall bed occupancy and lengths of stay for older people following the commencement of CRHT, in accordance with DH expectations. Achieving this reduction can be measured by comparing the numbers of admissions, and lengths of stay, in the two years prior to the CRHT commencing with the present year
- CRHT team to record the numbers of admissions that had been notified to, and seen by, the CRHT service prior to admission

- Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement
- Annual report to commissioning organisations of the numbers of complaints and SUIs received, detailing an action plan for service improvement
- A reduction in the number of people going in to long term residential care over a five year period
- Record the number of people with dementia who are offered, and uptake, personal budgets
- Record improvements in the standards of care provided by home care services over a five year period

## **Where are we now and priorities for change**

### **National Dementia Strategy Objective 7: Carers – the most valuable support for people with dementia**

Family carers are the most important support available for people with dementia. Active work is needed to ensure the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of their need and support through an agreed plan to maintain 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. It is especially important to recognise and support the need for carers to have a life of their own, as carers of people with dementia are more likely to experience stress, depression and isolation.

Approximately two thirds of people living with dementia are cared for at home, the majority of that care being provided by family and friends. Supporting the family carer is crucial in enabling people with dementia to remain at home or in their choice of place to live. When working with the person with dementia, the needs of the family carer must also be taken into account. One in 5 carers providing high levels of care over 50 hours per week report that they are not in good health, a rate twice that of non carers, and carers report high levels of psychological distress.

A 2008 survey of Norfolk carers included 58 carers of people with dementia. When asked about current problems, 42% reported lack of emotional wellbeing, 1 in 4 poor health and 1 in 4 not having any life of their own. When asked what would improve their quality of life, over a third said more practical help or respite to enable them to have a life of their own and almost 1 in 5 wanted better health or emotional wellbeing. When asked which service had made the most difference to them, most carers rated some form of respite highly, whether at home, at day care or in a care home. Emotional support from the Alzheimer's Society or other voluntary organisation was mentioned by 1 in 5.

### **Current situation in Norfolk**

GP practices add carers to their carers register and refer onto ASSD for a carers assessment.

As well as services for all carers such as carers' assessments, social work support, equipment etc, ASSD provides respite through specialist day centres across the county for people with dementia, as well as places in frail elderly day care and care homes. Current work on ASSD day opportunities identified the need to develop more specialist day care places for people with dementia. There are 4 housing with care respite flats and block booked beds in care homes. Crossroads provide sitting services specifically for people with dementia in their own homes. This is free to carers supported by the Carers Grant.

For people eligible for NHS continuing care, the NHS will commission support at home and respite in care homes.

### **Current situation in Norfolk contd**

The ASSD out of hours dementia service provides help and advice out-of-hours in people's homes or over the telephone. Emergency respite care for carers is now available for carers registered with In My Place.

Adult Education provides 'Understanding the person with dementia' courses aimed at carers, and works with Carers groups, offering training on dementia, reminiscence and life story work. Memory Boxes are available to borrow from Mobile Libraries.

The Alzheimer's Society and NWMHFT offer carers a set of six weekly/ fortnightly sessions with speakers on e.g. driving, benefits. The Alzheimer's Society provides emotional support, signposting and opportunities for support from other carers.

Age Concern Norfolk provides opportunities for breaks through Pabulum sessions and the Pabulum cafes.

The library service has set up 3 cafes for Carers of people with dementia, providing support, information and the chance to borrow a Memory Box.

West Norfolk Carers and Norwich & District Carers Forum offer support to all carers in groups and individuals. Carers of people with dementia also have access to services offered to all carers through the Carers Grant for Norfolk such as Short Breaks at Short Notice run by Crossroads and the Carers Education Grant run by Age Concern Norfolk.

The Carer's Emergency Respite service 'In my place' offers support when carers have an emergency which means that they cannot provide care

### **Norfolk priorities for action**

- Ensuring that the needs of carers for people with dementia are included as the Joint Commissioning Strategy for Carers is developed and implemented, especially with regard to a range of good respite provision and the development of services that allow carers to work, enjoy a social life or study whilst knowing that the person with dementia is appropriately supported
- Improving the recognition of the needs of carers of people with dementia and the value of their role in supporting people with dementia.
- Promoting the development of breaks that benefit people with dementia as well as their carers and which offer a personalised service.
- Ensuring that carers of people with dementia have access to timely and appropriate information and support that recognise changes in need.
- Ensuring that the needs of carers are considered in assessment and care planning in the community and in hospital.
- Ensuring that professionals are aware of the resources available to support carers.
- Ensure that carers have access to personal budgets
- Carers are supported to recognise and manage their own health needs
- Improving the involvement of carers in service design and development.

See also objective 5 (peer support) and 6 (community services).

**Objective 7: Implementing the Carers' Strategy for people with dementia**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
7.1	Information packs - these will be increasingly available for family carers.				
7.2	<b>Agree a joint health and social care model for day opportunities which will support joint commissioning and the expansion of services to meet needs of people within a person-centred approach and work towards commissioning more social care places.</b>	Development of model of day opportunities/day treatment, new specification for dementia day care	2009/10	ASSD and both PCTS	
7.3	Short-breaks. Improving the variety and flexibility of short break services available for families of people with dementia, both current bed-based within residential settings, and home based services and those developed in the future. This will utilise both social care and health funding and increasingly will be supported by the introduction of personal budgets and personal health budgets to offer greater flexibility and choices and innovative opportunities.				

**Proposed Quality Indicators (EOE guidance)**

- Record the number of family carers offered, and accessing, short breaks
- Record the number of family carers offered, and accessing, direct payments
- Record the number of carers of people with dementia who receive a carer's assessment, the time it takes to receive an assessment after diagnosis and their satisfaction at the service they receive.

