



## Joint Commissioning Strategy for Older People's Mental Health Services in Cambridgeshire

2011-2014

(to be reviewed annually)



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#### **Executive Summary**

Like the rest of the UK, Cambridgeshire has an increasingly ageing population. The population of people aged 65 and over is forecast to increase by 37% per cent during the next ten years. The forecast increase in the number of local people aged 85 years and over is an even higher 38% per cent.

Because of this rapid population growth, NHS Cambridgeshire and Cambridgeshire County Council have consistently identified care for older people as one of our top strategic priorities.

Similarly, the number of older people experiencing a mental health problem will also increase significantly in the next few years. We therefore need to plan now how we can redesign local services to be able to meet - within the available resources – the anticipated increase in demand upon local specialist older people's mental health (OPMH) services.

Dementia typically has the highest profile amongst the mental health problems from which older people can suffer, and features most prominently in national policy and guidance, but the prevalence of other common problems such as anxiety and depression is also relatively high amongst older people in comparison to most other age groups. Frequently memory problems and depression and anxiety also coexist in older people.

There are also increasing numbers of older people with long-term functional illnesses such as schizophrenia, schizoaffective disorders or bi-polar disorder, as well as those with non-progressive dementias, and we must plan how we propose to meet the needs of these groups.

This document includes national and local background information to put into context the reasons for developing an OPMH strategy, our informed view of the future need and requirements of older people's specialist mental health services and the key commissioning priorities for the next three years.

This Strategy was developed using feedback we have received from recent public consultations on proposed OPMH service re-design and the recommendations of the recent detailed review of local dementia services by the Adults Wellbeing and Health Overview and Scrutiny Committee.

We have also ensured consistency between this strategy and the Joint Commissioning Strategy for Older People recently developed by NHS Cambridgeshire and Cambridgeshire County Council.

A recurrent theme throughout this document is the evidence and feedback from local clinicians, patients and their carers, that earlier diagnosis and signposting to sources of help and support results in improved outcomes for patients with mental health problems. There are however opportunities for improvement throughout the care pathway. Other consistent themes include the need for staff training in a range of settings to raise awareness of dementia as a condition and of its management, and for partnership working between the local statutory and voluntary sector services to ensure that people are able to access the appropriate services/s that they need as promptly as possible.

We have therefore identified our commissioning priority as the re-design and roll-out of an Older People's Mental Health Service that:-

- Promotes greater awareness of dementia and other mental health problems in older people, amongst staff working in all health and social care settings including primary care, community and hospital-based health and social care services
- Supports the early identification of older people with a mental health problem and prompt guiding and access to the specialist expertise of both statutory and voluntary services as required. Offers a broad range of evidence based care, treatment and support options for older people with a mental health problem funded within available resources
- Focuses on an integrated and seamless service across primary and secondary care and across health and social care i.e. care for a patient is designed with the patient at the centre
- Involves partnership working at all levels, including with the voluntary sector
- Has a strong education and training element to up skill health and social care staff at every level in the management of dementia and other OPMH problems, and to increase general awareness and early identification of patients with an OPMH problem as above
- Effectively uses existing community resources. Has prevention, recovery and independence as a key aim underlying everything services do

Our progress against this strategy, once finalised, will be regularly monitored and reviewed by the Older People's Mental Health Steering Group. This is a multi-agency forum that co-ordinates local service planning work for older people with mental health problems, and its membership includes NHS and local authority commissioners and representatives from each of the major local service providers, service users and carers.

## 1. Introduction and Background

#### The purpose of this strategy

- 1.1 This document sets out the commissioning strategy of NHS Cambridgeshire and its successor GP-led commissioning consortia and Cambridgeshire County Council for mental health services for older people for the three years 2011-2014.
- 1.2 The re-design of mental health services for older people has been one of NHS Cambridgeshire's main strategic priorities for some years because of the scale of the forecast increase in the local population of older people over the next five to ten years, as if care service costs simply increase in line with population change they could nearly double by 2026<sup>1</sup>.
- 1.3 The publication of the National Dementia Strategy in 2009 raised the profile of and gave added impetus to this work. More recently, the National Operating Framework has identified improved dementia services as one of the three key priorities of the NHS during 2011/12. However there still remains a shortage of evidence on prevention of poor mental health.
- 1.4 Further, local GPs have consistently highlighted the lack of any appropriate provision for the increasing number of "older" people with functional mental health problems-typically anxiety and depression and increasingly for more severe and enduring illnesses such as schizophrenia historically associated with adult of working age as a major gap in local mental health services for older people.
- 1.5 This Strategy has been produced in consultation with a range of key stakeholders locally, including both NHS and voluntary sector service providers, local authorities, the Local Involvement Network (LINk) and representatives of local service users and their carers.
- 1.6 The document lists our commissioning priorities for service improvement over the next three years both for dementia and for other mental health problems commonly experienced by older people. In addition to the key stakeholders identified above, these priorities have been

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<sup>&</sup>lt;sup>1</sup> Under Pressure, Audit Commission, 2010

developed in partnership with local GPs who will be taking an increasing leadership role in the commissioning process in future.

1.7 Our progress against this Strategy once finalised will be regularly monitored and reviewed by the Older People's Mental Health Steering Group. This is a multi-agency forum that co-ordinates local service planning work for older people with mental health problems.

#### The need for this strategy

1.8 NHS Cambridgeshire and Cambridgeshire County Council have identified care for older people as one of our top strategic priorities because of the rapid increase in population that is predicted. The scale of this is set out in Table 1 below. We need to plan now how best to meet this increasing demand for older people's mental health services in the future

Table 1: Estimated older people population changes for Cambridgeshire for 65 years+

Cambridgesinie for 05 years+					
	2006	2011	2016	2021	% Change
Cambridge	13,800	15,200	17,700	20,200	46
East Cambs	12,700	14,600	17,300	19,400	53
Fenland	17,400	19,000	22,000	24,600	41
Huntingdonshire	22,700	27,200	32,900	36,500	61
South Cambs	21,500	27,000	34,300	40,100	87
Cambridgeshire	88,100	103,000	124,200	140,800	60

Source: NHS Cambridgeshire and Cambridgeshire County Council Joint Strategic Needs Assessment, Older People, 2010

1.9 Dementia is the name given to a group of diseases that affect the normal working functions of the brain. This can lead to a progressive decline of mental ability, affecting memory, thinking, problem solving, concentration and perception. Although dementia is primarily a condition associated with older people, there are also a small but significant number of people who develop dementia earlier in life, whose needs are often complex and different to those of older people with dementia

1.10 Dementia is the second most common mental health problem in older people and 20 % of people over 85, and 5 % over 65, have dementia. Dementia is the name given to a group of diseases that affect the normal working functions of the brain. This can lead to a decline of mental ability, affecting memory, thinking, problem solving, concentration and perception

There are a number of different types of dementia but the most common cause and the best studied is Alzheimer's disease (AD) (approximately 60% of all cases). Other causes are vascular dementia (VaD) (20%), dementia with Lewy bodies (DLB) (10%) and frontotemporal dementia (FTD) (2%). These diseases are not mutually exclusive and mixed pathologies are common. Heavy alcohol consumption is a predisposing factor.

1.12 A wide variety of cognitive symptoms occur in dementia, but memory loss is the most common and indeed is a core feature of any dementia illness. Short term memory loss is usually the presenting complaint with patients having difficulty in learning new information such as names, shopping lists and details of conversations. Later on in the disease distant memories are also affected. Other cognitive deficits include aphasia, apraxia, agnosia and executive deficits. In most dementias, including AD, the onset of memory problems is insidious and gradually progressive. In VaD cognitive changes are classically of sudden onset followed by a step-wise progression. Neuropsychiatric symptoms are very common in dementia. A wide variety of symptoms have been described including disorders of thought perception, affect and behaviour. Mood symptoms including depression and apathy are very common in all dementias. Marked changes in personality, including a decline in social and personal conduct with early emotional blunting are characterising features of FTD.

1.13 Sixty percent of people aged 65 and over have at least one limiting long term condition. In 2010 Cambridgeshire Older People's Enterprise (COPE) forum surveyed their members who attended the Annual General Meetings in 2008, two thirds reported a long term condition affecting daily life and just under half taking at least four daily medications. People with long term conditions, such as diabetes, often also have significant mental health conditions such as dementia or depression.

1.14 Furthermore, with older age comes an increasing likelihood of mental ill-health. Moreover, older people are far more likely to suffer depression through social isolation and physical ill-health and in many cases this is not identified until it becomes a significant problem.

1.15 The Department of Health estimates that 40% of older people seeing their GP, 50% of older people in general hospitals, and 60% of care home residents, have a mental

health problem.

- 1.16 Providing care for people with both physical and mental health needs requires services that are integrated and responsive in terms of access and flexibility in particular
- 1.17 There is evidence that older people are also increasingly likely to have substance misuse problems.

#### **Key themes**

- 1.18 A recurrent theme during the production of this Strategy has been the evidence (backed by feedback from service users, their carers and local GPs) that earlier diagnosis and guiding towards sources of help and support results in improved outcomes as mental health problems develop in older people.
- 1.19 There are nevertheless opportunities for <u>improvement</u> in service user experience and outcomes throughout local care pathways.
- 1.20 Other consistent themes include:-
  - The need for staff training in a range of settings to raise awareness and increase the identification of patients with dementia and other mental health problems. Staff training on management issues is also required.
  - The need for partnership working at all levels: between primary and secondary care, specialist physical and mental health care services and statutory and voluntary sector services, ensuring that people receive a seamless service and are able to promptly access the appropriate help when they need it.
  - The need for services to support independence, selfdetermination and recovery through integrated services.
  - The need for specialist provision of accommodation for people with all types of mental health needs. There are good examples locally where provision of good specialist accommodation has enabled us to improve the care of people with long-term mental health needs and reduce the number of hospital beds required.
- 1.21 Older People's Mental Health (OPMH) services aim to treat an individual's emotional and mental wellbeing. Good mental and psychological well-being is as important in older age as at any other time of life. Older people have good mental health, but are more likely to experience events that affect emotional well-being, such as

bereavement or disability.

1.22

We hope that developing this Strategy will contribute towards improving the mental health services which older people in Cambridgeshire receive, and prepare us for the changes we expect to see locally and nationally during the next three years. No plan can anticipate all the changes which will happen over a three-year period, but this strategy aims to enable us as commissioners, local service providers and other key stakeholders to work together with a clear and shared understanding of our aims and priority actions for the next three years

### National and Local Context

#### National policy in relation to OPMH service planning

- 2.1 Historically the focus of national mental health policy has been upon adults of working age. The National Service Framework (NSF) in 1999 set out a ten-year programme to deliver more services for adults in the community rather than in-patient settings, and introduced a number of specialist community-based services. More recently, the "Increased Access to Psychological Therapies (IAPT)" programme from 2008 onwards further raised the profile of services for adults with mild to moderate mental health problems, with a particular focus upon employment support.
- 2.2 The NSF for Older People published in May 2001 did highlight mental health problems, as an important health issues for older people, but did not include prescriptive service models or specific milestones for their implementation as did the NSF for Adult Mental Health.
- More recently the profile of mental health services for older people has been raised by the publication in February 2009 of 'Living Well with Dementia a National Dementia Strategy' subsequently most commonly referred to as the National Dementia Strategy (NDS). This has been developed in response to the forecast rapid increase in numbers of older people and their likely impact on both local health and social care services. Dementia is one of the most important issues we face as the population ages. There are estimated to be over 750,000 people in the UK with dementia and numbers are expected to double in the next thirty years.
- 2.4 The National Dementia Strategy set out a vision for transforming dementia services with the aim of achieving better awareness of dementia, early diagnosis and high quality treatment at all stages of the illness and in all settings.
- 2.5 The NDS was followed in November 2009 by the publication of a Department of Health report "The use of antipsychotic medication for people with dementia time for action" addressing the over-prescription of antipsychotic medication for people with dementia. Implementation of the 11 recommendations contained within that report is an integral

part of improving the care and experience of people with dementia and their carers.

- 2.6 Raising the quality of care for people with dementia and their carers has continued to be a major priority of successive governments. The current government has sought to accelerate the pace of improvement in dementia care, through local delivery of quality outcomes and local accountability for achieving them. This is a new outcomesfocused approach, a key element of which is ensuring greater transparency and provision of information for individuals. The aim is to enable people to have a better understanding of their local services, how these compare to other services and the quality of care that they can expect.
- 2.7 The new approach was set out in the document 'Quality Outcomes for People with Dementia: Building on the Work of the National Dementia Strategy' published in 2010. This Strategy provides a strategic framework within which local services can:
  - Deliver quality improvements to dementia services and address health inequalities relating to dementia;
  - Provide advice, guidance and support for health and social care commissioners and providers on the planning, development and monitoring of services
  - Provide a guide to the content of high-quality dementia services.

#### **The National Dementia Strategy**

- 2.8 The National Dementia Strategy identified seventeen objectives to be taken forward at national, regional and local levels to improve the quality of dementia care:-
  - 1. Raise awareness of dementia and encourage people to seek help
  - 2. Good quality early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way.
  - 3. Good-quality information for people with dementia and their carers
  - 4. Easy access to care, support and advice after diagnosis
  - 5. Develop structured peer support and learning networks
  - 6. Improve community personal support services for

- people living at home
- 7. Implement the New Deal for Carers
- 8. Improve the quality of care for people with dementia in general hospitals
- 9. Improve intermediate care for people with dementia
- 10. Consider how housing support, housing-related services, technology and telecare can help support people with dementia and their carers
- 11. Improve the quality of care for people with dementia in care homes
- 12. Improve end of life care for people with dementia
- 13. An informed and effective workforce for people with dementia
- 14. A joint commissioning strategy for dementia
- 15. Improve assessment and regulation of health and care services and of how systems are working
- 16. Provide a clear picture of research into the causes and possible future treatments of dementia
- 17. Effective national and regional support for local services to help them develop and carry out the strategy
- 2.10 In response to its publication, NHS Cambridgeshire mapped current local provision against each of these objectives in order to identify the major gaps and prioritise plans to address these. We also reviewed these gaps as changes to local services were implemented. The most recent results of that mapping exercise and review are set out in Appendix B.

#### **NICE Quality Standards for Dementia**

- The most recent NICE guidance on dementia was published in 2006 and is due for review in November 2011. Current national policy is not to offer population screening for dementia. Aligned with the goals of the National Dementia Strategy, NICE's quality standards are a set of specific, concise statements designed to act as markers of high-quality, cost-effective patient care, covering treatment and prevention. Derived from the best available evidence they were developed independently by NICE, in collaboration with NHS and social care professionals, their partners and service users, and address three dimensions of quality: clinical effectiveness, patient safety and patient experience.
- 2.12 Figure 1 shows how the ten NICE quality standards relate to the different stages of dementia. Primary Care Trusts in England are currently working to implement the national

Figure 1 10 NICE Quality Standards mapped against the stages of dementia

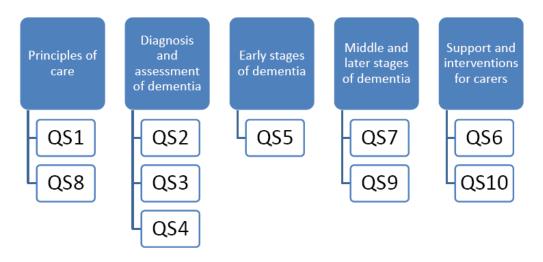


Table 2: 10 Nice Quality Statements

able 2.	To Nice Quality Statements
Number	Quality statements
1	People with dementia receive care from staff appropriately trained in dementia care.
2	People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3	People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4	People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.
5	People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of :  • advance statements • advance decisions to refuse treatment • Lasting Power of Attorney • Preferred Priorities of Care.
6	Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7	People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8	People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people's mental health.
9	People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
10	Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

#### **Key themes**

- 2.13 The National Dementia Strategy again highlighted good quality early diagnosis and intervention and support, information and advice as essential components of an effective service. In order to be as responsive as possible to people's wishes as well as to be effective and sustainable in terms of cost the NDS recommended that support and treatment should be provided as close to home as possible, including in people's own home. In this way people can be cared for at home for longer, and the time in institutional care can be kept to a minimum.
- 2.14 Whilst recognising the importance of the National Dementia Strategy and NICE guidance for dementia, we are also keen to ensure that priorities for service development and change locally do not focus solely on people with an organic mental illness. The results of the needs assessment undertaken within this strategy (see Chapter 3) show that there has been and will continue to be a significant increase in the number of older age adults with other mental health problems-typically anxiety, depression and problems such as phobias - living in Cambridgeshire over the next 5 to 10 years. This finding has been validated by feedback from local GPs and data from our pilot primary care mental health service in St Ives. We are therefore keen to ensure that early intervention and support in primary care and the community is available for both older people experiencing these common functional mental health problems and those that have a memory problem.
- 2.15 There are also increasing numbers of older people with long-term functional illnesses such as schizophrenia, schizoaffective disorders or bi-polar disorder, as well as those with non-progressive dementias, and we must plan how local services will meet the needs of these groups.
- 2.16 In writing this strategy we have considered a wide range of local information and evidence, including:
  - Estimates of the levels of mental health need of older people in Cambridgeshire
  - The range of services currently provided, how they work together, and how this compares with other similar areas
  - Work already undertaken to address local and national policy issues (e.g. the re-design of OPMH services in Huntingdonshire and Fenland in autumn 2010)
  - The resources we currently invest, and what we expect to have available in the future. It is important to be aware that there are significant financial challenges at present and efficiency savings will need to be made for a minimum of 3 years as below.