## Where are we now and priorities for change

### **National Dementia Strategy Objective 8: Improved quality of care in general hospitals.**

Identifying leadership for dementia in general hospitals; defining the care pathway for dementia there, and commissioning specialist liaison older people's mental health teams to work in general hospitals.

Up to 70% of people in acute inpatient hospital beds are older people. Up to half of these may be people with a degree of cognitive impairment, including those with delirium and dementia. Hospitals are particularly challenging environments for people with memory and communication problems, with cluttered ward layouts, poor signage and other hazards – especially if the attendance at hospital is **unplanned** after a fall for example. People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation. They are often viewed as 'difficult to manage', 'disruptive to staff and other patients' and require greater time to be given to them than resources often allow.

There are examples of people with dementia whose average length of stay exceeds 21 days and in some cases this can be as much as 48 days. The National Audit Office has estimated the excess cost of dementia in general hospitals may be more than £6million per average general hospital.

The NDS recommends developing an explicit care pathway for the management and care of people with dementia in hospital. This should include:

- Obtaining information from relatives and carers so as to be able to provide person centred care
- Ensuring people's nutritional needs are met and delivered
- Discharge pathways are fully integrated and fully including working with families and carers

### **The current situation in Norfolk**

Further information is being sought

There are specialist older people's mental health liaison nurses at QEH, JPH and NNUH. They provide advice to staff, and specialist assessments.

JPH has the 'Information About You' form which is completed before people come into hospital and which is used to provide person centred care. People with dementia also have an A&E 'fast track' card so that they are given some priority in A&E.

QEH individually assesses patient's nutritional needs and visibly identifies people who need help with meals etc. There are link nurses on each ward. In A&E people with dementia are placed in the quiet room which is less clinical and offers a less stressful environment.

## Norfolk priorities for action

- Identification of a senior clinician and specifically trained staff within the general hospital to take the lead for quality improvement in supporting and treating patients with dementia in all aspects of the hospital services and at all times, day or night.
- Development of an explicit care pathway for the management and care of people with dementia throughout the hospital, including for example 'reality orientation', support with food, clearer and more visible 'signage', by a team of experts across the hospital led by that senior clinician/manager.
- Care pathway planning in hospital ensures that discharge planning begins at least on admission and preferably before that by ensuring hospital alerted (e.g. by Primary Care/GP and/or Care home and/or Secondary MH Trust services) to patient dementia diagnosis even before they are admitted in case discharge preparations can begin earlier than admission and maybe even admission avoidance.
- Seamless 'follow up' to patient discharge as part of 're-admission' avoidance.
- Providing awareness and other training for all hospital staff to improve the quality of care through a focus upon person-centred services.
- All hospital nursing and clinical staff to be given more time to train specifically with patients with dementia and their families and informal carers to be better equipped to communicate with and manage their requirements and needs and beyond their clinical care needs.
- Use of better mechanisms across information sources, records and the patients in hospital that they have a diagnosis of dementia and so staff are better able to deal with their needs and requirements in ways more appropriate and fitting for people suffering from dementia.
- Understand the pathways within hospitals which can lead to changes to existing medication with which the patient arrives into hospital without reference to other professionals prescribing their medication or to their family/carers who are often the 'experts by experience' in this case.
- Ensure that basic 'wellbeing requirements' [such as food, washing, turning, etc] are given equal priority to the patient's clinical requirements throughout their stay in hospital.

The Department of Health is planning to produce a toolkit to support improved quality of care by December 2009

See also Objective 13 Workforce development

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

Recommendation	Planned developments	Timing	Lead agency	Outcomes
8.1 Each acute hospital should identify a senior clinician to lead a task force of staff for quality improvement in supporting those with dementia in hospital. This could be a shared appointment with for example NWMHFT.			Providers	
8.2 Acute hospitals should develop an explicit care pathway for the management and care of people with dementia in hospital, from a task force of staff, possibly led by that senior clinician.			Providers	
8.3 Extended assessment in acute hospitals to include specific information from both family carers and paid carers to better assist with the care of the person with dementia.			Providers	
8.4 Review the potential impact of specialist liaison older people’s mental health staff in local acute hospitals and voluntary sector mental health staff. There is a need to look at national work to see if the nature or coverage of the role needs to be extended, for example from medicine for older			Commissioners and providers	

people into other 'specialist areas' and to provide support to patients and staff. We will also look at the training and education of health staff to make sure they involve family members more, for example when supporting the discharge process alongside social services staff.

- |                                                                                                                                                                                                                                                        |                  |
|--------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|------------------|
| <p><b>8.5</b> Implement nutrition action plans in acute hospitals for people with dementia, where they are not already in place, including visible ways to ensure supported feeding always occurs.</p>                                                 | <p>Providers</p> |
| <p><b>8.6</b> Develop awareness training for all hospital staff on the health and social care support needs and requirements of those with dementia and their carers. This could potentially include information displays throughout the hospital.</p> | <p>Providers</p> |
| <p><b>8.7</b> Implement training of hospital staff in order to better understand the needs of people with dementia. This will ensure positive outcomes from all around involvement with patients with dementia and their carers.</p>                   |                  |

### **Proposed Quality Indicators (EOE guidance)**

- Record numbers of admissions, and repeat admissions, to any hospital for dementia related illness
- Lengths of stay in acute trusts for people with dementia should reduce to be in line with people without dementia, for the same condition, by April 2012
- The liaison service should record the number of people referred and seen by the service (expect 95% of all referrals to be seen by the service and have a co-ordinated discharge plan, to include onward referral rates)
- Record the number of Delayed Transfers Of Care (DTC's) for people with dementia (expect this number to fall significantly with a fully integrated service)
- Annual service user and family carer satisfaction survey on the accessibility, responsiveness and quality of service provided. Surveys should be conducted independently of the service provider and an annual report submitted to the commissioning organisation detailing an action plan for service improvement
- Annual report to commissioning organisations of the numbers of complaints and Serious Untoward Incidents (SUI's) received, detailing an action plan for service improvement
- Providers to record the number of staff on each in-patient ward who have received training on dementia. Evidence of dates and course attended to be provided upon request.

## Where are we now and priorities for change

### **National Dementia Strategy Objective 9: Intermediate care for people with dementia**

Intermediate care which is accessible to people with dementia and which meets their needs.

Intermediate care has twin objectives which are to avoid inappropriate hospital admissions and the broader objective of enhancing independence. It is the expected outcome of the intermediate care service that patients with health and social needs will remain in their home longer and where hospitalisation is deemed necessary will return home quicker.

The outcomes expected from an integrated intermediate service are:

- a personalised service for each patient
- improved quality of life for patient and their carers
- a greater degree of independence amongst people with disabilities
- a more appropriate /optimum use of healthcare services
- the provision of care closer to home
- better self management by patients and their carers

Patients will be supported to self care where possible with the proposed introduction of personal health plans and health budgets. Patients will be encouraged to embrace assistive technology as a means to support and manage their health care.

The July 2009 guidance on intermediate care from the Department of Health states:

'Intermediate care should also be inclusive of older people with mental health needs, either as a primary or a secondary diagnosis, if there is a goal that could be addressed within a limited period of weeks. Without specialist help, people with dementia are particularly likely to have a prolonged stay in hospital, due to difficulties in determining their longer term care needs, as they often recover their physical functioning more slowly. Their hospital experiences can be doubly traumatic, as the surroundings are disorientating and they are separated from familiar people and places. So providing appropriate support to reduce admissions and enable earlier discharge can have a significant impact on people's experiences and on efficiency, because of the numbers involved. Appropriate rehabilitation therapies with people with dementia and physical health needs have been shown to be successful in enabling them to return home and to stay out of institutional care'.

Intermediate care also applies to preventing inappropriate admissions to mental health hospitals, and supporting discharge and a return to improved independence.

## **The current situation in Norfolk**

Norfolk's intermediate care services are delivered in partnership between primary and secondary health care, social care and housing and the independent sector. Intermediate care includes community based rehabilitation services (rehabilitation includes nursing support, physiotherapy, occupational therapy, speech and language therapy, dietetics, podiatry and any other `therapy` overseen by a qualified practitioner). There are no specialist intermediate care services for older people with physical rehabilitation needs who also have more advanced or complex mental health needs

ASSD's Norfolk First Support provides a 6 week intensive re-ablement service in people's homes. This is a very flexible service and can offer intensive input until people are settled in a familiar environment.

There are specialist mental health liaison nurses attached to acute general hospitals to provide advice to staff and a specialist assessment service but these do not extend to intermediate care services in community hospitals or the community.

Services to support people at home and reduce inappropriate admissions to mental health hospitals include NWMHFT's Crisis Response and Home Treatment service in Great Yarmouth and their Intensive Support Teams in west and central Norfolk. The latter is being redesigned to improve support to people with dementia. Day treatment services also provide time limited rehabilitation.

An Out of hours dementia service attached to ASSD's Emergency Duty Team provides help and advice out-of-hours in people's homes or over the telephone and has reduced Mental Health Act assessments.

## **Norfolk priorities for action**

- Ensure that the needs of people with dementia and their carers are explicitly addressed in universal intermediate care services.
- Ensure that intermediate care team/services are able to demonstrate competency in mental health and dementia.
- Strengthen the LINK between intermediate care services, community mental teams, specialist assessment services and acute services

See also objective 6 on crisis services, objective 8 on general hospitals and objective 13 on workforce development.

**Objective 9: Improved intermediate care for people with dementia.**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>9.1</b>	Work in partnership with general health and social care colleagues to plan care that promotes independence and avoids unnecessary admission, particularly in relation to the management of other long term conditions, for example, coronary heart disease, pulmonary disease and Diabetes	Development of Integrated Care Organisations (ICOs) through pilot sites to promote an integrated multidisciplinary approach to supporting people to remain in their own home	2 years pilot project from DOH	NHS Norfolk and Norfolk County Council	Increase number of people supported to remain in their own home and reduce number of acute bed days
<b>9.2</b>	Review the evidence on the best ways of meeting the physical rehabilitation needs of people with dementia (specialist services versus universal services with specialist training and support.) and build into both commissioning and service provision.			PCTs and ASSD as commissioners	
<b>9.3</b>	Investigate the best options of supporting diagnosis and management of mental health conditions within community hospital beds such as extending general hospital based older people's mental health liaison service.			PCTs	

	Recommendation	Planned developments	Timing	Lead agency	Outcomes
9.4	Develop partnership work between intermediate care services to prevent general hospital admissions and the NWMHFT Crisis Resolution Home Treatment (CRHT)/ Intensive Support services. To include an assessment of the resource impact on CHRT teams.			Providers	
9.5	Liaise and refer people with dementia to specialist support services as and when required, for example, Independent Mental Capacity Advocate's (IMCA's), Deprivation of Liberty Safeguard specialists, specialists in the needs of younger people with dementia and people with learning disabilities, and dementia, drug and alcohol misuse.			Providers	
9.6	Conclude discussions between PCTs, NWMHFT and specialist assessment teams in community health services around the input of trained mental health specialists to assessments for continuing health care for individuals whose primary need is mental health related	Cascade training in continuing health care for NWMHFT staff. Complete dementia pathway redesign and service restructuring	Input in place from 2010 onwards	PCTs, NWMHFT	People with dementia have timely and expert assessments to give access to appropriate care

**Proposed Quality Indicators (EOE guidance)**

- Record the number of people with dementia who are referred, and subsequently access intermediate care services by April 2010. All people with dementia should have immediate access to intermediate care, if indicated, within the current intermediate care performance specifications.