- The experiences and aspirations of key stakeholders, including: service providers, commissioners, service users and carers.
- The recommendations of the recent Adults Wellbeing and Health Overview and Scrutiny Committee member-led review of local dementia services.
- 2.17 In developing this strategy we have also reviewed and evaluated other key projects and work that has been undertaken locally, in order to ensure that the proposals and recommendations made within this strategy support and inter-link with other local strategies.
- 2.18 There are other recent and ongoing changes in national policy and circumstances that will impact upon how OPMH services are commissioned in future which were considered when finalising this policy:-
  - <u>'No Health without Mental Health'</u> the vision, values and general philosophy of care set out in this document are consistent with the recent direction of local planning work to improve services.
  - Personalisation of Care This is a challenging area for commissioners of services for older people. There is greater potential for the use of individualised budgets for older age adults than for many other groups. During the life-time of this strategy we anticipate that there will be significant progress nationally in the implementation of individualised budgets, particularly in social care. This will require us to work with people who use services, and their families and carers, to support them in making their individual decisions on how best to use the resources available to them. Whatever the challenges personalised care plans have the potential to drive new thinking on how current financial challenges could best be addressed and also strengthen partnership working to deliver care.
  - NHS Reforms The Coalition Government announced a number of reforms to the NHS in its White Paper, "Equity and Excellence: Liberating the NHS", which was published in July 2010. The White Paper set out plans for local GPs to take control of the commissioning of health care for their patients. The commissioning of health services will transfer between now and April 2013 to newly-established local "Clinical Commissioning Groups".

The local commissioning of mental health services will in future be led by local "Clinical Commissioning Groups" – typically made up of smaller, locality-based "clusters" or "consortia" of local GPs. The detailed future commissioning structures have still to be clarified but all of the emerging commissioning groups in Cambridgeshire have confirmed that they wish to continue to commission mental health services for older people jointly on a countywide basis.

- <u>Partnership Working</u> We also know that partnership working will be even more important than at present. Key partnerships will include those between:-
  - Primary and secondary care clinicians;
  - NHS (health) and local authority (social care and housing) commissioners;
  - Statutory and voluntary sector service providers;

Resource Outlook - It is also clear that the resource environment will inevitably be very challenging for the NHS during the next three years. The NHS has an efficiency savings target of £20 Billion during the four years 2011/12 to 2014/15 and local mental health services have - like the rest of the NHS — to seek to identify ways in which care pathways can be improved whilst also demonstrating that they are as efficient as possible and provide excellent value-for-money.

The NHS National Operating Framework for the 2011/12 financial year requires all service providers to deliver a 4 per cent annual efficiency saving as a minimum requirement. We anticipate this scale of efficiency saving to be required again in each of the next two financial years. This means that the local mental health services must deliver at least a 12 per cent efficiency saving during the three years that this strategy covers. Local authority commissioners must seek even greater levels of efficiency saving. In practice, and for a number of reasons including the current relatively high level of inflation and demographic pressures already highlighted, the level of efficiency saving required from current services is likely to be even greater than this.

Greater Focus on Quality of Care and Outcomes -an important consequence of the challenging financial climate is that in future there will be a much greater focus upon quality and outcome measures for services, in addition to the process and activity measures which are currently monitored. Our Action Plan needs to set out how we will embed quality and outcome measures in our routine contracting and monitoring processes.

#### The Future Need for OPMH Services in 3. Cambridgeshire

#### Joint Strategic Needs Assessment

Source: NHS Cambridgeshire and Cambridgeshire County Council Joint Strategic Needs Assessment, Older People, 2010

- 3.1 This section provides a summary of the detailed work that was undertaken locally to produce a Joint Strategic Needs Assessment (JSNA) for older people for Cambridgeshire (Date). The key outputs from that exercise that are relevant to assessing the future need for OPMH services are summarised below. These have formed the evidence-base to identify the commissioning priorities outlined later in this document.
- 3.2 In Cambridgeshire in 2009, there were 95,500 people aged 65 or over (almost 16% of all residents), 44,000 people aged 75 or over (7% residents), and 11,600 people aged 85 and over (2% residents). Overall, this is similar to the national picture but there is variation within Cambridgeshire (Figure 2, Table 3). The district with the greatest number of older residents is Huntingdonshire. The proportion of the population aged 65 and over ranges from 11.8% in Cambridge to 19.6% in Fenland.

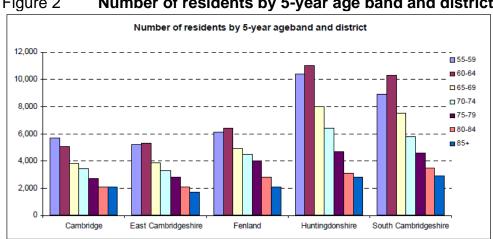


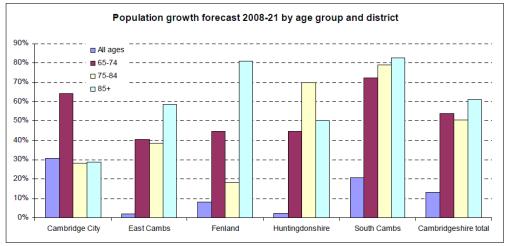
Figure 2 Number of residents by 5-year age band and district

Table 3 2009 population estimates for 65years+ in Cambridgeshire

	55-59	60-64	65-69	70-74	75-79	80-84	85+
Cambridge	5,700	5,100	3,800	3,400	2,700	2,100	2,100
East Cambs	5,200	5,300	3,900	3,300	2,800	2,100	1,700
Fenland	6,100	6,400	4,900	4,500	4,000	2,800	2,100
Huntingdonshire	10,400	11,000	8,000	6,400	4,700	3,100	2,800
South Cambs	8,900	10,300	7,500	5,800	4,600	3,500	2,900
Cambridgeshire	36,300	38,100	28,100	23,400	18,800	13,600	11,500

3.3 Figure 3 below shows the relative population change, by locality, for the total population and the population aged over 65 by age band. The greatest relative population change overall is seen in South Cambridgeshire and Cambridge City. In South Cambridgeshire this growth includes major increases in the population aged over 65. In contrast, Cambridge City shows very slight increases in the populations aged 65 to 74 and 85+, along with a decline in the population aged 75-84. Each locality, apart from Cambridge City, is forecast to show marked population growth among older people. While Huntingdonshire is forecast to show only a 3% rise in the total population, the population aged 85+ is forecast to rise by 59%.

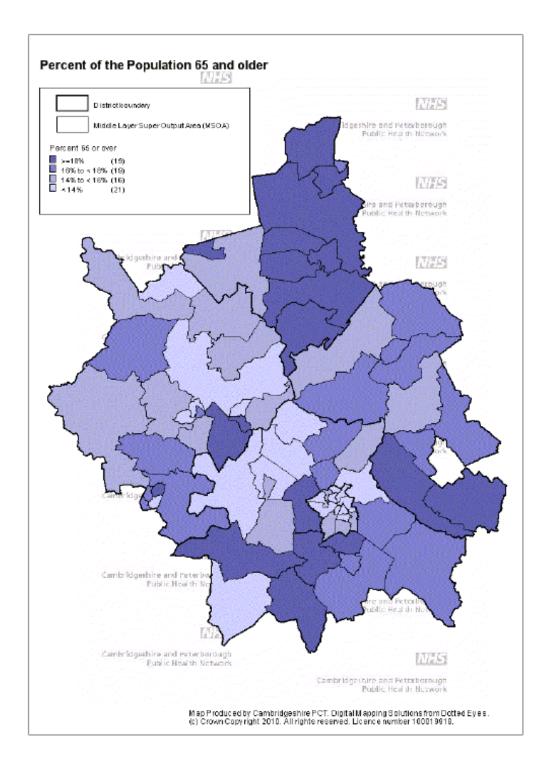
Figure 3 Population growth forecast 2008-21 by age group and district



Source: http://www.cambridgeshire.gov.uk/business/research/

Figure 4 below shows that older people comprise more of the population in rural areas than urban.

Figure 4 Cambridgeshire's Older Population Mapped by Region



- 3.4 Moreover people in Cambridgeshire are living longer and is higher than the national average. Between 1991/3 and 2006/8 life expectancy at birth has increased for both males (to around 78 years of age) and females (to around 82 years of age).
- 3.5 Although Cambridgeshire in the majority is prosperous with very good health outcomes, seven small areas are in the most deprived fifth of England, two in Fenland and five in Cambridge and there is a strong relationship between income and health.
- 3.6 In relation to dementia the key conclusions arising from the JSNA data are:-

- In the 20 years from 2010 to 2030, the expected number of people with dementia in Cambridgeshire is expected to double from 7,000 to more than 14,000
- Dementia is predominantly a disorder of later life but there are at least 150 people in Cambridgeshire under 65 with dementia
- The incidence (number of new cases) of dementia and prevalence (number of people at any one time) increases exponentially with age
- Dementia affects men and women in all social and ethnic groups
- Only around a third of people with dementia are diagnosed and treated
- Dementia is a terminal condition but people can live with it for on average 7-12 years

Figure 5 Number of New Dementia Cases in Cambridgeshire 2006-2021 by Age

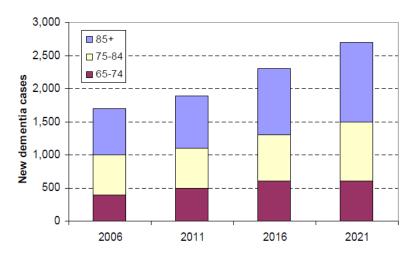


Table 4 Incidence of Dementia per year, by Age and Local Authority

Area	Age group	2006	2011	2016	2021%	change
Cambridgeshire	65-74	380	470	580	620	64%
	75-84	600	650	740	910	52%
County Council	85+	750	840	1000	1160	55%
County Council	Total with dementia	1720	1950	2310	2690	56%
	% population aged 65+	2.0%	1.9%	1.9%	1.9%	
	65-74	50	70	80	90	74%
Cambridge City	75-84	100	100	100	120	25%
Council	85+	140	150	160	160	14%
Council	Total with dementia	300	310	340	380	29%
	% population aged 65+	2.1%	2.0%	1.9%	1.9%	
	65-74	50	60	80	80	52%
East	75-84	90	90	110	130	45%
Cambridgeshire	85+	100	120	140	160	64%
District Council	Total with dementia	240	280	330	380	54%
	% population aged 65+	1.9%	1.9%	1.9%	1.9%	
	65-74	70	80	100	110	47%
Fenland District	75-84	120	130	130	150	19%
	85+	130	150	210	230	81%
Council	Total with dementia	320	360	430	490	50%
	% population aged 65+	1.9%	1.9%	2.0%	2.0%	
	65-74	100	130	160	160	54%
Luntingdonobiro	75-84	150	160	200	250	72%
Huntingdonshire District Council	85+	180	210	240	290	58%
District Courier	Total with dementia	430	500	590	700	62%
	% population aged 65+	1.9%	1.8%	1.8%	1.9%	
	65-74	90	130	160	170	91%
South	75-84	140	160	200	270	85%
Cambridgeshire	85+	190	210	250	310	61%
District Council	Total with dementia	430	500	620	750	76%
	% population aged 65+	2.0%	1.8%	1.8%	1.9%	

Figure 6 Estimated and Forecast Number of People with Dementia by Age for Cambridgeshire

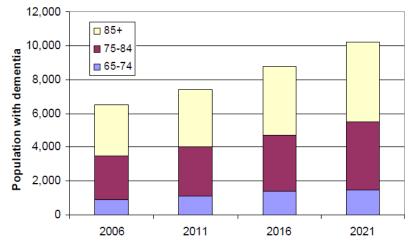


Table 5 Estimate of Population with Dementia (prevalence) by Age and Local Authority

Area	Age group	2006	2011	2016	2021	% change
Cambridgeshire County	65-74	890	1,100	1,370	1,460	64%
	75-84	2,650	2,860	3,260	4,050	53%
Council	85+	3,040	3,420	4,060	4,730	56%
Council	Total with dementia	6,580	7,380	8,690	10,240	56%
	% population aged 65+	7.5%	7.2%	7.0%	7.3%	
	65-74	130	150	200	220	74%
	75-84	440	430	450	550	25%
Cambridge City Council	85+	580	610	630	660	14%
	Total with dementia	1,140	1,190	1,280	1,430	25%
	% population aged 65+	8.3%	7.8%	7.2%	7.1%	
	65-74	130	150	180	200	52%
Foot Combuidacehine	75-84	390	420	480	570	45%
East Cambridgeshire District Council	85+	410	490	570	670	64%
District Council	Total with dementia	930	1,060	1,230	1,440	55%
	% population aged 65+	7.3%	7.3%	7.1%	7.4%	
	65-74	180	190	230	260	47%
	75-84	540	570	570	650	19%
Fenland District Council	85+	520	630	840	950	82%
	Total with dementia	1,240	1,390	1,650	1,850	50%
	% population aged 65+	7.1%	7.3%	7.5%	7.5%	
	65-74	240	310	370	370	54%
Hunting along bing District	75-84	640	710	860	1,100	72%
Huntingdonshire District Council	85+	740	850	990	1,180	59%
Council	Total with dementia	1,630	1,870	2,220	2,650	63%
	% population aged 65+	7.2%	6.9%	6.7%	7.3%	
0 11 0 1 11 11	65-74	220	300	390	410	92%
	75-84	640	730	890	1,180	86%
South Cambridgeshire	85+	790	850	1,030	1,280	61%
District Council	Total with dementia	1,650	1,870	2,310	2,870	75%
	% population aged 65+	7.7%	6.9%	6.7%	7.2%	

3.7 In relation to common mental health problems other than dementia, there is limited information available because of under reporting and low diagnosis and identification rates. However the number of older people with depression in Cambridgeshire is expected to increase from 8,600 in 2010 to 14,500 in 2030.

The National Mental Health Development Unit (2011) Management of depression in older people: why this is important in primary care states that;

- 1 in 4 older people have symptoms of depression that require treatment.
- Risk increases with age, with 40% over 85 years old are affected
- Fewer than 1 in 6 older people with depression discuss the symptoms with their GP and only 50% of these receive adequate treatment
- Up to 40% of residents of care homes may be depressed
- Physical illness increases the risk of depression
- Depression is associated with increased mortality and risk of physical illness
- Untreated depression is the leading cause of suicide among older people, with men living alone a particularly high risk

The prevalence of anxiety disorders in community setting is estimated

between 1 -15% depending on the study with Generalized Anxiety Disorder being the most common<sup>2</sup>

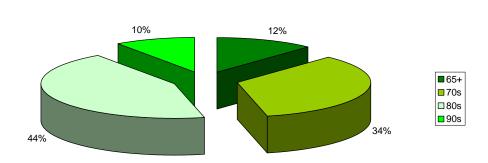
The Office of National Statistics published The Mental Health of Older People in 2003 which showed;

- 10% of people aged 60 74 in private households have a common mental health disorder (depression, anxiety, phobias)
- One third of these had difficulty with one or more common ADLs.
- Women more likely than men, 12% vs 8%
- Likelihood increases with decrease in household income
- Likelihood decrease with age (more so for men than women)

The older people's primary care mental health service pilot in St Ives identified that approximately 60% of their referrals are female. Figure 7 breaks down referrals received by age. It can be seen that a majority of referrals are for individuals in their 80s.