## Where are we now and priorities for change

### **National Dementia Strategy Objective 10:**

**Consider 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.

Housing is central to the promotion and maintenance of independence. Housing should be based on need, so people with dementia should have a choice as to where they live, which will include a range of housing options covering both the physical environment and support services. Options range from their own home, supported by assistive and domiciliary care, to sheltered housing, specialist housing with care and care homes. Evidence to date is that appropriate design and assistive technology can provide cost effective and personalised support. In addition services such as care and repair and handymen schemes provide support to older and disabled people around home maintenance, as well as a wider preventative and signposting service.

We need to work together with district and borough councils, Supporting People, housing associations and independent providers, to provide flexible housing options for people with dementia and their family carers. The NDA suggests that close LINK need to be made with national work on the effectiveness of housing with care, design, and assistive technology and telecare/ telehealth.

### **Current situation in Norfolk**

The **community care alarm service** is available across Norfolk. It also supports the Prompting Service, a free telephone reminder service for people with mild to moderate memory loss living in their own home.

ASSD's **assistive technology** service provides various pieces of equipment suitable for people with dementia, including sensors to detect unexpected/dangerous movement or activity. There are 5 SMART houses for equipment demonstration. Integration with health services is increasing.

The district councils have an obligation to provide **housing options services** for the public and these exist in Kings Lynn and West Norfolk, greater Norwich (Norwich, South Norfolk and Broadland) and Great Yarmouth).

## **Current situation in Norfolk contd**

**Sheltered housing** is widely available across Norfolk and many residents have mild/moderate dementia, however often schemes will not accept people who have dementia at the time of admission. A major review of sheltered housing found that older people ideally want to live in their own home for as long as possible and think it is important that people can stay in sheltered housing as their needs increase. Older people also supported the idea of sheltered housing staff supporting people in the wider community.

**Greater Norwich Housing support scheme (ASSD)** provides intensive, enabling, time limited support to vulnerable older people with a mental health problem, with the planned outcome of being able to remain in their own home or move to more appropriate accommodation.

**Housing with care:** 42 flats for people with dementia within the schemes linked to ASSD and four respite flats. There are very limited options to buy housing with care in the private sector and no schemes catering for dementia. The commissioning strategy for care homes and housing with care shows an estimated shortfall of 380 housing with care places by 2015 and 1340 by 2020, which people have said is their preferred option

## **Norfolk priorities for action**

- To continue to develop the use of assistive technology and telecare to support the needs of people with dementia and their carers in an integrated fashion
- To ensure that the forthcoming housing and support strategy for older people and the strategy and action plan for sheltered housing include the needs of people with dementia and their carers as they develop.
- To work together to deliver the commissioning strategy for housing with care and care home places (The Strategic Model of Care) so that there is an adequate supply of local housing with care places to meet the needs of the growing number of people with dementia.
- To ensure that staff working within housing and housing-related services develop the skills needed to provide the best quality care and support for people with dementia

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

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>10.1</b>	<b>Assistive technology</b> to continue to develop services with a wide range of partner agencies and through staff training to ensure that Assistive Technology and Community Alarm services are available for those with Dementia and their Family Carers to support their capacity and capability to remain living at home. To include looking at the possibility of responsive services such as Swift and Night Owls responding to alarms and assistive technology.	Develop clinics for people who don't yet meet ASSD eligibility criteria; improve information and access to AT in rural areas, train staff in primary care, acute hospitals and NWMHFT	2009/10 and ongoing	ASSD	<p>Give people the means to continue living independently at home</p> <p>Delay or avoid the need for residential care</p> <p>Bring peace of mind to family and friends</p>
<b>10.2</b>	<b>Adaptations</b> – we will ensure a co-ordinated approach to supporting people to get the adaptations and equipment need to support their ability to remain living at home. This entails working together with Supporting People, District/Borough Councils, Housing associations, Care and Repair Agencies and Equipment services to ensure that these are available and forthcoming.				<p>Give people the means to continue living independently at home</p> <p>Delay or avoid the need for residential care</p>

10.3	<b>Housing with care</b> – we will ensure that Housing with Care options are more widely available, by developing new services, incorporating rented and leasehold options. We will also review services to ensure that they are providing what they are “doing what they are set up to achieve”.	The work on the Strategic Model Of Care will identify and take forward the development of HWC across Norfolk	2009/10 and ongoing	ASSD	A greater choice of housing with care, including tenure options, enabling people to live in their own homes for longer
10.4	<b>Housing options</b> – we will ensure that housing options services develop to meet the needs of vulnerable older people, such as people with dementia, and their families.	Housing options services are in development in Breckland and North Norfolk, and periodically reviewed in other areas.	By 2001 for services in development	District councils	People have better advice and information on the options and can plan better for the future

**Proposed Quality indicators (EOE guidance)**

- Record the numbers of people with dementia who have access to telecare and tele-health
- Record the number of people who are offered, and access, assistive technology and housing with care

## Where are we now and priorities for change?

### **National Dementia Strategy Objective 11: Improving care for people with dementia in care homes**

Improving quality of care for people with dementia in care homes through the development of explicit leadership for dementia care within care homes, defining the care pathways there, the commissioning of specialist in-reach services from community mental health teams and through inspection regimes.

One-third of people with dementia live in care homes and at least two-thirds of all people living in care homes have a form of dementia. There is no doubt that residential care may be the most appropriate and effective way of meeting the needs of someone with dementia and a service of choice. There are care homes that provide excellent care for people with dementia, but it is an extremely challenging task and quality varies across the sector with care homes for people with dementia being disproportionately represented in the care homes designated by the Commission for Quality Care as “poor”.

It is estimated that one-third of people with dementia live in care homes. This amounts to approximately 4,500 people in Norfolk – 1,750 men and 2,750 women. The majority of these people are spread across the 88 Care Homes and 28 Care Homes with Nursing in Norfolk that are registered with the Care Quality Commission to accommodate people with dementia. The remaining people – many of whom will have an undiagnosed dementia - live in the additional 63 Care Homes and 23 Care Homes with Nursing that are registered solely for older people.

The quality of care is variable, with a disappointingly high proportion of Homes rated by CQC as either “adequate” or “poor” - approximately 20% of Care Homes and 35% of Care Homes with Nursing. This is believed to be a direct reflection of the difficulties in delivering a high quality of care to people with dementia within a group setting.

### **The current situation in Norfolk**

The use of anti-psychotic drugs has been subject to a major review by NHS Norfolk.

Adult Social Services have implemented a programme that has successfully improved the quality of care across their 11 dementia care homes.

A multi-agency Dementia Provider Forum has been established by Adult Social Services.

The NWMHFT Older Persons Training and Education Team are providing a significant amount of training to the Care Home sector on Dementia Care Mapping.

The NWMHFT Day Treatment model is being adjusted so that staff can provide an enhanced in-reach service into Care Homes

## **The current situation in Norfolk contd.**

The NWMHFT are building a Dementia Intensive Care Unit that will act as a “Centre of Excellence” to help increase quality of care provision across Care Homes.

Adult Social Services are developing a strategy to utilize the commissioning process to drive improvement within the Care Homes quality-rated “poor”.

Telecare and assistive technology are being piloted within Care Homes.

A strategic model has been developed by Adult Social Services to identify and plan future Care Home needs across the county. With the growth in the number of older people, it has been calculated that by 2020 an additional 1,184 Care Home places and 682 Care Home with Nursing places will be required for people with dementia in Norfolk

The National Dementia Strategy lists the following suggestions on how the Objective can be delivered:

- Identification of a senior staff member within the care home to take the lead for quality improvement in dementia care in the care home.
- Development of a local strategy for the management and care of people with dementia in the care home, led by that senior member of staff.
- Only appropriate use of antipsychotic medication for people with dementia.
- The commissioning of specialist in-reach services from older people’s community mental health teams to work in care homes.
- The specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry etc.
- Readily available guidance for care home staff on best practice in dementia care.

### **Norfolk priorities for the future:**

- Spreading the learning from the anti-psychotic drug review across all Care Homes.
- Extending the current Dementia Forum to become a county-wide provider network promoting good practice through newsletters, conferences etc.
- Further exploring and piloting the potential of telecare and assistive technology.
- Building on the potential of enhanced in-reach by NWMHFT.

NOTE: This Objective needs to be cross-referenced with the following Objectives: Objective 10: Housing support, Objective 12: End of life care  
Objective 13: Workforce

**Objective 11: Living well with dementia in care homes**

Recommendation	Planned developments	Timing	Lead agency	Outcomes
11.1 Complete the review of the local anti-psychotic drug initiative, and share the learning on the management/ guidelines for the use of drugs and medication in the treatment of dementia with all care homes in Norfolk	Issue of guidance to GPs  Launch of training programme for care homes	2009 - 2011	NHS Norfolk	Changes in prescribing practice Financial savings Improved non-pharmacological responses to behavioural and psychological problems Improved quality of life for people with dementia
11.2. Establish a Norfolk Dementia Provider Forum, building on the existing Norfolk County Council Adult Social Services Dementia Provider Forum and other forums including Norfolk Mental Health Provider Forum. This will encourage leadership in each area, including in each care home, and act as a network to promote good practice		Launch April 2010	Adult Social Services	Enhanced awareness of good dementia care and commitment to raise the standard.  Improved quality of life for people with dementia.

11.3. Maximise the capacity to deliver in-reach services to care homes by NWMHFT to prevent crises and preventable hospital admissions.	Primary Care Dementia Worker pilot	2009 - 2014	Norfolk & Waveney Mental Health Foundation Trust	Improved quality of life for people with dementia
	Reconfiguration of Day Treatment Services to allow increase capacity			
11.4. Continue to test the potential of telecare and assistive technology within the care home setting and consider the opportunities from award winning tele-health and tele-care services already operating across Norfolk.		2009 - 2014	NHS Norfolk Adult Social Services	A reduction in the use of prescription drugs to control behaviour

**Proposed Quality Indicators (EoE guidance)**

- CQC record improvements in the standards of care within care homes over a five year period

## Where are we now and priorities for change?

**National Dementia Strategy 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 DoH End of Life Strategy. Local work on the End of Life Strategy to consider dementia.

People with Dementia are described by the National Dementia Strategy as often having inequitable care and dying without the symptom control received by patients with other conditions. Nationally 64% of people with dementia live in the community and 36% in care homes with the proportion residing in care homes increasing with age. GP's have on average 20 deaths per year with an estimated 35% of these due to dementia, frailty and decline. This is higher than cancer.