Referrals to OPMH Pilot Project October 2010 - March 2011

Figure 7 Referrals Received Presented by Age Groups.

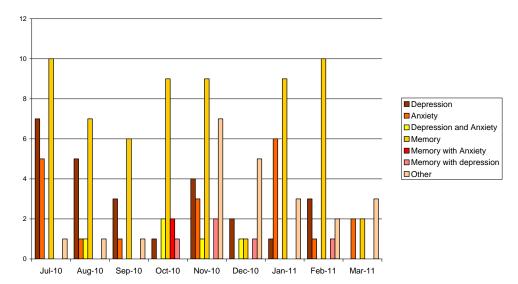


The majority of referrals are received for people experiencing anxiety and depression as shown in Figure 8. Other problems include issues with memory and co-morbid anxiety and depression. Less common problems are aggression, hallucinations, & suicidal ideation.

Figure 8 Reason for Referral

<sup>&</sup>lt;sup>2</sup> - http://bit.ly/li8HEs - paper published in 2008.

#### Types of problem/ Reason for referral



3.8 Currently, around 85% of older people do not access social care services<sup>3</sup> and most support is provided informally by networks of family and friends. Around 12% of older people within Cambridegshire providing unpaid care in 2001. Carers over 60 provide care worth twice public spending on care services for older people<sup>4</sup>

<sup>&</sup>lt;sup>3</sup> Audit Commission, Don't Stop Me Now, Preparing for an ageing population, 2008.

<sup>&</sup>lt;sup>4</sup> Under Pressure, Audit Commission, 2010

# 4. Current Investment, Service Provision and Service Planning in Cambridgeshire

4.1 This section summarises in turn the current investment in older people's mental health services by both NHS Cambridgeshire and Cambridgeshire County Council, the provision of these services, and the main local work streams to improve these services.

#### **Current Investment**

4.2 The current investment by NHS Cambridgeshire in older people's specialist mental health services is approximately as follows:-

Table 6 Investment in Older People's Mental Health Services by NHS Cambridgeshire

Type of Service	Investment (2010/11)
Specialist Mental Health Services	£18,200,000
commissioned from NHS Trusts	
Services Commissioned from Voluntary	£550,000
Agencies	
Total	£18,750,000

4.3 The current investment by Cambridgeshire County Council in older people's mental health services is approximately as follows:-

Table 7 Investment in Older People's Mental Health Services by Cambridgeshire County Council

Type of Service	Investment (2010/11)
Social care services integrated with CPFT [social workers, support workers, admin, etc]	£0.3M
Spot purchased - independent sector/third sector purchasing [nursing and residential care, supported living, home support]	£8.7
Block purchased services from the third sector [day care, support services]	£0.04M
Central services	£0.04M
Total	£9.05M

4.4 Both NHS and local authority commissioners will be operating in a very challenging financial climate during the three-year period of this Strategy. The likely scale of efficiency savings that will be required was set out in Section 2.18 above.

#### **Current Service Provision**

- 4.5 Currently, NHS Cambridgeshire commissions from Cambridgeshire and Peterborough NHS Foundation Trust and local voluntary organisations, a range of services in the community that aim to provide:-
  - Earlier diagnosis for people with dementia and other mental health problems such as anxiety and depression
  - Easier access to services by providing them closer to people's homes
  - Support for patients and carers to facilitate self-management and independence
  - Care at home to prevent people moving into care homes or going into hospital when there is an alternative management option.
  - A more integrated and seamless approach to patient care

#### **Current NHS Provision**

- 4.6 NHS Cambridgeshire currently commissions from the Cambridgeshire and Peterborough Foundation Trust seven care pathways for older people with mental health needs. These are illustrated in more detail in Appendix A. People are assessed on referral and allocated to the pathway most appropriate to their needs.
- 4.7 These seven pathways are:-
  - Community care for functional mental health problems this
    pathway is for older people who are experiencing mood or affective
    disorder, a psychotic disorder or neurosis (i.e. a functional illness).
    Patients may have a mental illness that requires the use of
    legislation is resistant to treatment, presents a risk to the patient or
    other people or they may have significant social, behavioural or
    psychological needs.
  - Community care for moderate to severe dementia this pathway is for older people with moderate to severe dementia.
  - Community care for people in the early stages of dementia this
    pathway is provided for people who are recently diagnosed with
    dementia and for whom dementia drug treatment might be suitable.

- Intermediate care this pathway is for older people experiencing a
  functional illness or dementia who are at risk of admission to
  hospital or a care home. They may present with significant
  problems where risks to themselves or others may be present.
  They may also have complex physical and social care needs and
  need intensive support and treatment over a few weeks in order to
  be able to recover at home rather than in hospital.
- In-patient treatment pathway this pathway is for people experiencing an acute or long-term functional illness or moderate to severe dementia whose needs cannot be safely met at home. They may have a mental illness that requires the use of legislation is resistant to treatment, presents a risk to themselves or other people, or the patient may have multiple social, behavioural or psychological needs. They are likely to require specialist assessment and treatment within an in-patient (hospital) setting, a range of ongoing interventions from the multi-disciplinary team, a complex care plan integrated with other statutory agencies, and assessment of their continuing care needs which cannot be carried out in the community.
- Young onset dementia pathway this pathway is for people under the age of 65 who suffer dementia and who have one or more significant social, behavioural or psychological needs. Younger people with dementia require specialist support. They may have dependent children and be unable to continue working because of their dementia.
- Day therapies pathway this pathway is for people experiencing an acute or long-term functional illness or moderate to severe dementia. They may be at risk of admission to hospital or their treatment may require the use of legislation. They are likely to require specialist assessment and treatment and a range of ongoing interventions from the multi-disciplinary team, including psychotherapeutic group and/or individual therapy and art therapies. People will access day therapy services until such time that they have recovered sufficiently.
- 4.8 More details about the time periods for contact with each pathway, the interventions that are delivered, the outcomes anticipated and the specialist staff delivering each pathway are contained in the pathway diagrams in Appendix A.

#### **Current Local Authority Provision**

The following services can be provided as part of a personal budget following an assessment of need under the NHS and Community Care

Act providing the person meets the Council's eligibility criteria of Critical and Substantial Needs.

#### 4.9 **Nursing Care Homes**

Care provided in nursing care homes is available for people over the age of 18 who live in the county and whose outcomes can no longer be achieved when living independently in the community. This would usually be due to support needs resulting from a combination of physical or learning disabilities, sight or hearing impairment, physical or mental frailty or ill health.

#### **Residential Care Homes**

Residential homes are available for people over the age of 18 who live in Cambridgeshire and whose outcomes can no longer be achieved when living independently in the community. This would usually be due to support needs resulting from a combination of physical or learning disabilities, sight or hearing impairment, physical or mental frailty or ill health. Accommodation, meals and personal care is provided including help with eating, washing, bathing, dressing and toilet needs.

#### **Respite Care**

This would involve someone staying for a few nights at a respite care centre or having care at home to give their informal carer a short break. Respite is only available to those who have informal carers.

#### Intermediate Care

This is provided to people who would benefit from a short period of active rehabilitation. The aim is to provide services to help the person regain physical skills and confidence.

#### **Supported and Other Accommodation**

Supported tenancies cover a range of accommodation and adapted properties set up to enable people with learning or physical difficulties, or with sight or hearing loss, to live in their own home, regardless of the level of disability.

These are usually shared by a small group of tenants with staff, based in the home, providing support with day to day living, from a few hours a day, up to 24 hours a day. Help and support is also offered for setting up and maintaining a home, managing finances, claiming benefits and developing domestic and life skills.

#### **Domiciliary Care**

This involves care workers assisting a service user at home to help them with personal care e.g. getting up and going to bed, washing and bathing, going to the toilet, getting dressed.

#### **Day Care and Day Services**

Day Centres offer a chance to get out of the house and meet other

people. They also provide meals and a range of social activities. Day care is offered to people who need some help with personal or practical care and are unable to get out and about by themselves.

Day care is usually available in a resource centre, community building or a residential home and offers more support than an ordinary day centre can provide. People are supported to access a range of other services.

Professional caring staff can provide support with personal care, such as going to the toilet, reminding someone to take their medication or help with washing or bathing. A hot meal and drinks during the day are provided as well as a chance to socialise and to take part in leisure and craft activities.

#### **Equipment and Adaptations**

Items of minor equipment are available for people over the age of 18, who live in Cambridgeshire and who need practical help due to sight or hearing loss, physical or learning disabilities, frailty or illness. These are provided to help people maintain their independence and quality of life as well as keeping them safe in their own homes.

Major housing adaptations can also be provided such as stair lifts, through-floor lifts or large ramps to avoid people having to move out of their own home and to enable them to continue to live there as independently as possible. People who live in their own property, may be able to apply for a Disabled Facilities Grant (DFG) via their district council

For people who live in rented accommodation, these adaptations may be available via their landlord

#### **Personal Budgets & Direct Payments**

Social care in Cambridgeshire is delivered via Self-Directed Support This involves identifying and allocating a Personal Budget - an up front sum of money to meet someone's needs.

Personal Budgets are available to all adults who are eligible for support from Adult Social Care. There are few constraints on how they are used as long as it is legal and keeps the person safe and healthy and meets their assessed support needs. Recipients have the option to take their Personal Budget as a Direct Payment.

As part of Self-Directed Support the person would need to complete a Support Questionnaire outlining their circumstances and social care support needs. The completed questionnaire is then used to estimate the amount of money needed to provide the support which is then used to plan the support.

A Direct Payment is an amount of money provided to a service user to arrange and purchase their care and support themselves. They can choose to take all or part of their Personal Budget as a Direct Payment which can be used to employ individuals, purchase support through an agency or for other chosen options.

#### Meals

Community Meals, often known as 'meals on wheels', can help ensure that people receive proper nutrition on a daily basis, whatever their circumstances. This service is for people aged 18 and over, normally older people, who are unable to prepare and cook one hot meal a day. This may be a permanent situation due to sight loss, a physical or learning disability, illness or a temporary situation such as recovering after a stay in hospital, to help you maintain independence and quality of life. To receive the hot meals on wheels service an assessment for eligibility is required.

#### **CCC Universal Information, Advice and Guidance Tool**

The Your Life, Your Choice website provides a universal information and advice website that will increase people's awareness of the choices available to them regarding adult social care services, which they may need, to remain living independently in their own homes.

#### **Current Voluntary Sector Provision**

- 4.12 In addition to these core NHS pathways, NHS Cambridgeshire also commissions services from local voluntary agencies, in particular the Alzheimer's Society. People accessing these services come from all age groups and typically present with cognitive impairment or dementia of any form. There are often carers and/or family involved.
- 4.13 These services offer a range of interventions and activities to service users and their carers:-
  - Outreach services these offer information and support for people with dementia and their carers at a person's home or an agreed venue or local drop-in centre.
  - Peer Support groups these are structured group sessions for people with dementia and/or their carers to discuss the diagnosis of dementia and its consequences in an informal environment in the presence of, and supported by, peers (people with dementia and/or their carers).
  - Outings and Events Outings and events are available to people with dementia who may attend with family, friends or carers. They

enable and support social interaction with the specific intention of reducing social isolation and helping people with dementia and their families to feel part of society.

- Carer information sessions these offer experiential learning from peers and information sharing around key services, facilitated by dementia support workers.
- Carers' assessments these are offered to carers of people with dementia or mild cognitive impairment.

#### **Service Provision in Primary care**

- 4.14 There is increasing evidence that identifying mental health problems in older people at an earlier stage and providing some help promptly results in better outcomes including enhanced quality of life for both service users and their carers. Since September 2009, a Primary Care Older People's Mental Health Service has been piloted in the St Ives area with the aim of establishing how best such a service can best be delivered in primary care, or other local community settings, within the available resources.
- 4.15 Primary Mental Health Care (PMHC) is suitable for people with mild to moderate mental health problems, for example those that have become anxious in old age, or who are feeling low because they are not able to do what they used to. These are problems that are important to identify quickly because they can often lead to more serious problems, including dementia. PMHC services provide access to advice, support and guidance on how a person with a mental health problem (and their carers) might help themselves, access support in the community and provides access to secondary care advice and services if required access. PMHC services also provide some treatments e.g. psychological therapy.

#### **Current Work Streams**

- 4.16 The main focus of service planning and re-design during the past two years has been upon each of the following:-
  - OPMH Primary Care Mental Health Service:- During the past two years we have been exploring the potential benefits of providing more services in primary care and the community for older people with dementia and other mental health problems, in order that people may be diagnosed and guided to effective help at a much earlier stage of their illness. Primary care mental health teams for adults with mild to moderate mental health problems have been well-received by service users and GPs since they were introduced locally in 2005. There is much evidence that earlier diagnosis improves the quality of life and general experience of dementia for

both those affected and their carers. This focus upon raised awareness and earlier diagnosis is also a key objective of the National Dementia Strategy published in 2009.

We have been piloting a primary care service model in St. Ives to explore what such a service for older people might look like, which interventions would be most effective, where it would be best delivered, the preferences of service users, etc. This work has generated much information about what model of service works best in meeting the needs of older people with dementia and other mental health problems. The feedback has been extremely positive and we are using this to design future services for this patient group.

- Developing Local Specialist Accommodation (e.g. Hilton Park and Wulfstan Way have enabled more people to be discharged from acute beds and regain their autonomy within the community with support from specialist providers, ultimately leading to better clinical outcomes.
- Hospital care In any hospital, such as Hinchingbrooke or Addenbrookes, there will be around 60-70% of beds occupied by older people. Many older people in an acute hospital will have a mental health problem such as anxiety, depression, delirium or dementia.

A recent report from the Alzheimer's Society 'Counting the Cost' <sup>5</sup>reported that most people with dementia are leaving hospital with poorer mental health than when they arrive. Patients typically find the environment challenging and although staff work hard to deliver high quality care, they do not always have the resources or skills to do this. These problems can slow down patient recovery and increase the time patients spend in hospital.

One major concern we have is that there are many older people in hospital with mental health needs that have not been identified, or if they have been identified, there is little or no specialist help available to them. This can result in poor patient experience and also longer lengths of stay in hospital. An important objective of our proposed changes is to develop services that will ensure prompt access to specialist older people's mental health help and support within local hospitals.

There is also plenty of evidence that the experience of people with dementia, or another mental health problem, who enter local hospitals for treatment for physical health problems unrelated to their mental health problems is often poor. This arises mainly from lack of awareness of hospital staff of dementia as a condition, how

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<sup>&</sup>lt;sup>5</sup> Counting the Cost (2009) Alzheimer's Society

to recognise the symptoms, and how best to manage the problems faced by people with dementia in the unfamiliar hospital setting. Consequences of this include longer stays in hospital and poorer outcomes. We will continue working with our service providers to implement a number of measures aimed at improving the experience of people with dementia in local hospitals.

#### Ramsey Dementia Pilot-Case Finding:-

This 2 GP practice pilot project (Ramsey) aims to identify patients with dementia who are at the highest risk of hospital admission. Two dementia project workers will be working closely with dementia patients and their carers – including work identifying risks for hospital admission and developing admission prevention plans for individual patients. The plot is funded for 12 months until April 2012.

#### • Dementia Drug Medication Review project

This 1 year project aims to provide holistic patient medication reviews for all patients prescribed medication for the management of dementia and NICE guidance will be followed. The project supports work around antipsychotic prescribing for the management of the behavioural and psychological symptoms of dementia, being carried out by local GPs and specialists.

The programme is designed to maximise engagement of key clinicians within Cambridgeshire and Peterborough Foundation Trust (CPFT) to ensure the cost effective use of these drugs in line with PCT priorities.

The implementation of this programme will be funded from within existing prescribing budgets. The key performance indicator is cessation of these medications when use is no longer clinically appropriate or consistent with NICE guidance on the cost-effective use of these drugs.

This programme will help manage the impact and costs of the anticipated changes in the NICE technology appraisal guidance on the use of donepezil, rivastigmine, galantamine and memantine that is expected to widen the criteria for their use in 2011.

Failure to implement the programme will lead to additional cost pressures for the health system and a missed opportunity to secure value for money in the use of these drugs at this key point in time.

Implementing this programme will also improve patient safety through review of antipsychotics in line with national and local priorities.

In addition to the above, the project aims to develop options for shared care guidelines for acetylcholinesterase inhibitors -

guidelines to be agreed by all GPs and relevant secondary care mental health staff.

In summary there is a need to:

Ensure that the patient is only taking dementia drugs during their illness when the balance of risk and benefit is appropriate.

Ensure that dementia drugs are prescribed and used in a cost effective manner in line with NICE guidance, including the use of antipsychotic medications.

Link the use of dementia drugs and antipsychotics in people with dementia into the system-wide work to support this group of patients and their carers in their own homes and in care homes, in line with national and SHA priorities and requirements.

## 5. Emerging Vision and Key Commissioning Priorities

#### **Gap Analysis**

- 5.1 A multi-stakeholder local workshop in September 2011 identified that main gaps in local services as;
  - Primary Care
    - Lack of equitable access to primary care older people's mental health service throughout Cambridgeshire
    - Awareness of mental health problems in older age in primary care professionals
    - Consistent practice regarding the prescribing of dementia drugs
    - Lack of information on local services, including wider community resources
  - Community Mental Health Services
    - Stronger links between mental health and other community services, including social care
    - Wider breadth of intervention options
    - Up skilling of existing staff required
    - Lack of information on local services, including wider community resources
  - Care Homes
    - o Consistent training in OPMH care
    - Consistent guidance as to appropriate prescribing of anti-psychotic drugs
    - Lack of alternative specialist accommodation e.g. step up/step down, supported living, extra care
    - Appropriate end of life care for people with dementia
  - Mental Health Inpatient Services
    - o More community provision to further reduce bed

- numbers
- Implementation of the Releasing Time to Care Programme
- Local district hospitals
  - Secured funding of the liaison and dementia nurses at each DGH
  - Pilot of the Complex Case front of house dementia team
  - Expansion of the This is Me patient passport

#### **Emerging Vision**

5.2 As commissioners, our vision is to develop a high quality, sustainable, "lean", seamless and integrated Older People's Mental Health Service, with a focus on primary care and community services

#### Over-arching aims

- Ensuring a patient focussed approach with strong partnership links to the local authority and other community and third sector organisations
- Increasing OPMH service throughput and thereby capacity, within existing resources, to enable us to provide sufficient coverage for our demographically ageing population.
- Ensuring that OPMH services commissioned are equitable and meet the needs of patients, carers and primary and secondary care professionals
- Ensuring mental health services commissioned are evidence based and value for money
- Seeking ways to provide "more for less" whilst maintaining the quality of care provided
- Work in partnership across agencies providing health and social care and the voluntary sector
- Target individuals with greatest capacity to benefit and maximise effectiveness of any intervention
- Engage with older people in service development
- Engage with older people in activities to promote and maintain good health
- Challenge and tackle social isolation
- 5.3 It is important for us as commissioners to set out clearly what we expect from the services we commission. In this context, our aim is to commission services which:
  - Result in the best possible outcomes for our users including older people with mental health problems, their carers and families. "Outcomes" include fewer symptoms of ill-health, the ability to lead as normal a life as possible, and maintaining contacts with family and friends for as long as possible
  - Result in high levels of patient and professional satisfaction
  - Raise professional and public awareness and understanding of OPMH problems

- Offer early diagnosis and support
- Ensure equitable access to a range of evidence-based services, both specialist and in the community, promptly and as close to home as possible
- Provide support for patients to live as independently as possible at home, and for as long as possible
  - Reduce hospital length of stay appropriately
  - Have the lowest possible number of complaints and untoward incidents (for example, falls or suicide attempts)
  - Embed OPMH education and training at both primary and secondary care level
  - Demonstrate excellent value for money
- 5.4 Services which meet these achievements should, we believe, have the following characteristics:
  - A person-centred approach to assessment, treatment and care –
    patients should receive a service that is as seamless and integrated
    as possible across all the interfaces: physical and mental health,
    primary and secondary care and statutory and voluntary
    organisations
  - A holistic approach to mental and physical health needs
  - Well-integrated links between health and social care with single inter-agency care plans and a single point of access
  - Make use of opportunities to link with organisations and services beyond health and social care in the wider community
  - Use treatments and approaches for which there is good research evidence
  - Be responsive to both common and unusual needs
  - Be committed to user and carer involvement, with this involvement demonstrably influencing the way services are developing
  - Be keen to share information, knowledge and skills with other services, and with the people and families who use them

#### **Key Priorities by Care Setting**

- The priorities for mental health commissioning in Cambridgeshire over the next three years are described below and set out in more detail in the Action Plan to be found in Appendix C. In order to make our plans and the monitoring of progress more manageable, our priorities have been grouped by care setting:-
  - Primary Care: Our intention is to roll out a new primary care
    pathway for older people with mental health problems which will
    include elements based on the successful experience of the St.
    Ives pilot. This will be delivered in partnership by both statutory and
    voluntary service providers. One of its priorities will be to raise

awareness and ensure earlier diagnosis and access to help and support for people with dementia and other mental health problems. The service will include new support worker roles which offer practical help to people at a relatively early stage of their illness, including access to other community resources. Because many people with a mental health problem also have a range of other physical health problems, close working with other community and practice-based health services will also be essential.

 Community Mental Health Services: The new primary care service will be complemented by an expanded range of treatment options available in the community and in specialist day therapy centres.

Given the continued financial pressures expected over the coming years and the expectation of a drive towards more integrated services, it is essential that local community services are organised to provide care and treatment in the most efficient and effective way. Local GP commissioners, secondary care clinicians and managers will work collaboratively to undertake a review of the existing local community care pathways, integrate a new primary care pathway and redesign the structure and function of local community services

As with primary care, we need to provide more information about and make better use of wider community resources that can help older people with mental health problems.

• Care Homes and Specialist Accommodation:-in any care home there will be a large proportion of residents with a mental health problem such as anxiety, depression, delirium or dementia. If the individual has a fall or their physical health deteriorates, their comorbid mental health problem often leads to the home feeling anxious and inappropriate admissions occur which are not always in the best interest of the service user. Our intentions are to maintain the level of care home training we commission and extend into other clinical areas where possible, such as ambulance services. Consistent practice across local care homes is another priority.

We also need to explore alternative forms of specialist accommodation locally. Given the challenging financial pressures facing the local health and social care economy, and the success there has been locally developing the ability to support people with longer term mental health conditions in specialist accommodation rather than in-patient wards, we aim to develop relationships and offer support to a larger number of independent sector partners. This will lead to an increase in the range of support accommodation available, which will allow us to further reduce the number of inpatient beds that are required locally.

 Mental Health In-Patient Services:- Due to improved community based care, the usage of beds in acute mental health wards has been steadily falling in recent years. As we continue to improve and strengthen community services we expect this trend to continue, even taking account of the increase in the population of older people that is forecast as mentioned above.

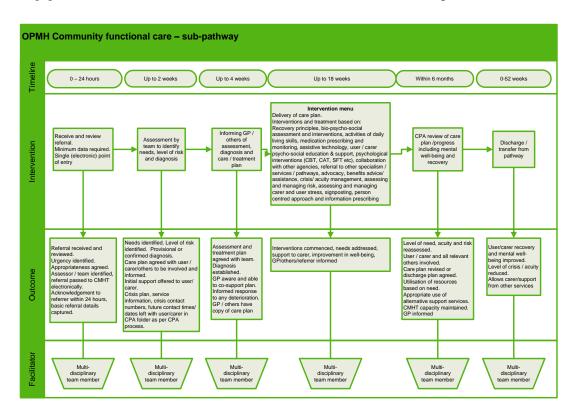
We will also make better use of our wards, and improve patient experience, by implementing the 'Time to Care' Programme.

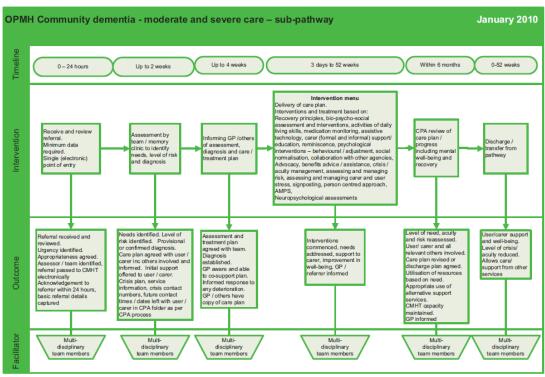
• Local District Hospitals: - In any hospital, such as Hinchingbrooke or Addenbrookes, there will be around 60-70% of beds occupied by older people. Many older people in an acute hospital will have a mental health problem such as anxiety, depression, delirium or dementia. We need to strengthen the practice of and specialist support available to staff working in local hospitals, so that these patients can be better managed during their hospital stay and be safely discharged more quickly.

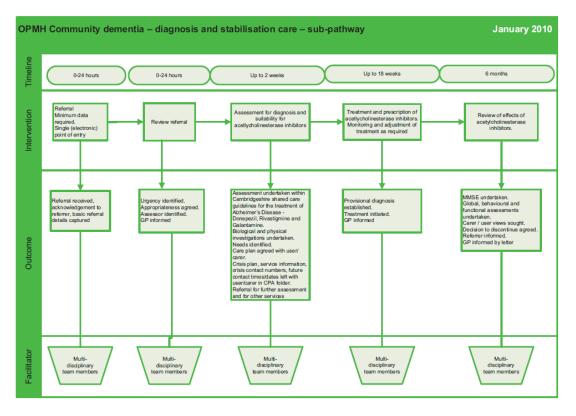
# 6. Local Implementation and Reporting Arrangements

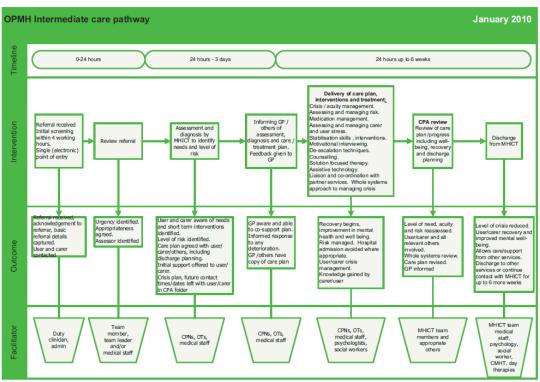
- 6.1 The Older People's Mental Health Group will have the responsibility for monitoring our progress in delivering this strategy. Its specific responsibilities will include:-
  - Taking the action plan forward to address each of the initiatives
  - Regular review of progress against the action plan. Revision of plans depending on progress, or on changes in the national or local context
  - Ensuring regular feedback to other key local commissioners, and other stakeholders, including:
    - a. GP commissioning consortia or "clusters";
    - Representative service user and carer organisations, including LINk;
    - c. The Cambridgeshire County Council Overview and Scrutiny Committee;
  - Development of new quality and outcome monitoring for older people's services at Locality level.

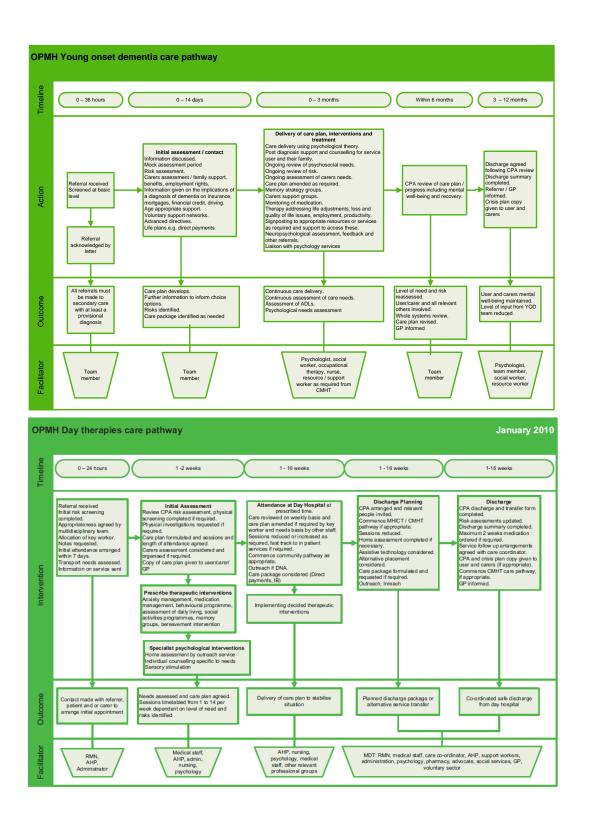
### Appendix A – Current Local CPFT Pathways











# **Appendix B**

#### NHS Cambridgeshire NDS Mapping Exercise March 2011

3 key steps;

- 1 Ensure **better knowledge** about dementia and remove **stigma**
- 2 Ensure **early diagnosis**, support and treatment fro people with dementia and their family and carers
- 3 **Develop services** to meeting changing needs better

RAG	N	Comments	
Red	0	Significant amount of work needed	
Amber	15	Some progress already made	
Green	0	Recommendation already implemented	
Grey	3	Responsibility of regional or national agency	
Total	17		

#### **List of Acronyms Used**

CCC	Cambridgeshire County Council	IC	Intermediate Care
CCS	Cambridgeshire Community Services	IMCA	Independent Mental Capacity Advocacy
CLAHRC	Collaborations for Leadership in Applied Health Research and Care	ISP	Independent Sector Provider
COPE	Cambridge Older People's Enterprise	JSNA	Joint Strategic Needs Assessment
CPFT	Cambridgeshire and Peterborough NHS Foundation Trust	LOS	Length of Stay (typically in a hospital bed)
CQC	Care Quality Commission	MH	Mental Health
CSCI	Commission for Social Care Inspection	NDS	National Dementia Strategy
DeNDRoN	Dementias and Neurodegenerative Diseases Research Network	NICE	National Institute for health and Clinical Excellence

YOD	Young Onset Dementia	ОРМН	Older people's Mental Health
EoE	East of England	QOF	Quality Outcomes Framework
IAPT	Improving Access to Psychological Therapies	U3A	The University of the Third Age

No	Objectives	Outcomes	RAG	Local Initiatives Progress
1	Raise awareness of dementia and encourage people to seek help	The public and professionals will be more aware of dementia and will understand dementia better. This will;  • Help remove the stigma of dementia  • Help people understand the benefits of early diagnosis and care  • Encourage the prevention of dementia  • Reduce other people's fear and misunderstanding of people with dementia.	AMBER	<ol> <li>Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)</li> <li>MH promotion Strategy-Public Health Team</li> <li>Partnership working with the Alzheimer's Society         <ul> <li>Dementia Advisor</li> <li>Dementia Support Worker</li> </ul> </li> <li>EoE anti-stigma and awareness raising campaigns.</li> <li>COPE (2000+ members)</li> <li>U3A (2300+ members)</li> </ol>
2	Good quality early diagnosis, support and treatment for people with dementia and their carers, explained in a sensitive way.	<ul> <li>All people with dementia will have access to care that gives them;</li> <li>An early high-quality specialist assessment</li> <li>An accurate diagnosis which is explained in a sensitive way to the person with dementia and their carers</li> <li>Treatment, care and support as needed after the diagnosis.</li> </ul> Local services must be able to see all new cases of people who may have dementia in their area promptly.	AMBER	<ol> <li>Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)</li> <li>Dementia QOF for GPs-although this is not an early detection tool.</li> <li>CPFT dementia protocol in place for GPs reference guide</li> </ol>
3	Good-quality information for people with dementia and their carers	People with dementia and their carers will be given good- quality <b>information</b> about dementia and services  • At <b>diagnosis</b> • During their care	AMBER	Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)     Partnership working with the Alzheimer's Society

				<ul> <li>Dementia Advisor</li> <li>Dementia Support Worker</li> <li>Dementia Liaison Nurse</li> <li>CAMTED education and training programme</li> </ul>
4	Easy access to care, support and advice after diagnosis	People with dementia and their carers will be able to see a dementia advisor who will help them throughout their care to find the right;  • Information  • Care  • Support  • Advice	AMBER	<ol> <li>Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)</li> <li>Partnership working with the Alzheimer's Society         <ul> <li>Dementia Advisor</li> <li>Dementia Support Worker</li> </ul> </li> <li>Dementia Liaison Nurse.</li> <li>CAMTED education and training programme</li> </ol>
5	Develop structured peer support and learning networks	People with dementia and their carers will be able to;  Get support from local people with experience of dementia  Take an active role in developing local services	AMBER	<ol> <li>Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)</li> <li>Partnership working with the Alzheimer's Society         <ul> <li>Dementia Advisor</li> <li>Dementia Support Worker</li> </ul> </li> <li>Peer Support Workers Groups</li> </ol>
6	Improve community personal support services for people living at home	There will be a range of flexible services to support people with dementia living at home and their carers.  Services will consider the needs and wishes of people with dementia and their carers.	AMBER	<ol> <li>Day therapy, increased modalities and location delivery</li> <li>choices pilot, individualised budgets</li> <li>Ramsey Dementia Project</li> <li>EK INTENSIVE SUPPORT SERVICE</li> <li>Partnership working with the Alzheimer's Society         <ul> <li>Dementia Advisor</li> <li>Dementia Support Worker</li> </ul> </li> <li>ICT CPFT</li> <li>SC, lead OP Care Teams</li> </ol>