A palliative approach should be integral part of a care approach from diagnosis until death with a focus on maximising the quality of life of the person with Dementia and their family. It is important that an integrated approach is taken with Health, Social Care and Mental Health stakeholders and professionals in the delivery of an equitable service for people with dementia at end of life and their families.

### **Current situation in Norfolk**

Dementia patients are amongst those patients with the most unmet need in relation to palliative care. Staff caring for this patient group are often ill-equipped and supported to care for patients at end of life. Conversely generalist staff may not have the skills or knowledge to deal with the complexities of the condition such as mental capacity. The Marie Curie Delivering Choice Programme in Norfolk has identified that operational staff would welcome more education on end of life care for this client group and stronger LINK with Specialist palliative Care. They also highlighted the development of a defined end of life pathway for dementia patients to support staff in the delivery of high quality end of life care. An improved partnership approach between all organisations that work to deliver a robust 24 hour service is imperative to support patients in their preferred place of care and death.

### **Norfolk priorities for action:**

- To develop service models in consultation with stakeholders, commissioners and the public that support collaborative working and will enable the specific need of this client group to be met whilst echoing the priorities set out in the local End of Life Care Strategies

being implemented by the PCTs and Norfolk Adult Social Services, thus allowing equitable care for all.

- Initiating demonstration projects, piloting and evaluation of models of service provision prior to implementation, given the current lack of definitive data in this area.
- Developing better end of life care for people across care settings which reflects their preferences and makes full use of the planning tools in the Mental Capacity Act.
- Develop local end of life care pathways for dementia consistent with the Gold Standard framework, LCP and PPC as identified by the End of Life Strategies.
- Commission providers to use the end of life 'tools' within the National end of life framework
- Commission safe effective services, which are monitored through contracts, which include the setting of quality standards, working closely with providers and people who use services.
- Workforce development across all care settings to enable the delivery of high quality palliative care for people with dementia.

The actions will be taken forward as an integral part of the work on end of life in Norfolk which is being supported by the Marie Curie Delivering Choice Programme. Therefore no specific action plan is listed.

## Where are we now and priorities for change

**National Dementia Strategy Objective 13: Workforce competencies, development and training in dementia.** An informed and effective workforce for people with dementia. All 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 care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

The importance of improving the standards of knowledge and awareness of dementia amongst health and social care professionals has been a consistent theme throughout the listening and consultation events for the National Dementia Strategy. People with dementia and their carers have asserted that this is imperative if the quality of care and service given is to improve.

People working in dementia services need to have sufficient knowledge and understanding to meet the needs of those people diagnosed with dementia – especially those with a dual diagnosis which is often the case for example with people who have a learning disability. Otherwise this skill base will not be available to support fully and flexibly people with dementia, reduce health inequalities and improve more quickly the quality of their lives. Health and social care staff need to be able to spot early signs, meet people's increasing needs and support their clients with treatment and conditions management strategies – increasingly in accordance with personal health plans.

Two thirds of people with dementia live in their own homes and access all services, so that awareness and skills are needed in all sections of the workforce and society. In providing good dementia care in care homes the top challenges are developing a staff team with the right attributes, attitudes and skills and keeping them motivated.

### **The current situation**

Adult Education provides courses that challenge misperceptions about the causes of and the experience of dementia, thereby reducing the attitudes which lead to the stigma associated with memory loss and behaviour change. Largely attended by professionals.

Adult Social Services Learning and Development team: all courses open to NCC, independent and voluntary sector employees, and personal assistants. Vocationally related level 2 course - Promoting the mental health and well-being of older people.

Short courses in Mental Capacity Act;

Dementia Care Foundation – 1 day on Understanding Learning Disability and Dementia.

NWMHFT provide training in Dementia Care Mapping; Person Centred Care; Dementia Care Strategies; Clinical Supervision. Outreach training by ward staff to Care Homes. The planned Dementia Intensive Care Unit in Norwich will provide research, in/ outreach and development.

NWMHFT drafting a workforce plan for dementia services reflecting the NDS.

In September 2008, the Directors of Adult Social Services (ADASS) and the East Of England NHS produced a 'Commissioning dementia training and education' paper. This recommended that Primary Care Trusts (PCTs), Local Authorities (LAs) and partner organisations apply the following principles to commissioning dementia training and education:

- ❖ A whole systems integrated approach based on a clinical, biophysical and social outcomes for people living with dementia and their carers
- ❖ Training and education needs to have a clear practical focus relevant to the work of the learners – where possible addressing real needs of real clients
- ❖ Training and education should be commissioned to support continued and sustained learning, rather than 'ad hoc' programmes that have little sustainable impact on quality of care
- ❖ Training and education should be progressive and mapped to a skills escalator, for example, the NHS skills escalator
- ❖ Training and education programmes should be accredited, or externally verified, and linked to vocational awards wherever possible, for example, National Vocational Qualifications (NVQ's)
- ❖ Training and education programmes should include a range of teaching methodologies that can adapt to individual learning styles, including long distance learning
- ❖ Commissioned training and education programmes should be made available to family carers
- ❖ Training and education is evidence based and contemporaneous and should meet regulatory standards
- ❖ Mandatory specialist vocational courses on dementia should be commissioned for all care staff who work directly with people with dementia
- ❖ Mandatory training and education around dementia, raising awareness, communications skills, attitudes and dignity skills should be an integral part of foundation training and education of all health, social care and third sector staff and commissioners should work with foundation training and education organisations to ensure this is implemented
- ❖ A workforce must be available with the skills to manage younger people with dementia and people with learning disabilities and dementia and training and education should be available that targets the needs of these specific groups of people
- ❖ Equality- training and education should be sensitive to the needs of people from different cultural and ethnic backgrounds
- ❖ Training and education must adhere to legislation on mental health, The Mental Health Act (2007), Mental Capacity Act (2005) and the Single Equality Act (2008)
- ❖ The approach to training and education takes account of existing and developing ethical frameworks, to facilitate and assist the management of dilemmas occurring when making decisions about dementia care
- ❖ Commissioners will expect all training and education providers to demonstrate how all training and education programmes promote the dignity and respect of the individual
- ❖ Training and education at a team level is preferable for sustained quality improvements