7	Implement the New Deal for Carers	Carers will:      Have an assessment of their needs     Get better support     Be able to have good-quality short breaks from caring.	AMBER	<ol> <li>Respite beds, CPFT outreach</li> <li>Carers prescription</li> <li>Day centres, mental health outreach to community services</li> <li>Befriending schemes, Age UK</li> </ol>
8	Improve the quality of care for people with dementia in general hospitals	This way people with dementia will get better care in hospital:  • It will be clear who is responsible for dementia in general hospitals and what their responsibilities are  • They will work closely with specialist older people's mental health teams.	AMBER	<ol> <li>Dementia Liaison Nurse</li> <li>Psychology support</li> <li>Environment</li> <li>Staff training</li> <li>Carer/relative training</li> <li>Increased identification</li> <li>Complex Care Team RIF bid</li> <li>This is Me, Patient Passport</li> <li>Ward G4</li> </ol>
9	Improve intermediate care for people with dementia	There will be more care for people with dementia who need help to stay at home.	AMBER	Intermediate care team     Local specialist older people's services     Transitional care
10	Consider how housing support, housing-related services, technology and telecare can help support people with dementia and their carers	Services will:  1. Consider the needs of people with dementia and their carers when planning housing and housing services  2. Try to help people to live in their own homes for longer	AMBER	Doddington Extra Care Facility     Developments     Assisted technology strategy     ROD
11	Improve the quality of care for people with dementia in care homes	Services will work to ensure;  • Better care for people with dementia in care homes  • Clear responsibility for dementia in care homes  • A clear description of how people will be cared for  • Visits from specialist mental health teams  • Better checking of care homes	AMBER	<ol> <li>CAMTED education and training programme</li> <li>LES for care homes</li> <li>Dementia drug prescribing reviews         <ul> <li>Medication reviews</li> <li>Appropriate prescribing for BPSD</li> </ul> </li> <li>Respite beds, CPFT outreach</li> </ol>

12	Improve end of life care for people with dementia	People with dementia and their carers will be involved in planning end of life care.  Services will consider people with dementia when planning local end of life services.	AMBER	<ol> <li>CAMTED education and training programme</li> <li>LES for care homes</li> <li>Macmillan team</li> <li>End of Life work stream at NHS C</li> </ol>
13	An informed and effective workforce for people with dementia	All health and social care staff who work with people with dementia will;  Have the right skills to give the best care Get the right training Get support to keep leaning more about dementia.	AMBER	<ol> <li>CAMTED education and training programme</li> <li>OPMH dementia liaison nurse</li> <li>Roll out of Older People's Mental Health Primary Care Service (OPMHPCs)</li> <li>Contract development within Care Homes</li> <li>County workforce group</li> </ol>
14	A joint commissioning strategy for dementia	Health and social care services will work together to develop systems to:  Identify the needs of people with dementia and their carers  Best meet these needs  There is guidance in the strategy to help services to do this.	GREEN	JSNA     Older People's Commissioning Strategy     Collaborative and partnership working across county and organisations both strategically and at individual service user level.
15	Improve assessment and regulation of health and care services and of how systems are working	There will be <b>better checks</b> on care homes and other services to make sure people with dementia get the best possible care.		Responsibility of CQC but we need to ensure appropriate interfaces with them.
16	Provide a clear picture of research about the causes and possible future treatments of dementia	People will be able to get information from research about dementia.  We will do lots of things to indentify gaps in the research information and do more research to full the gaps.		CLAHRC-research department older people's services     SHA dementia drugs project     Research Nurse     JSNA very well done-exemplar based research

			<ul> <li>5. Good information on previous commissioning strategy, good projections i.e. strategic plan and implementation plan/</li> <li>6. Professor is currently being recruited</li> <li>7. Alzheimer's national research</li> </ul>
17	Effective national and regional support for local services to help them develop and carry out the Strategy	The Government will give advice and support to local services to help them carry out the <b>Strategy</b> .  There will be more good-quality information to help develop better services for people with dementia.	EoE are appointing a lead for the NDS.  Regional dementia network-newsletter CSIP website.

In addition to this we feel it is of importance to highlight **marginalised groups** and how easy it is for them to access these services such as;

- Prisoners
- Homeless (Supporting People)

## **Appendix C**

OSC Dementia Report- May 2011

# CAMBRIDGESHIRE COUNTY COUNCIL ADULTS WELLBEING AND HEALTH SCRUTINY COMMITTEE

Review of access to care support and advice for people with dementia and their carers following diagnosis

#### FINAL REPORT AND RECOMMENDATIONS

**JUNE 2011** 

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#### REVIEW: BACKGROUND AND APPROACH

#### 1. BACKGROUND

- 1.1 The Health and Adult Social Care Scrutiny Committee (which has since been replaced by the Adults Wellbeing and Health Scrutiny Committee) agreed in October 2009 to conduct a member-led review of dementia services. The review was conducted between February and December 2010.
- The review group consisted of Cllrs Caroline Shepherd (Chair); Sue Austen, Viv McGuire, Richard West and Jeff Dutton (until May 2010), and two co-opted members of Cambridgeshire LINk, Janet Feary (LINk Social care group) and Ian Raine (LINk mental health group). LINk brings together individuals and organisations to have a stronger voice in health and social care.

Officer support was provided by Jane Belman, Scrutiny and Improvement Officer.

- The review group was assisted by officers from NHS Cambridgeshire, Cambridgeshire and Peterborough NHS Foundation Trust (CPFT), and Cambridgeshire County Council Community and Adult Services. The officers briefed members on dementia and its implications, the National Dementia Strategy, the issues it raised for local services, and how it was being implemented locally.
- 1.4 Alzheimer's Society (AS) staff in Cambridgeshire supported the review by providing information, and by facilitating meetings between review group members and people with dementia and their carers.

#### Focus of recommendations

- 1.5 The recommendations in this report are formally directed at NHS Cambridgeshire, CPFT, Cambridgeshire Community Services NHS Trust, and the County Council, as key partners in implementing the National Dementia Strategy in Cambridgeshire.
- 1.6 GPs in Cambridgeshire are increasingly taking responsibility for commissioning healthcare services, in preparation for the setting up of GP commissioning consortia as proposed in the NHS White Paper, 'Equity and Excellence' and the Health and Social Care Bill currently in Parliament. In view of this, we are also submitting the report and recommendations to the GP commissioning clusters, GP mental

health leads and to the GP Senate for their consideration.

#### 2 REASONS FOR REVIEW

- 2.1 The Committee decided to review dementia services because dementia has a major impact on the lives of people with the condition and their carers, and because, largely as a result of the ageing population, the number of people with dementia is set to increase considerably over the next few years.
- The review group agreed to focus on the local implementation of objective 4 of the National Dementia Strategy (NDS) 'Easy access to care, support and advice after diagnosis'. This objective was selected because it was one of the NDS objectives identified in the local NHS dementia service mapping as needing a significant amount of work; a view reinforced by feedback from the Alzheimer's Society and Age UK Cambridgeshire.

There is evidence that intervention at this stage can have a positive impact on the quality of life of both the person with dementia and their carers, and help to maintain their independence. Work on this objective would also encourage early diagnosis, another NDS objective. There was therefore scope for scrutiny of this topic to add value to the work being done locally to implement the NDS.

Reflecting the reality of people's experience of dementia, there are inter-relationships between the different objectives in the NDS. Some of the review's findings and recommendations are therefore also relevant to other NDS objectives, particularly Objectives 2,3,5,6 and 7.

The full list of NDS objectives can be found on page 9

#### 3 OBJECTIVES OF REVIEW

3.1 The review aimed to:

2.4

- Identify actions that will contribute to the achievement of objective 4 of the NDS 'Easy access to care, support and advice after diagnosis'.
- identify where there were inequalities of access to services, including geographical variations in access to services
- make recommendations in relation to the above

The review examined the experience of older people with dementia and their carers living in different settings, wherever and by whom the diagnosis was made. It did not examine in depth the experience of people with young onset dementia (i.e. onset below the age of 65)

#### 4 METHODOLOGY

Note: Further details of source material are given in Appendix 5.

The review group obtained evidence as follows:

# 4.1 Dementia, the National Dementia Strategy, and the implications and issues for Cambridgeshire

- 4.1.1 The review group considered briefings and questioned officers from NHS Cambridgeshire, CPFT and Cambridgeshire County Council on:
  - the nature and prevalence of dementia, and its implications for people and services in Cambridgeshire
  - the National Dementia Strategy
  - Health, social care and other support provision for people with dementia and their carers
  - Issues and weaknesses in relation to current provision, and what was being done to address these, through implementation of the NDS recommendations.
  - Local pilot projects aimed at improving diagnosis, support, and care pathways.
- 4.1.2 The review group considered material produced by AS nationally on:
  - Dementia and its implications
  - Lessons from local practice, including the experience of dementia advisers

#### 4.2 The Experience of People with Dementia and their carers

Note: In this report a carer is defined as a person who provides practical and/or emotional support to a relative, friend or neighbour who is ill, frail, disabled, or experiencing mental distress, but who is not employed to do so.

People who are paid to provide care are referred to as care staff or care workers.

#### a) the views of people with dementia and carers

4.2.1

With the assistance of AS staff in Cambridgeshire, members met with carers and people with dementia who attended AS support groups, drop-in sessions or social groups. People were asked about:

- their experience of seeking and receiving a diagnosis
- what care, support and advice they had received at diagnosis and subsequently
- what they considered worked well and less well in terms of the care, support and advice they had received or were currently receiving
- what recommendations they would make for the future

Meetings took the form of focus groups or 1-1 discussions. Members obtained the views of a total of 38 carers and people with dementia. To ensure that the review captured the experience of people throughout the County, 2 sessions were held in Fenland, 2 in Huntingdonshire, 1 in Cambridge, 1 in S Cambridgeshire, and

1 in East Cambridgeshire, with people who attended the following:

- Whittlesey carers group
- Chatteris carers group
- Ely drop-in
- Cambridge drop-in
- Histon carers group
- 4.2.3Hartford pub lunch club
  - St Ives carers group

Participants were given an oral and/or written briefing on the nature and purpose of the review, confidentiality arrangements, and the areas of questioning.

The briefings and questions can be found in Appendices 3 and 4

#### b) the views and experience of local AS staff and volunteers

4.2.4 Members met with AS staff and volunteers who worked with people with dementia and their carers in Huntingdonshire, Fenland, and the southern part of the County. This included a discussion with the then recently appointed dementia adviser for Fenland.

# c) The views and experience of NHS and local authority professionals and other staff who work with people with dementia and their carers

4.2.5

Members had structured discussions with the following

- 4 out of the 5 GP mental health leads, who cover the Cambridge area, Huntingdonshire and East Cambs. There was no GP mental health lead in Fenland at the time of the review
- Community mental health teams (CMHTs) for Fenland, Huntingdonshire (which included staff involved in the St Ives Older People's Primary Care Project); and Southern Cambridgeshire.
- Cambridgeshire Community Services (CCS) NHS Trust Planned Care Managers
- Sheltered Housing officers S. Cambs District Council

4.2.6

In each case, people were asked for their views, based on their professional experience, on;

- What worked well and less well at present in terms of people with dementia and carers accessing care, support, and advice at the point of and following diagnosis, and why
- How well other agencies worked with them and with each other to ensure co-ordinated services.
- What should be done differently, and by whom
- What good practice should be built on

#### 5. CONTEXT: DEMENTIA AND ITS IMPLICATIONS

#### 5.1 Dementia

Note: the information on dementia, its prevalence and cost is taken from 'Dementia UK' a report prepared for the Alzheimer's Society by the Personal Social Services Research Unit (PSSRU) and the Institute of Psychiatry at King's College London in 2007. This was updated in 2010 by a briefing from Alzheimer's Society, which also took into account estimates from a 2008 King's Fund report 'Paying the Price: The cost of mental health care in England'

This material provides the most up to date evaluation of the current and projected numbers of people with dementia.

- 5.1.1 Dementia describes a group of symptoms associated with a progressive decline of brain functions such as memory, understanding, judgement, language and thinking.
- 5.1.2 During the course of the disease, the chemistry and structure of the brain changes, leading to death of brain cells.

Symptoms include;

- Loss of memory for example, forgetting the way home from the shops, or being unable to remember names and places, or what happened earlier the same day.
- Mood changes particularly as parts of the brain that control emotion are affected by disease. People with dementia may also feel sad, frightened or angry about what is happening to them.
- Communication problems a decline in the ability to talk, read and write.

In the later stages of dementia, the person affected will have problems carrying out everyday tasks, and will become increasingly dependent on other people.

5.1.3

There are over 100 types of dementia, caused by different diseases of the brain. Alzheimer's Disease is the most common form, affecting around 62% of people with dementia; followed by vascular dementia (resulting from one or more strokes) affecting 17%; with a combination of the two affecting 10%. The way each person experiences dementia, and the rate of their decline, will depend on many factors, including the type of dementia they have, their physical make-up, their emotional resilience and the support that is available

5.1.4 to them. People with dementia can live for several years after diagnosis.

The impact of dementia on the quality of life of those with the illness and their families is profound. Family carers are often older and in

poor physical health themselves, and depression is common.

#### 5.2 Prevalence of dementia

- 5.2.1 Dementia can affect people of any age, but is most common in older people. The prevalence of dementia increases with age. It is estimated that one in six people over 80 and one in 14 people over 65 have a form of dementia. The number of people with dementia is steadily increasing, largely as a result of people living longer.
- 5.2.2 AS estimates that there are currently 750,000 people in the UK with dementia, including over 16,000 who are under 65. The total is projected to rise to 940,000 by 2021. (Alzheimer's Research UK gives a higher estimate of 820,000 people in the UK currently with dementia).
- 5.2.3

  It is estimated that only about one-third of people with dementia receive a formal diagnosis at any time in their illness ('Improving Services and Support for People with Dementia: National Audit Office 2007')

#### 5.3 Costs of dementia

5.3.4

- 5.3.1 AS estimates that around 63.5% of people with late onset dementia (i.e. onset over the age of 65) live in private households, whereas around 36.5% live in care homes.
- 5.3.2 The 2007 Dementia UK report estimated the annual cost per person over 65 with dementia, based on 2005/6 figures as follows:
  - people in the community with mild dementia £16,689
  - people in the community with moderate dementia £25,877
  - people in the community with severe dementia £37,473
  - people in care homes £31,296.
- The highest costs related to residential and nursing home care for those with advanced dementia (41% of the total cost), and informal care inputs by family members and other unpaid carers (36%). This includes estimates for lost income for those carers under 65 who have to give up employment or cut back their work hours, loss of taxes paid to the Exchequer, and receipt of Attendance Allowance or Disability Living Allowance.
  - Other costs relate to social care, especially day provision (15%) and to NHS care (8%).
- Updated figures estimate the financial cost of dementia in 2010 as around £20 billion a year in the UK. The figure for England is £16.5 billion a year, estimated to rise to £23 billion by 2018.

#### 5.4 Local facts and figures

This information is taken from the Joint Strategic Needs Assessment for Cambridgeshire: Phase 4 Summary: Cambridgeshire County Council and NHS Cambridgeshire January 2011.

- 5.4.1 In Cambridgeshire in 2009 there were around 95,500 people aged 65 and over almost 16% of residents. The proportion of the population aged 65 and over ranges from 11.8% in Cambridge City to 19.6% in Fenland. Huntingdonshire has the largest number of older residents.
- 5.4.2 With the exception of Cambridge City, the number of older people in the County is expected to rise steadily until at least 2021. Older people comprise a higher proportion of the population in rural areas than in urban, and this proportion is expected to increase.
- 5.4.3 The number of older people with dementia in Cambridgeshire is expected to double from 7,000 to 14,000 over the next 20 years, as life expectancy increases. Local NHS officers estimate that there are 205 people in the County with young onset dementia (i.e. between the ages of 30 64).