- ❖ Training and education providers need to ensure organisational managers understand the reasons for training and education and commit to supporting staff through the training and education process and subsequent change in practice.
- ❖ Commissioned training and education programmes must be independently evaluated for impact on quality of care for people with dementia and their carers.

This document provides additional guidance on learning outcomes and quality indicators.

### **Norfolk priorities for action**

- Develop a Norfolk workforce strategy through local networks to take on board the implications of the dementia strategy in order to make available training on dementia for all staff in health, social care and housing sectors who are in contact with people with dementia.
- Commissioners, with input from people with dementia and their carers, to specify the necessary potentially mandatory dementia training across the whole care pathway including End of Life for service providers but also for those who care for people with dementia including family carer(s) and services in the community.
- All providers who support or care for people with dementia or their carers/family to have a baseline awareness of their current staff audit in relation to dementia – and develop an action plan to reach the overall required standards.
- Clear guidelines for who monitors the quality of training and recommend accreditation mechanisms to standardise the approach across the County using existing systems, e.g. NVQ; VRQ, etc.
- Ensure that increasingly providers are encouraged to train and support staff to become ‘person-centred’ rather than the current ‘task-orientated’.
- Influence training for staff in universal services (e.g. Receptionists, Help Desk staff, Porters, Clerical teams, etc) so that there is more awareness training on the subject of dementia across the widest possible staff who could be asked to deal directly or indirectly with people diagnosed with dementia or their carers.

**Objective 13: Workforce competencies, development and training in dementia**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>13.1</b>	Develop a Norfolk workforce strategy through local networks, and linking with regional plans to take on board the implications of the dementia strategy. This will ensure a coordinated approach to staff training and development around dementia issues for all staff in health, social care and the housing sectors especially, who are in contact with people with dementia.			ASSD and both PCTS	
<b>13.2</b>	Commissioners, with input from people with dementia and their carers will specify the necessary potentially mandatory dementia training across the whole care pathway, including end of life for service providers. This will also cover training those who care for people with dementia, including family carers and services in the community.			ASSD and both PCTS	
<b>13.3</b>	Require all providers who support or care for people with dementia or their carers to have a baseline awareness of their current staff in relation to dementia, and to develop an action plan to reach the overall required standards.			ASSD and both PCTS	

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>13.4</b>	Influence training for staff in universal services for example, receptionists, help desk staff, porters, and clerical teams. This will ensure there are more skills and awareness training around dementia across the widest possible range of staff that may be in contact either directly or indirectly with people diagnosed with dementia or their carers.			ASSD and both PCTS	

### **Proposed Quality Indicators (EOE guidance)**

The EOE strategy sets out indicators covering:

- Skills and Experience of Trainers
- Training methodologies
- Learning outcomes
- Organisational responsibility

## Where are we now and priorities for change

### **National Dementia Strategy 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 should be informed by the World Class Commissioning guidance.

The National Dementia Strategy listed joint commissioning as one of the keys to delivering change in dementia services. The joint commissioning strategy needs to build on the Joint Strategic Needs Assessment and be developed in consultation with people with dementia and their carers. Joint commissioning, based on integrated care pathways, will require needs to be met flexibly by a combination of providers across health, social care, housing and even education too.

Some services will be able to adapt to meet the needs of people with dementia, but sometimes specialist services will be needed – even if the specialist role is simply to allow the person with dementia and their carer to positively contribute to their future requirements and planning.

The cost of these services and the numbers of people which they must cover will need to be properly understood to enable effective, long-term service commissioning. This will require PCTs and local authorities to collect and share quality information especially about outcomes which they can obtain collaboratively from all providers of services to people with dementia and their carers.

In June 2009 the Department of Health published its joint commissioning framework for dementia. Within this it set a number of key principles that should be integrated into all commissioning activity:

- Keep the person with dementia and their carers at the centre of all commissioning activity
- Work across the commissioning community
- Build quality and dignity into every service
- Ensure people's legal rights are maintained
- Commission services that maintain and enhance an individual's abilities
- Include all groups of people affected by dementia

### **The current situation**

Stakeholders from within NHS Norfolk, NHS Great Yarmouth and Waveney, Norfolk ASSD, LINK, statutory and third sector providers and GPs, have been working to develop a draft Norfolk wide joint commissioning strategy to support the delivery of the National Dementia Strategy (NDS) in Norfolk. The work to date has been 'validated' by a wide range of stakeholders attending

and participating in a September 2009 event.

Specific research has been commissioned to get in depth views from people with dementia and their carers on how they want services to support them. We have taken a draft joint strategy to our respective Boards, Cabinet, etc in October 2009 and then go out to public consultation on the priorities and the timing on what will be a 5 year plan. During the consultation phase we plan to hold stakeholder workshops to develop our pathways and service models in areas where we think we are weak at present.

The first draft of the Integrated Dementia Care Pathway has been produced in line with other pathways for long term conditions.

A Dementia Commissioning Tool is being used to bring together activity information across health and social care with demographic data and financial information to support modelling and decision making.