#### 6. THE NATIONAL DEMENTIA STRATEGY

#### 6.1 Overview

6.1.1 The Department of Health published: 'Living well with dementia; A National Dementia Strategy' in February 2009. The overall goal was for:

"people with dementia and their family carers to be helped to live well with dementia, no matter what the stage of their illness or where they are in the health and social care system"

6.1.2

The NDS aimed to ensure that significant improvements were made to dementia services across three areas: improved public and professional awareness; earlier diagnosis and intervention; and a higher quality of care. The Strategy, which was informed by feedback from people with dementia, carers, professionals and other stakeholder groups identified the following 17 objectives:

Objective 1: Improved public and professional awareness and understanding of dementia

Objective 2: Good quality early diagnosis and intervention for all

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

Objective 4: Easy access to care, support and advice following diagnosis

Objective 5: Development of structured peer support and learning networks for people with dementia and carers

Objective 6: Improved community personal support services

Objective 7: Implementing the Carers' Strategy for carers of people with

dementia

Objective 8: Improved quality of care in general hospitals

Objective 9: Improved intermediate care

Objective 10: Housing support, housing-related services and telecare to support people with dementia and their carers

Objective 11: Living well with dementia in care homes

Objective 12: Improved end of life care

Objective 13: An informed and effective workforce

Objective 14: A joint commissioning strategy

6.1.3 Objective 15: Improved assessment and regulation of health and care services and of how systems are working

Objective 16: A clear picture of research evidence and needs

Objective 17: National and regional support for implementation of the Strategy

6.1.4 PCTs and local authorities were expected to make continued progress towards meeting these objectives over the following 5 years, with Department of Health support at national and regional levels.

In September 2010, a Department of Health update 'Quality Outcomes for People with Dementia: building on the National Dementia Strategy' set out a series of outcomes which those implementing the Strategy should work towards.

By 2014, people with dementia should be able to say:

- I was diagnosed early
- I understand, so I make good decisions and provide for future decision making
- I get the treatment and support which are best for my dementia and my life
- I am treated with dignity and respect
- I know what I can do to help myself, and who else can help me
- Those around me and looking after me are well-supported
- I can enjoy life

6.2.2

- I feel part of a community and I'm inspired to give something back
- I am confident my end of life wishes will be respected. I can expect a good death.

#### 6.2 Early diagnosis and support

- 6.2.1 Objective 4 of the NDS 'Enabling easy access to care, support and advice following diagnosis' arose from the need expressed by people with dementia and their carers for someone they could approach for help or advice at any stage of the illness: 'someone to be with us on the journey'. It stated that 'Current health and social care services normally discharge people after diagnosis once their case is stable and the care package is being delivered'.
- The NDS specifically recommends that there should be a dementia adviser who can facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers. The adviser would do this by acting as a point of contact following diagnosis, providing information and advice, and signposting to additional help and support, complementing the work of health and

social care professionals. Several local demonstrator projects were

6.2.3 set up in different parts of the country to test this approach.

Objective 4 relates closely to NDS Objective 3- 'Good quality information for those with diagnosed dementia and their carers'. This includes information on the illness and the services available both at diagnosis and throughout the course of their care, including what

6.2.4 options exist for those diagnosed to plan ahead to ensure their wishes are considered in the future.

The NDS also highlights the importance of early diagnosis and early intervention once diagnosed (Objective 2). It states that underdiagnosis is the current norm, and that when diagnoses are made, it is often too late for those suffering from the illness to make choices.

6.2.5 Often, diagnoses are made at a point of crisis.

There is some evidence that early diagnosis and intervention not only improves the quality of life for people with dementia and their carers, but is cost effective. One cost-benefit analysis referenced in the NDS suggests that investing in services for early diagnosis and intervention could save £120m social care spending and £125m in private spending in England over 10 years if it reduced care home admissions by 10%.

#### 6.3 Local Implementation

- 6.3.1 In response to the National Dementia Strategy, in 2009 NHS
  Cambridgeshire, in liaison with Cambridgeshire County Council,
  CPFT, CCS NHS Trust, AS and other agencies, conducted a service
  mapping exercise which identified the level of progress against each
  of the NDS objectives.
- 6.3.2 Objective 4: Easy access to care, support and advice following diagnosis, was identified as one of four objectives where a significant amount of work was needed. The others (Objectives 5 peer support; 8 improved care in general hospitals and 12 end of life care) are outside the scope of this review.
- 6.3.3

  A number of good practice projects and pilots have been initiated in different parts of the County to help implement the NDS objectives. These are however localised and time-limited
- 6.3.4 Those particularly relevant to Objective 4 are:
  - A dementia adviser service, provided by AS, which is being piloted in Fenland. This supports people who have received, or are in the process of receiving a diagnosis of dementia, through providing information, help with accessing services, and a personal contact throughout the duration of their dementia.
  - The Older People's Primary Care Mental Health Pilot (OPPCP) in

St Ives. This provides a single point of access to diagnostic, treatment and support services for older people with mental health issues, including those who may have dementia. The project, which includes an AS support worker, has close links with local GPs and other health professionals who refer people to it Information on both these initiatives can be found in Appendix 2

CPFT are also developing a peer support project, which will provide ongoing support to carers of people with dementia, from volunteers who have been carers themselves.

#### 7. REVIEW: FINDINGS AND RECOMMENDATIONS

#### **SUMMARY**

#### **Evidence base**

- 7.1 These findings and recommendations draw together:
  - The experience of people with dementia and their carers. They are the outcome of in-depth small-group and 1-1 discussions with 38 carers and people with dementia, who attended an AS carers support group, drop-in, or lunch club. Sessions were held throughout the County, and the findings can therefore be considered a fair reflection of the views and experience of carers and people with dementia in Cambridgeshire who take part in these activities.

The issues that participants raised were similar across the County and were consistent with those raised by AS workers, and with evidence from NHS professionals.

- The views and experience of AS Society staff and volunteers
- The views and experience of NHS and local authority professionals and other staff who work with people with dementia and their carers

### 7.2 **Key Findings**

The findings showed a lack of consistency in the extent to which the pathways worked effectively for individuals or their carers from when they first sought a diagnosis through to obtaining care and support

7.3 after diagnosis. There was a need for stronger inter-agency working at an operational level to address this.

Key stages in the pathway where improvements were needed were:

- Obtaining a diagnosis
- 7.4 Accessing support and advice after diagnosis

Accessing appropriate health and social care services after diagnosis

Key issues relating to the above were:

- The crucial role played by GPs in enabling people to be diagnosed early and to access support, and the importance of GPs having training, information and support in order to ensure that they identify and respond appropriately to people showing signs of dementia.
- The importance to people with dementia and carers of being aware of and having access to support and information on diagnosis and through all the stages of the condition, and the value that they place on this.
- The importance of effective interagency working across health, social care and other provision in ensuring that people received co-ordinated services. This included rolling out the approach taken by the St Ives Older People's Primary Care Project; strengthening the interface between CMHT's and CCS NHS Trust social care staff and greater involvement of sheltered housing officers.

7.5

- The need to increase the availability of person-centred services, by encouraging a more diverse range of services, training for care providers, and reviewing the level and range of provision of day and respite care.
- In conducting the review, members were also made aware of other areas where improvement was needed in hospital and other healthcare services and in social care.

The findings and recommendations are detailed below.

# 7.7 Overarching Recommendation

The review and its recommendations aim to build on the interagency work that is being undertaken or planned by the NHS and County Council to implement the National Dementia Strategy locally. The Committee therefore makes the following overarching recommendation

#### **Recommendation 1**

- a) The findings and recommendations of the review are incorporated into an updated agreed interagency strategy and timetabled action plans for taking forward the National Dementia Strategy in Cambridgeshire.
- b) The organisations and individuals within them who have lead responsibility for co-ordinating and delivering each aspect of the strategy and plans are clearly identified.

- c) Particular attention is paid in the action plans to ensuring that throughout the county:
- agencies work with each other and with GPs effectively at an operational level
- the referral and care pathways for individuals during and after diagnosis are clear and operate effectively in order that people with dementia and their carers are able to access well co-ordinated support and services wherever they live.

#### 8. OBTAINING A DIAGNOSIS

#### **Findings**

- 8.1 The diagnostic process
- 8.1.1 NICE-SCIE clinical guideline CG42 on dementia recommends that "a basic dementia screen should be performed at the time of presentation, usually within primary care" When someone goes to their GP with symptoms which could indicate dementia, such as memory problems, the GP should therefore undertake an initial screen. This includes identifying other possible causes, such as depression or physical health problems, and using a standard screening test.
- The guideline recommends that "A diagnosis of dementia should be made only after a comprehensive assessment". If people have suspected dementia, GPs (or other health professionals) should therefore refer people to their local Older People's Mental Health Services provided by CPFT. The service provides a consultant-led, specialist, multidisciplinary assessment, diagnosis and treatment of patients with memory problems or suspected dementia. Professionals involved include psychiatrists, community psychiatric nurses, psychologists, occupational therapists, social workers and team support workers. The assessment process should include a
- 8.1.3 carer's assessment, benefit check and liaison with other agencies as required.
  - Diagnosis is made by a specialist mental health doctor, usually following a referral by a GP. A detailed assessment for health and social care needs is undertaken and a plan agreed with the person with dementia and their carer. Dementia drugs are prescribed according to NICE guidelines if appropriate.
  - (at the time of this review, those at the mid-stage of dementia). The person is reviewed and if their needs are stable then the care of the
- 8.1.4 person, including monitoring of dementia drugs returns to their GP. Secondary mental health services will sustain involvement with many people with moderate or severe dementia, and re-review an individual should they or their carer request this.

8.1.5 This approach may not operate consistently in practice, however. The GP mental health lead in East Cambridgeshire reported that CPFT had asked GPs in the area to only refer people who may need or qualify for dementia drugs, had behaviour problems, or needed accommodation.

NICE-SCIE clinical guideline CG42 on dementia recommends that:

- 'Memory assessment services (which may be provided by a memory assessment clinic or by community mental health teams) should be the single point of referral for all people with a possible diagnosis of dementia.'
- 'Primary healthcare staff should consider referring people who show signs of mild cognitive impairment (MCI) for an assessment by memory assessment services to aid early identification of dementia, because more than 50% of people with MCI later develop dementia.'
- 'Memory assessment services that identify people with MCI ...should offer follow up to monitor cognitive decline and other signs of possible dementia in order to plan care at an early stage'
- Memory assessment services should 'offer a responsive service to aid early identification and include a full range of assessment, diagnostic, therapeutic and rehabilitation services to accommodate the needs of people with different types and all severities of dementia, and the needs of their carers and family'

CPFT run memory clinics in Peterborough and Huntingdonshire, and memory services in Cambridge City, South Cambs, East Cambs and Fenland.

8.2 <u>Carers experience</u>

8.1.6

- 8.2.1 It was common for the process of diagnosis to start when a carer or other family member, or sometimes the individual themselves, realised that something was wrong and went to their GP. Some GPs were very responsive, and CMHTs reported that GPs were now referring to them much earlier than in the past.
- 8.2.2 However in many instances carers, sometimes with back-up from other family members, had to be very persistent before their GP would act, at a time when they were dealing with the stress of the situation and often had health problems of their own. GPs would on occasion insist on confidentiality grounds that the person with suspected dementia, as the patient, had to come to the surgery themselves, even though, as a result of their dementia, they might lack awareness of their condition and not keep appointments. The more responsive GPs would in these circumstances work with the carer to arrange to see the person, e.g. through a home visit. In other instances, individuals with symptoms which might indicate dementia had made several visits to a GP themselves before dementia was considered.

AS experience reinforced that of the carers we spoke to. People could be fobbed off, sometimes repeatedly, if GPs did not recognise

the signs of dementia, or did not want to tell people. In these circumstances, AS staff encouraged people to go back to their GP or to try another GP. This seemed to be a particular problem in E Cambs and in Fenland, possibly exacerbated by a deferential attitude

8.2.4 toward GPs on the part of some older people – an unwillingness to 'bother the doctor'.

AS staff were also concerned that people with less common dementias, such as those related to strokes, MS, or alcoholism (seen as an increasing problem in Fenland) might not be identified.

#### 8.3 <u>Issues</u>

- 8.3.1 In the experience of AS staff, it could be a relief for people with early stage dementia to be told what was wrong with them. If someone is diagnosed early, they can prepare for the future and put their affairs in order delayed diagnosis denied them that right. It also delayed or removed the opportunity to benefit from medication, and delayed access to support and services for the individual and for their family carer. Anger was a common response to late diagnosis.
- 8.3.2 A failure to diagnose early could also result in a diagnosis, and future care decisions, being made in a crisis situation, such as when the carer became ill or died, or when the person with dementia was admitted to hospital.

The GP mental health leads, who have a special interest in mental health issues, including dementia, emphasised that much depended on the level of knowledge and commitment of individual GPs. Even if a GP perceived that a patient was showing signs of dementia, for example by repeated requests for GP visits for physical problems, they could be unwilling to diagnose if they could not see any benefit to the patient from doing so. Being able to offer something – such as access to treatment, services or support, was an incentive to diagnosis. Without this, the impact of knowing, in their view, might not always be helpful in the early stages to the person with dementia or their carers. It was therefore important not only for these services

- 8.3.4 to be available, but also for GPs to know about them and have confidence in them.
- There was still considerable variation in the extent to which individual 8.3.5 GPs referred patients to the CMHTs for diagnosis, although GPs generally were referring a lot earlier.
- GP mental health leads and others highlighted the need for GPs to be trained in dementia issues, in order to ensure that they identified and referred people with possible dementia, and were better able to provide support to people with dementia and carers once diagnosed.

These findings are borne out by a national study: "GP attitudes,

awareness and practice regarding early diagnosis of dementia"\*\*. This showed that older GPs were more confident than younger GPs in diagnosing, managing and giving advice about dementia, but less likely to feel that early diagnosis was beneficial, and more likely to feel that patients with dementia can be a drain on resources with little positive outcome. Younger GPs were more positive and felt that much could be done to improve quality of life. However, GPs in all age groups had a limited understanding of dementia.

\*\*(British Journal of General Practice Sept 2010)

#### 8.4 Local initiatives

- 8.4.1 CPFT were using external funding to pilot tailor made training based in surgeries to raise GP awareness in relation to early diagnosis and support.
- 8.4.2
  One of the local NDS implementation priorities is the provision of primary care mental health workers to train and provide specialist support to GPs in relation to diagnosis and signposting, building on the experience of the St Ives OPPCP ( see Appendix 2 for details)

#### 8.5 Recommendations

#### **Recommendation 2**

**CPFT and NHS Cambridgeshire ensure that:** 

- a) there is sufficient capacity, and a clear and well-understood referral pathway, to enable GPs throughout Cambridgeshire to refer all people with a possible diagnosis of dementia to a memory assessment service
- b) memory assessment services throughout Cambridgeshire are compliant with the NICE-SCIE guidance, and that there is a consistent approach to the service throughout the County in line with best practice.

#### **Recommendation 3**

CPFT and NHS Cambridgeshire, working with AS and other agencies, further develops and implement a systematic programme of training for GPs and other practice staff on dementia. This should cover how to recognise and respond to possible dementia, including the less common forms; the value of diagnosis and importance of referral; the referral and care pathway; information and support services, including those provided by AS and other voluntary organisations; and how to access them. It should include good practice in communicating with carers and in dealing with confidentiality issues in a way that is in the best interests of the person with dementia.

The aim should be to have at least one named GP or other professional in every practice (or in the case of single GP practices, small groupings of practices) with a good

understanding of dementia, who patients of that practice can access. In addition, all GP commissioning clusters should have at least 1 GP with a special interest in and understanding of dementia, who can help provide leadership and peer support for practices in the cluster.

#### **Recommendation 4**

Once diagnosed, all patients with dementia should be given the opportunity to have at least one named person, who could be a family member, friend, support worker or volunteer, whom the GP (and other professionals as appropriate) can contact and liaise with as needed.

#### **Recommendation 5**

CPFT and NHS Cambridgeshire take forward the local NDS priority of providing primary care mental health workers to train and provide specialist support to GPs in relation to diagnosis and signposting.