There are a range of areas where we are jointly commissioning at present; these include the Department of Health dementia adviser pilot, Alzheimer's Society services, assistive technology, the development of housing with care and this work will continue. This includes joint work in Great Yarmouth on a Dementia Centre, involving the PCT, Norfolk ASSD and NWMHFT.

#### **Norfolk's priorities for action:**

- To agree key priorities with all stakeholders (including statutory sector, voluntary sector and those using dementia services and their carers) for the first two years of the strategy to allow our efforts to focus on where it is most needed in Norfolk, where we can deliver better outcomes and where freed up resources can drive developments even where NHS resources are 'tight'.
- To ensure that the development of the strategy gives equal opportunity for locality focus on priorities led by practice based commissioners and potentially engaging for example District Councils – especially through the collaborative workshops planned for the public consultation phase.
- To ensure that the joint commissioning strategy changes how mainstream services across health and social care are provided and that within this framework we aim to develop more integrated person-centred services replacing many of the current 'task-orientated services and results.
- To progress this strategy by making LINK with other policy initiatives and strategies in Norfolk such as 'dignity in care', the end of life strategy and the carers strategy.
- To ensure that people with dementia and their carers are involved in the development of this plan so that they benefit from more individualised services with the introduction of personal budgets and personal health budgets.

**Objective 14: A joint commissioning strategy for dementia**

	<b>Recommendation</b>	<b>Planned developments</b>	<b>Timing</b>	<b>Lead agency</b>	<b>Outcomes</b>
<b>14.1</b>	Develop an agreed integrated pathway for dementia with new service models as required to underpin investment decisions.	To be developed in the consultation phase	November 2009-February 2010	Commissioners	
<b>14.2</b>	Develop the use of the dementia commissioning tool (DCT) to support dementia services investment decisions.	Complete work inputting data to support priority setting	Autumn 2009	NHS Norfolk	
<b>14.3</b>	Work with the NHS programme boards and clinical networks covering primary care, planned and unplanned acute care, long term conditions and end of life care so that they meet the needs of people with dementia and their families in their commissioning decisions. Make sure it is embedded in the performance management of providers.		By February 2010	NHS Norfolk and NHS Great Yarmouth and Waveney	
<b>14.4</b>	Work with partners in the Local Area Agreement to ensure that mainstream services take full account of the needs of people with dementia and their carers.	Revision of the Joint Strategic Needs Assessment		Commissioners, especially ASSD	
<b>14.5</b>	Strengthen the locality focus on dementia by working innovatively with Practice Based Commissioners (PBC).	Locality focus to consultation on strategy.		Commissioners	

Increase the participation of people with dementia, their carers and service providers in the Norfolk mental health locality groups. Use these groups to shape the potential future development of the dementia adviser service currently being piloted, and to coordinate with pilots of other 'navigator roles' for people diagnosed with a long term condition.

### **Proposed Quality Indicators**

## APPENDICES

### Appendix A

## **Key influencing documents**

### **National and regional**

- National Dementia Strategy (DH February 2009)
- National Dementia Strategy - impact assessment (DH February 2009)
- National Dementia Strategy Implementation Plan (DH July 2009)
- National Dementia Strategy Joint Commissioning Framework (DH July 2009)
- NHS Next Stage Review (DH 2008)
- Putting People First (DH 2008)
- Towards the best together (DH 2008)
- Valuing People Now (DH 2007)
- Carer's Strategy (DH 2008)
- End of Life Strategy (DH 2008)
- See me, not just the dementia –CSCI (2008)
- NICE guidelines and technical appraisals (2006)
- National Service Frameworks on Mental Health, Older People, Coronary Heart Disease and Long Term Conditions, particularly in relation to healthy living. (DH)
- Our Health, Our Care, Our Say (DH 2006)
- The Commissioning Framework for Health and Wellbeing (DH 2006)
- The World Class Commissioning Framework (DH 2007).
- The NHS Operating Framework (DH 2008)
- Mental Capacity Act 2005: deprivation of liberty safeguards
- Everybody's Business –Integrated mental health services for older adults: a service development guide (CSIP 2005)
- Intermediate Care: Halfway Home. (DH Revised guidance July 2009 Gateway ref. 12004)
- Living well with dementia: Transforming the quality and experience of dementia care for the people of Suffolk. Suffolk CC , NHS Norfolk and Great Yarmouth and Waveney December2008
- Commissioning Dementia Services: an integrated commissioning strategy. NHS East of England (EoE) and the Association of Directors of Adult Social Services (ADASS) September 2008
- Commissioning dementia education and training. An integrated commissioning strategy. NHS East of England (EoE) and the Association of Directors of Adult Social Services (ADASS) September 2008

## **Norfolk**

- Joint Strategic Needs Assessment for Norfolk 2008–2011
- Mental Health Needs Assessment of Older People in Norfolk (NHS Norfolk March 2009)
- The Mental Health Needs of the Elderly Population in Norfolk NHS Norfolk March 2009)
- Strategy and Action Plan for Sheltered Housing in Norfolk (Supporting People 2008)
- Strategic Model of Care – Care Homes. Reports to NCC Cabinet March 2008. August 2008
- Commissioning Strategy for Day Opportunities for Older People and People with Physical and Sensory Impairments. (Report to NCC Cabinet July 2008). Locality Commissioning Plans (Autumn 2008)
- Consultation Document on the Commissioning Strategy for Carers in Norfolk. (NCC , NHS Norfolk and Great Yarmouth and Waveney June 2009)
- NHS Norfolk Strategic Plan
- NHS Great Yarmouth and Waveney Strategic Plan