#### 9. SUPPORT AFTER DIAGNOSIS

#### **Findings**

#### 9.1 Support needs

- 9.1.1 Carers and AS staff emphasised the isolating effect of living with someone with dementia. This sense of isolation was often keenly felt just after diagnosis, when carers and the person cared for felt they were left alone to cope with both the practical and emotional implications, with little or no information or support. For the carer, this could include dealing with very demanding behaviour on the part of the person cared for; often the carer, as an older person, was also struggling with their own ill-health. Once diagnosed, it was very much left to people to initiate contact with their GP or social services if their situation then deteriorated or they felt unable to cope. AS staff reported that a high proportion of carers were on anti-depressants.
- 9.1.2

  The sense of isolation could be compounded by the stigma and fear associated with dementia, and the belief that little could be done to alleviate it. Several people commented that in terms of public perception, dementia was at the stage that cancer was 25 years ago.
- 9.1.3

  One AS staff member likened the experience for people at the point of diagnosis as being 'put into a rowing boat and pushed out in the middle of the lake with no oars.'
- 9.1.4

  Many felt that AS were the first to offer meaningful help or advice, and they would not have known how to access services or social support if it was not for AS. People's experience of and levels of confidence in, GPs varied, with some being seen as more supportive

than others. People sometimes saw a different GP each time, which made it hard for the person with dementia or their carer to form a 9.1.5 relationship.

GPs are required to keep a register of and annually review diagnosed dementia patients, but this review is very basic, covering for example a medications review, and a brief review of the carer's state and in itself does not address the support needs of the patient or the carer.

CMHT staff identified a gap in support after diagnosis, particularly where people were not in need of specialist support or did not quality for medication, and were therefore discharged from mental health services and referred back to their GP after diagnosis.

If people needed social care services, but were self-funding, they could just be given a list of providers without receiving any help or guidance. An example was given by an AS worker of a carer in tears because they thought their relative would have to go into a home; a person with dementia made a distressed call to a councillor because she had been given a list of care home providers with her name on it.

9.1.8

9.1.6

9.1.7

It was important for carers to hear the experience of other carers, especially at the early stages, in order to put their own situation in perspective. Links with other carers could provide a reality check, helping them realise that they were not alone, and were not a failure or to blame when things went wrong. Carers could talk amongst themselves about issues and experiences that they would not want to share with professionals or with their families.

#### 9.2 The role of Alzheimer's Society

9.2.1 A very strong message from carers and people with dementia throughout the County was how much they valued the support provided by Alzheimer's Society. As well as providing an opportunity for people to meet others in similar situations and to share experiences, AS was often the main or only source of information, advice or support on dementia and how to deal with it, what services or benefits were available, and how to access these – for example, benefits such as carers grant or attendance allowance; equipment and adaptations; assistive technology; social care. Their helpful attitude, flexibility and advocacy on behalf of people with dementia and carers contrasted at times with people's experience of public services. One carer commented:

'They (The AS workers) saved my life; I would be lost without them'.

9.2.2

However, most people had found out about AS by chance. Both carers and AS staff told us that when people received a diagnosis, whether from a GP or mental health specialist, they were seldom informed about the support that AS or other groups could offer – while

some professionals did do this, it was not systematic. People reported that they had found out about AS by word of mouth – in one instance, a chance encounter in the street with an acquaintance. One carer reported that she bought books and watched TV programmes in order to find out about dementia, until her daughter found out about AS from a professional contact. Another reported

9.2.3 that the person with dementia was told about AS, but not her as the carer.

More work was needed to raise the profile of AS with GPs; AS often had difficulty establishing links with GPs or getting their information

- 9.2.4 into GP's surgeries. This was also identified as an issue by one of the GP mental health leads
- 9.2.5 This evidence suggests that many people who would benefit are not aware of, and therefore do not access, the support that AS and other groups provide.
- 9.2.6 Even when people are given contact details for AS or other support services on diagnosis, it may be difficult for them to initiate contact, especially when they are in a state of shock. A more helpful approach would be for people to be referred to these services at this point.

CCS NHS staff highlighted the importance of funding voluntary organisations such as AS, in order that people with dementia and carers could access advice and support, and professionals had somewhere to refer people.

AS staff themselves were concerned that there were people that they were not reaching, and that rising demand on their services might exceed their capacity in future.

Information on the role of AS nationally and locally can be found in App. 1

#### 9...3 Information

- 9.3.1 Both carers and AS staff emphasised the need for information. This needed to be given alongside support, and the right kind of information given at the right times. The information that people were given from statutory bodies about services and how to access them was not always clear or helpful. One group of carers specifically recommended that all those giving a diagnosis should as a minimum provide a booklet with details about groups such as AS and other sources of help.
- 9.3.2

  Financial issues were a common concern; carers were generally not aware of the benefits they might be entitled to, and often needed

encouragement and support to claim them. Self-funders were sometimes cautious about spending money on e.g. sitting services, because they felt they needed to keep hold of any capital they had in order to pay for support when the dementia became more advanced.

9.3.3

9.3.4

9..4

The importance of information was also highlighted by GPs and other professionals. GP mental health leads wanted a single source of information, that GPs (and carers) could call on; this would help them to link patients to support services. It was felt that GPs generally had limited awareness of the role of the voluntary sector, or of the range of services that AS and other groups such as Crossroads or Age UK provided locally. One suggestion was that all GPs should have a package of information on dementia, including a flow chart setting out how they should respond when people came to them and how they should be followed up; and a checklist of sources of support and other information that they could give out.

Another suggestion was to link with CATCH, the commissioning grouping of GPs in Cambridge and S Cambs, which was building a

Good practice examples

The AS Fenland dementia adviser had put together an information pack aimed at people with dementia, which brought together material from AS nationally about the different practical and emotional aspects of living with dementia with information about local services and resources. NHS Cambridgeshire has stated its intention to extend this service.

website as a resource on where GPs should refer or signpost people.

Carers praised a Crossroads course 'Caring with Confidence' that AS in Huntingdonshire provide for carers. The course, which runs for one session a week over 6 weeks, provides information and practical advice on the essentials of looking after someone, the services available to them and how to obtain them, communication with professionals, and looking after yourself, with the aim of helping carers make a positive difference to their life and that of the person they care for..

CPFT run a 3-day carers' education programme for carers referred via their services.

Memory groups, to help people at the very early stages of dementia to cope with memory problems are run as part of the OPPCP project in Huntingdonshire

CPFT is developing a peer support project involving carers who will be trained to work as volunteers with other carers. It will provide support and signposting, and will cover Cambridge, S Cambs, E Cambs and N Herts. This links to NDS Objective 5: Development of structured peer support and learning networks for people with dementia and carers

#### 9.5 Recommendations

#### **Recommendation 6**

**NHS Cambridgeshire and Cambridgeshire County Council** 

- a) maintain their current level of funding for support services for people with dementia and their carers
- b) identify where there are gaps in support at present, and work with provider organisations to extend the level and range of support services available
- c) identify and commission service development to meet future demands.

#### Recommendation 7

NHS Cambridgeshire and CPFT work with AS, GP mental health leads and other appropriate agencies to

- a) raise GP awareness of the role of AS and other support groups, and to develop working relationships between these groups and GP practices
- b) ensure that NHS professionals provide information about and offer a referral to AS and/or other agencies as appropriate on diagnosis as a matter of course, wherever the diagnosis is made. This offer should be made to both the person with dementia and their carer.

#### **Recommendation 8**

NHS Cambridgeshire work with CPFT, GP mental health leads, the County Council, AS and other voluntary organisations, to ensure that all GPs have access to an information resource, online and paper-based as appropriate, that is regularly updated, covering dementia; their role in diagnosis, support, and follow-up of patients and carers; social care services; and the services and support available locally, including that provided by voluntary organisations. It should be clear who is responsible for producing and updating this resource, and it should be adequately funded.

Complementary to this, all GPs and practices should have access to named individuals such as a gateway worker, dementia adviser and/or other professional, who can advise the GP and facilitate liaison with other services.

#### **Recommendation 9**

NHS Cambridgeshire, CPFT, the County Council and CCS NHS Trust work with AS and other voluntary organisations to ensure that social care staff who deal with people with dementia and carers around the time of diagnosis or subsequently, signpost people to AS and other sources of support. This includes those

providing information to self-funders.

#### **Recommendation 10**

a) The dementia advisor service is rolled out across the County, funded on an ongoing basis, with the capacity to act as a first point of contact and support for people at the point of diagnosis. Every memory assessment service should have a direct link to a dementia adviser and to local AS and other support services. b) NHS Cambridgeshire and the County Council work with AS and other groups to develop and disseminate locally appropriate and comprehensive information material throughout the County, linked to the dementia adviser service, which people with dementia can use or work through with the support of the adviser or carer.

#### **Recommendation 11**

NHS Cambridgeshire and CPFT work with AS, Crossroads and other appropriate agencies to take forward the following initiatives throughout the County:

- a) deliver carers education courses, building on the Crossroads 'Caring with Confidence' courses and on CPFT's own carer education programme.
- b) provide memory groups for people at the early stages of dementia
- c) Evaluate and if successful roll out the CPFT peer support project as early as possible.

#### 10. INTER-AGENCY WORKING

#### 10.1 Overview

#### **Findings**

- 10.1.1 All the health and social care professionals and AS staff emphasised the importance of, and need for closer working and communication between primary care, mental health services, social care, AS and other voluntary organisations. This is key to ensuring that people obtained a diagnosis, and had access to care, support and advice. One GP described the current system as 'all spokes and no hub'. Another professional commented on the need for a strategic, wholesystem approach to tackling dementia.
- 10.1.2

  GPs emphasised the importance of close working between themselves, CCS NHS Trust staff, including community matrons, and mental health services. Groupings of GPs in Cambridge, S Cambs and Hunts were having talks with CCS NHS Trust with the aim of
- 10.1.3 strengthening links.

Carers and people with dementia themselves reported mixed experiences, with examples of both well and badly co-ordinated

services. One concern was that services did not always communicate well with carers, which was a source of anxiety and

10.1.4 could hamper their ability to support their relative with dementia.

AS staff found local variation between the CMHTs in their level of 10.1.5 responsiveness to enquiries, and the level and quality of information provided.

> The OPPCP in St Ives was cited by AS staff and by all the professionals involved as an example of good practice; the GP mental health leads strongly supported the rollout of this project to other parts of the County. Through a gateway worker, a role that GPs felt was key, the project provides a single point of access and referral to diagnostic, treatment and support services for older people with mental health issues, including those with suspected dementia. The project includes an Alzheimer's Society support worker.

10.1.6 Project staff reported that there had been an increase in GP referrals. and fewer inappropriate referrals, since it was set up, and that it had improved the pathway between primary and secondary care.

> Co-locating AS staff with the CMHT, as was the case in Huntingdonshire and Fenland, facilitated closer working between the two organisations

## 10.1.7 Good practice examples

The CMHT in Fenland has links with voluntary organisations, including Age UK carers support groups, Crossroads, and AS. The AS Fenland dementia adviser sits with the team

The Cambridge CMHT works with AS when they are closing a case, for example because a behaviour problem has been resolved, to ensure that there is continuity of support for the individual and the carer.

The County Council's Carer's Directory is a helpful source of information, and is distributed by AS

## 10.1.8 Recommendation

#### **Recommendation 12**

NHS Cambridgeshire and CPFT roll out the OPPCP approach to the rest of the County as soon as possible, with particular reference to:

- the gateway worker role
- close links between CMHTs, GPs, other parts of the NHS, social care, and the support and services provided by AS and other organisations.

The following were identified as specific areas where improvements in interagency working were needed.

### 10.2 CCS NHS Trust and CMHT Interface

## **Findings**

#### Roles and responsibilities

- 10.2.1 Some CCS NHS Trust and CMHT staff identified issues around the interface between the two organisations, particularly in relation to when it was appropriate for people to be referred to and from the CMHTs, and what support could be expected from CMHT. These situations tended to arise when people's condition became more severe. On the one hand, CMHT staff from Cambridge, S and E Cambs in particular felt that people were often referred to them who did not meet their criteria, simply because they had a dementia diagnosis or had previously received their services. The teams would not generally see, for example, people whose condition was stable or deteriorating gradually.
- 10.2.2

On the other hand, some CCS NHS Trust staff felt that they did not always get the support and guidance that they needed from CMHTs, including in crisis situations, and that there was a lack of clarity or consistency about what support they could expect. There was a view that CPFT criteria for accessing their services had been tightened up, which placed greater pressure on CCS staff.

10.2.3

There were inconsistencies in that CCS NHS Trust staff could refer people directly to mental health services in the South of the County, but not in the North, where they were expected to go via GPs. This

10.2.4 could cause delays.

Where there was disagreement about responsibilities for a particular case, this was resolved by negotiation, but this was time consuming for both parties. There was concern that this problem could be exacerbated by the combination of increased financial pressure on

10.2.5 both organisations and the growing demand on their services.

The expectation that GPs and CCS NHS Trust staff would support people who might in the past have been considered to meet the criteria for CPFT intervention had implications for GP and CCS NHS

10.2.6 Trust staff training and support.

CCS NHS Trust staff commented that there appeared to be a lack of clarity by the commissioners - NHS Cambridgeshire and Cambridgeshire County Council - as to what services they were buying from CCS NHS Trust and from CPFT – and it was therefore left to the providers to sort out who should be doing what. They recommended that NHS Cambridgeshire and the County Council

should be much clearer about the interface between CCS and CPFT, and make sure that the processes involving the two agencies worked well.

CPFT and CCS NHS Trust are finalising a review of the interfaces between the two organisations.

#### Arranging social care support

- 10.2.7 Some CMHT staff expressed frustration at the difficulties they had in arranging social care services. It was felt that the system could be inflexible and bureaucratic when they tried to arrange person-centred services, and that more needed to be done, including working with a wider range of providers, to facilitate this.
- 10.2.8 The administrative and IT processes relating to CMHT staff undertaking assessments and arranging services were a source of frustration, and very time consuming; one team commented that they set up the care first, and sorted out the paperwork later. Carers themselves reported very slow needs assessments.

AS staff who conduct carers' assessments on behalf of CCS NHS Trust, reported long delays between them submitting the assessment and it being recorded on the SWIFT database and the carer receiving the grant.

#### 10.2.9 Recommendation

#### Recommendation 13

CPFT and CCS NHS Trust working with NHS Cambridgeshire and the County Council take forward their interface review to ensure that:

- There is agreement about the respective roles and responsibilities, including funding arrangements, of CCS NHS Trust and CMHTs, and these are clearly communicated and understood by the staff concerned
- Consideration is given to whether any changes in configuration of services would improve outcomes for service users
- There is clarity about what support CCS NHS staff can expect from CMHT's, and capacity within the teams to deliver this support
- Any service gaps arising near the interface between the responsibilities of the two organisations are identified and addressed
- There are clear and consistent referral arrangements between the two organisations
- CCS NHS Trust staff training needs around dementia are identified and addressed
- The interface agreements between CPFT and CMHTs are

updated as required

 the administrative and IT aspects of arranging social care services and carers grant work smoothly, including training of staff where needed.

## 10.3 The Role of Sheltered Housing Officers

## **Findings**

- 10.3.1 Sheltered housing officers (SHOs) provide support to older people living in sheltered housing, which is mainly provided by district councils and housing associations. Their roles include identifying support needs and assisting people to access services such as home care; liaising with agencies, and dealing with emergency situations.
- 10.3.2 The S Cambridgeshire District Council SHOs felt strongly that because of their regular contact with residents, they could play a much more effective role than at present in ensuring that people with dementia were diagnosed and supported. They were concerned that there were residents with dementia or other mental health problems who were not being identified, who may only get help when a crisis occurred

10.3.3

10.3.4

In order to do this, however, they needed:

- formal training in how to work with people with dementia
- Information on identifying signs of possible dementia, in order that they could initiate intervention by a GP
- Information that provided a clear pathway so that they knew what to do in different situations, for example if a resident stopped eating, or there were concerns about the quality of home care being provided.

They also asked to be routinely included in case conferences, to be told when a resident had been diagnosed with dementia, and to have access to copies of assessments of residents, in order to be better able to act as a resource to keep an eye on residents, and give early

10.3.5 warning if someone's condition deteriorated.

Confidentiality requirements mean that such information could only be shared with the consent of the resident (or family members on their behalf), but it was not routine to seek this consent and thus to enable SHOs to access the information when it might be both helpful to do so

- 10.3.6 and acceptable to the resident concerned.
- SHOs could also identify and report when home care agencies were providing a poor service e.g. providing food and not waiting to see that the person had eaten it.

Recommendation

## **Recommendation 14**

NHS Cambridgeshire, CPFT,CCS NHS Trust and the County Council work with GPs and sheltered housing providers to ensure that:

- SHOs are given information and training to enable them to support people with dementia more effectively
- There are clear arrangements for liaison with other agencies when SHOs have concerns about an individual, or about the quality of services they are receiving.
- Consent to share information with SHOs is proactively sought from residents with dementia and their carers as a matter of course, in order that SHOs can play a more active role as a partner with GPs, and other health and social care professionals in providing care and support. This includes, where appropriate, SHOs being a named contact for GPs and other professionals ( see recommendation 4)

## 11. CARE AND SUPPORT SERVICES

#### 11.1 Introduction

- 11.1.1 People with dementia require a range of care and support services in order to maintain their quality of life, and that of their carers. The availability and quality of these services however varied considerably.
- 11.1.2 Two aspects that were considered particularly important in achieving improvement across the different service areas were the effective implementation of Self Directed Support and training for care providers. Findings and recommendations in relation to these and to specific service areas identified as in need of improvement are set out below.

## 11.2 Self-Directed Support (SDS)

## **Findings**

11.2.1 AS and CMHT staff highlighted the importance of using SDS to develop far more person-centred care than was available at present, across all areas of service. This is consistent with Objective 6 of the NDS. Examples include enabling people with dementia to take part in activities such as going to the pub, going swimming, or working on an allotment. The Council therefore needed to contract for a wider range of services, and with a wider range of organisations than at present, in order for the benefits of SDS to be realised. This included funding and contracting with voluntary organisations that provided many of these services. Linked to this was a need to encourage and support some voluntary organisations to develop and diversify their services.

11.2.2

The need for a more person-centred approach to home care was highlighted. The current way in which home care is provided, which is task-focused and delivered at set times, is not always helpful to people with dementia, who may need a more flexible approach. In the limited time they have available, care workers may inadvertently disempower people by doing things for them rather than help them do it for themselves. Having different care workers come in each time was also not helpful.

11.2.3 There was a lack of provision of night-time support.

Crossroads in Cambridge recently undertook a local Dementia Choices pilot, part of a two year national Mental Health Foundation project, funded by the Department of Health, which began in April 2009. The overall aim of Dementia Choices is:

"To explore, support and promote different forms of self-directed support, including direct payments, individual budgets and personal budgets, for people living with dementia and their carers."

The aim of the pilot was to identify the barriers to people with dementia and their carers taking up SDS, and to recommend solutions.

One of the issues emerging from the pilot, which also reflected the experience of AS staff, was a low level of awareness of SDS on the part of people with dementia and their carers.

#### Recommendations

#### **Recommendation 15**

The County Council, as part of its SDS implementation plan, works with NHS Cambridgeshire and other agencies to:

- a) promote the development of a more diverse range of services for people with dementia and their carers
- b) support existing services, including home care providers, to develop a more person centred approach.

#### **Recommendation 16**

The County Council works with CCS NHS Trust and other agencies to ensure the effectiveness of its promotional work in raising awareness of SDS on the part of people with dementia, their carers, and the staff that work with them.

Care assessments of the person with dementia should always be undertaken with the carer or with another individual in a support role, who can help ensure that the service is tailored to the person's needs and choices.

11.3 Training for care providers

## **Findings**

11.3.1 A strong message from AS, CMHTs and other statutory sector staff was the importance of training and support on dementia for staff in care homes; those providing domiciliary care, and day services. This

would both improve the quality of care, and therefore the quality of life of people with dementia, and potentially increase the level of provision available for them.

A key aspect of this was enabling staff to understand why people with dementia might behave in a certain way in particular situations, and how to respond to this.

11.3.2

CMHT staff reported that lack of staff expertise in working with people with dementia in care homes, including those with dementia units, led both to admissions to CPFT's dementia ward, and difficulty in finding care home placements for people ready for discharge from the ward.

11.3.3

As part of the NDS implementation programme, CPFT with NHS Cambridgeshire had a programme of training for care home staff and managers, which included those providing respite and homes that had day provision, using external funding. This was initially run successfully in the South of the County, and was subsequently extended to Huntingdonshire, Fenland and East Cambridgeshire as funding had become available. Members were also informed that there was an intention to provide training for day service providers.

11.3.4

Both AS staff and statutory sector professionals highlighted the need for training for domiciliary care staff in how to deal with people with dementia. There was not however any systematic plan to ensure that domiciliary care workers were trained in dementia issues. At present, the level of training that domiciliary care workers receive seems to be left to the discretion of individual care providers, and CPFT reported low take up of the training that they offered. This means that the quality of care given to people with dementia varies according to the level of skill and commitment of the individual care worker.

11.3.5

From April 2012, the County Council's contract with care providers requires that the provider has a policy/procedure that ensures that each member of staff has a learning and development plan. The plan records the programme of activity that meets mandatory and professional requirements for their designated role, for example the Skills for Care knowledge and skills set for dementia where the service supports people with dementia, and enables staff to meet their professional registration and development requirements.

## Recommendations

## **Recommendation 17**

NHS Cambridgeshire, CPFT and the County Council (working with Northamptonshire County Council under the shared services arrangements)

- Sustain its programme of care home training throughout the County on an ongoing basis
- Develop and sustain a systematic programme of training for

- respite and day service providers, with an implementation plan and timetable for doing so
- Develop and sustain a systematic training programme for domiciliary care providers, with an implementation plan and timetable for doing so.
- Allocate resources to the above

#### **Recommendation 18**

Compliance with the new contractual requirement on domiciliary care providers is closely monitored to ensure that relevant staff at all levels are properly trained in the care of people with dementia, that any deficiencies in the level of training of existing staff are addressed, that this training is regularly updated and that staff performance is effectively monitored.

**Specific Services** 

## 11.4 Respite Care

## **Findings**

- 11.4.1 AS and CMHT staff in Hunts and Fenland considered that there was a deficit in the availability of both residential and daytime respite care. This particularly affected carers of people in the mid-stages of dementia who could not be left alone, even for short periods. This placed considerable pressure on carers and made it difficult for them to access support groups. The existing sitting services provided by Crossroads worked well, but had limited capacity.
- 11.4.2

CMHT staff in Hunts reported that residential respite could take a long time to arrange. There was a lack of respite beds locally, which meant that people went to a different home each time. This resulted in a lack of continuity for the individual, although this was important in easing the transition to permanent care.

11.4.3

Carers gave examples of their relative being asked to leave their respite care placement because the home could not cope with their behaviour. In one case, a person was moved from one home to another - the first home had not been informed that he had dementia.

11.4.4

Good communication with carers when respite care was being arranged, or when their relative had reached the stage of needing permanent residential care was crucial; poor communication caused

11.4.5 carers considerable worry.

Difficulty in obtaining respite in a crisis situation could result in admission to hospital, or a placement a long way from home. Fenland CMHT highlighted the need for increased capacity for emergency intensive home-based respite, for example when carers went into hospital. In their experience, this was often not available,

11.4.6 especially at the end of the week; this could result in inappropriate hospital admissions.

There was local variation in the level of flexibility of respite provision. In one area, for example, social care staff were willing to arrange

- 11.4.7 rolling respite, or respite for more than 6 weeks a year if this was needed, but this was not universal.
- **11.4.8** Respite provision was also needed which did not separate people with dementia from carers.

#### Recommendation

#### **Recommendation 19**

NHS Cambridgeshire, the County Council and CPFT review the level and range of provision of residential and non-residential respite care services for people with dementia throughout the County, and take steps to address the service gaps identified with a focus on ensuring access to person-centred services.

11.5 Day services

## **Findings**

11.5.1 CPFT focuses its day provision for older people with mental health issues including PWD, on time-limited day therapy for people with more severe problems. NHS Cambridgeshire and CPFT recently agreed changes to OPMH services in Huntingdonshire and Fenland. These include plans to expand the range and scale of day therapy provided at existing centres in Huntingdon, Doddington and Wisbech and to provide additional services through outreach into existing day centres in other towns in the area. It is intended to broaden the range of therapies available, to include, for example talking therapy, cognitive behavioural therapy, cognitive stimulation therapy, music and art.

11.5.2

As part of the NDS implementation, it was intended to widen the range of day opportunities available for people with dementia at different stages of the condition, partly by training staff in existing

11.5.3 centres to work with them.

It was however apparent from CMHT and AS staff we spoke to that there was a shortage and insufficient range of day provision for people with dementia, especially in Huntingdonshire, Fenland and South Cambridgeshire, as follows

- Provision for people whose condition was more severe, or who
  had behaviour issues. An example was given of a Fenland
  resident with hoarding behaviour who had been rejected by one
  day centre and had no alternative provision.
- Services that would occupy people throughout the day, provide a routine, stimulation such as art or reminiscence therapy, and

enable people to socialise with others. This was particularly important in rural areas, where people could not easily get into town.

- Community based activities that were not on the traditional day centre model. This included activity that did not have a 'dementia' label; and activities where people could go out and socialise.
- More tailored provision for people with early dementia, who should not be mixed in with people whose condition was more advanced.

#### 11.5.4 Recommendations

#### **Recommendation 20**

NHS Cambridgeshire, the County Council and CPFT review the level and range of provision of day services for people with dementia throughout the County, as part of the current review of older people's day services, and take steps to address the service gaps identified, with a focus on ensuring access to person-centred services.

#### **Recommendation 21**

NHS Cambridgeshire and CPFT ensure that people have access to a wide range of day therapies, delivered in different locations, throughout the County.

## 12. HOSPITAL CARE

## **Findings**

One of the priority areas for local implementation of the NDS was Objective 8: Improve the quality of care for people with dementia in general hospitals.

This related both to people already diagnosed with dementia, and those whose dementia only becomes apparent when they are admitted to hospital with a physical health problem such as a respiratory infection. Once in an unfamiliar environment, such individuals can guickly become very confused and disorientated.

12.2

Members were informed of work underway with all the hospitals as part of the implementation of the NDS. In addition to new dementia nurse staffing at Addenbrookes, this included a new dementia liaison nursing post and liaison psychiatry for older people with mental health issues at Hinchingbrooke, as part of recently agreed changes to older people's mental health services in Huntingdonshire and Fenland. OPPCP staff emphasised the need for these liaison arrangements to

12.3 be permanent.

While outside the scope of the review, members received feedback from AS staff, carers, and professionals about the importance of this issue. Drawing on carers experiences, AS staff highlighted the need for training for ward based hospital staff in caring for people with

#### dementia. Issues included:

- the importance of involving and communicating with the carer as well as the person with dementia, and ensuring that confidentiality rules are not interpreted in a way that prevents this.
- Understanding that people with dementia often communicate through behaviour – which the carer may well be able to interpret
- Ensuring that people received basic care i.e. that they were fed, hydrated and kept clean
- Providing facilities for carers, who were often exhausted by looking after their loved one in hospital

## Good practice example:

AS has produced 'This is me', a leaflet, which provides information about an individual so that professionals are better able to support them in an unfamiliar place, such as a hospital or residential care setting.

#### Recommendation

#### **Recommendation 22**

NHS Cambridgeshire and CPFT continue to give work on Objective 8 a high priority in implementing the NDS. This work should include:

- Training for ward-based staff
- Close monitoring to ensure that people are receiving basic care
- A permanent dementia liaison nursing post and liaison psychiatry capacity in all the hospitals used by Cambridgeshire residents
- Facilities for carers
- Dissemination and use of the AS 'This is me' leaflet

#### 13. OTHER AREAS FOR IMPROVEMENT

While conducting the review, members were made aware of a number of issues where it was considered that improvement in processes or in service levels were needed. These are set out below.

## Named social work contact

13.1 Several carers were concerned that they did not have a named social work contact, but had to deal with a different person every time that they contacted services, for example to resolve an issue or to arrange respite care. This resulted in a lack of continuity. One carer reported that their case worker had left and was not replaced, leaving it to her to repeatedly phone to ask for a reassessment and a new case worker.

## Financial assessment

13.2 Some carers reported very slow financial assessments, which could

leave them with substantial bills to pay. Carers found it difficult sometimes to understand the bills they received, and had to phone up in order to get a clear explanation.

#### Equipment services

13.3 Obtaining equipment or assistive technology could take several months, by which time needs could have changed.

## Support for people living alone

14.4 Hunts CMHT felt that there was a gap in support for people with dementia who lived alone, whose family members lived at a distance, who did not meet social service eligibility criteria. In some cases, volunteer visiting schemes could help, but such provision was very patchy. This issue relates to the County Council preventive strategy.

## Access to psychological therapies

13.5 Health professionals were concerned that older people should be able to have access to psychological therapies, to help with both dementia and depression

## **Transport**

13.6 Lack of transport is a key concern in rural areas, and was highlighted by Fenland CMHT and Huntingdonshire GP mental health leads as a major barrier to accessing those services that were available.

## 13.7 Recommendation

#### **Recommendation 23**

To: Cambridgeshire County Council, NHS Cambridgeshire, CCS NHS Trust and CPFT as appropriate.

Action on the issues above are taken forward in the updated NDS strategy and action plan, through other relevant joint initiatives, such as the transport strategy and preventive strategy, and in individual service improvement plans.

Jane Belman, Scrutiny and Improvement Officer 20th June 2011

# Appendix D

## First Draft Local Action Plan - September 2011

No	Setting	Lead Organisat ion	Actions	To Deliver NDS Objectives	To Implement OSC Recommen dations	Timeline	RAG Status as of Dec 2011
1	Primary Care	NHS C/CPFT	Finalise service model for new OPMH primary care team, including skill mix and capacity, and outcome measures, prior to roll-out throughout Cambridgeshire.	1, 2, 3, 4, 5, 13	1, 2, 3, 4, 5, 6, 7, 8, 9, 11, 12,	April 2012	
			Explore ways to secure additional and sustainable funding for CAMTED-OP training services, to raise awareness of mental health problems in older age amongst primary care professionals.			Dec 2011	
			Conduct local review of drugs prescribed for the management of dementia and develop new primary care guidelines for the treatment of dementia.			Dec 2011	
			Ensure the new ABIC and local commissioning group websites have access to information on local services (statutory and voluntary) to enable the most effective use to be made of wider community resources.			Ongoing	
2	Communi	NHS C/CPFT/C CS/Local Vol Orgs	Strengthen links with local community services and social care staff to;  Raise awareness of dementia and other MH problems	1, 4, 5, 6, 7, 9, 10, 13	1, 6, 8, 9, 10, 13, 15, 16, 18, 20, 21,	Ongoing	

			<ul> <li>Train more staff to manage people with dementia and other MH problems</li> <li>Explore opportunities for developing a more integrated approach to the management of older people who have both mental and physical health problems</li> </ul>			
			Roll out redesigned day therapy services			April 2012
			Review existing community care pathways, to integrate with new primary care pathway, embed the needs of patients with functional illness, and redesign the structure and function of local services.			Ongoing
			Develop relationships with businesses to promote our services and create mutually beneficial services i.e. dementia cafes in Tesco			Ongoing
3	Care Homes and	NHS C/CCC/C PFT/CCS	Explore ways to secure additional and sustainable funding for CAMTED training of care home staff.	7, 11, 12, 13	6, 14, 15, 17,19,	Dec 2011
	Specialist Accomm	11 1/000	Conduct review of local prescribing of anti-psychotic drugs for people with dementia			April 2012
	odation		Explore potential for improving choice and access to respite/step- up/step- down beds in local care homes			Sept 2012
			Expand where possible local provision of specialist accommodation for older people with long-term mental			Ongoing
			health needs  Ensure local "end-of-life" strategy reflects needs of people with dementia			April 2012

4	In-Patient Wards	NHS C/CPFT	Continue to review capacity requirements and configuration of local wards		22	Ongoing
			Implement the "Releasing Time To Care" program in local wards to:  • reduce staff stress and improve wellbeing • improve efficiency of care • increase efficient use of resources • reduce length of stay			April 2012
5.	Local District Hospitals	NHS C/CPFT/L ocal	Evaluate OPMH dementia liaison roles and secure recurrent funding.	8, 12, 13	22	April 2012
	Hospitals	Hospitals	Develop business case for a 'Complex Case' team at each local hospital to reduced avoidable hospital admission of people with dementia and to reduce the lengths-of-stay of people appropriately admitted.			April 2012
			Expand use of "This is Me" patient passport			April 2012
6.	Quality and Outcome Monitorin g	NHS C/CPFT	Agree appropriate quality and outcome measures for all local OPMH pathways to include:			April 2012
			Embed and feed into culture of service delivery, practice and transformation work streams			April 2012
			Ensure IT procurement can meet the above requirements			April 2012
7.	Links to	NHS	Ensure Cambridgeshire Joint OPMH strategy is consistent			April 2012

Older	C/CCC	with the Cambridgeshire Joint Strategy for Older People		
People's				
Strategy				