



## **SOMERSET DEMENTIA STRATEGY**

**July 2010**



# SOMERSET DEMENTIA STRATEGY

## CONTENTS

	Page
<b>CONTENTS</b>	
<b>IMPACT ASSESSMENT</b>	
<b>EXECUTIVE SUMMARY</b>	
<b>1 INTRODUCTION .....</b>	<b>1</b>
Background.....	1
Purpose of the Strategy .....	2
The Somerset Vision.....	2
<b>2 NATIONAL AND LOCAL CONTEXT .....</b>	<b>4</b>
<b>3 EXISTING SERVICES AND BENCHMARKING DATA .....</b>	<b>8</b>
Existing Services.....	8
Healthcare Market Analysis: Dementia Fast Track .....	11
World Class Commissioning .....	12
Examples of Good Practice Nationally .....	13
<b>4 RAISING AWARENESS AND UNDERSTANDING .....</b>	<b>19</b>
Good practice examples in Somerset .....	19
Key priorities .....	22
<b>5 EARLY DIAGNOSIS AND SUPPORT .....</b>	<b>25</b>
Good practice examples in Somerset .....	26
Key priorities .....	31
<b>6 LIVING WELL WITH DEMENTIA .....</b>	<b>34</b>
Good practice examples in Somerset .....	37
Key priorities .....	43
<b>7 FRAMEWORK FOR DELIVERING THE DEMENTIA STRATEGY .....</b>	<b>47</b>
Workforce .....	47
Partnership Working .....	47
Governance .....	48
Good practice examples in Somerset .....	48
Learning and Development.....	49

	Key priorities .....	<b>50</b>
<b>8</b>	<b>IMPLEMENTATION PLAN .....</b>	<b>52</b>
<b>APPENDICES</b>		
<b>APPENDIX 1</b>	National Dementia Strategy Objectives .....	<b>53</b>
<b>APPENDIX 2</b>	Summary of Key Priorities .....	<b>56</b>
<b>APPENDIX 3</b>	Summary of the Feedback from the Information and Engagement Process .....	<b>63</b>

## CONFIRMATION OF EQUALITY IMPACT ASSESSMENT FOR NHS SOMERSET DOCUMENTS/POLICIES/STRATEGIES AND SERVICE REVIEWS

Main aim of the document / policy / strategy / service (*EIA Form Part 2, 1.1*):

The Somerset Dementia Strategy aims to provide a framework to implement improved, responsive and quality services for people with dementia and their carers across Somerset and improve health related outcomes.

Outcome of the Equality Impact Assessment Process:

The impact assessment process has shown the strategy has no negative impacts and positive impacts on age and disability.

What actions have been taken and are planned as a result of the equality impact assessment. Provide details of action plan (copy attached or reference provided) with timescales / review dates as applicable:

No specific actions resulting from the equality impact assessment, however the review of equality and this particular group will take place through the Somerset Dementia Strategy Group and a further equality impact assessment will take place at the end of the final phase (end of 2011/12).

Groups / individuals consulted with as part of the impact assessment:

As part of strategy consultation, the following were consulted with and this informed the Equality Impact Assessment.

- NHS Somerset
- Somerset Community Health
- Yeovil District Hospital NHS Foundation Trust
- Carers UK East Somerset
- Taunton and Somerset NHS Foundation Trust
- Somerset Partnership NHS Foundation Trust
- Somerset County Council
- Patients, carers and members of the public



## EXECUTIVE SUMMARY

It is estimated that currently there are over 570,000 people in England living with dementia with this figure likely to double over the next 30 years in the absence of any medical breakthrough in treatment. Dementia costs the UK economy £17 billion a year with costs in the next 30 years rising to £50 billion a year.

The National Dementia Strategy has identified 17 key objectives which when implemented will result in significant improvements in the quality of services provided to people with dementia and should promote a greater understanding of the causes and consequences of dementia.

Within Somerset, it is currently estimated that there are 7,640 people with dementia of which 145 are aged under 65. Both the number and proportion of people aged over 65 with dementia is set to increase. By 2021 the expectation is that there will be almost 11,500 people with the condition.

The Somerset Dementia Strategy aims to provide a framework to implement improved, responsive and quality services for people with dementia and their carers across Somerset and improve health related outcomes. The strategy is a partnership approach to ensure that a seamless service is provided. The implementation of this strategy will be phased over the next 3 years as it is recognised that within Somerset, dementia is a key priority for all agencies concerned.

The focus of the Somerset Dementia Strategy is:

- to raise awareness and understanding of dementia within the general public
- ensure there is early diagnosis, support and intervention for people with dementia and their carers
- provide a higher quality of care to enable people to live well with dementia

This strategy will be a catalyst for change in the way that people with dementia are viewed and cared for within Somerset. The implementation of this strategy will ensure that people with dementia and their carers are supported throughout and receive the highest possible standard of care.



# SOMERSET DEMENTIA STRATEGY

## 1 INTRODUCTION

1.1 The National Dementia Strategy was published in February 2009 and is a key step towards achieving the goal of building health and social services for dementia that are fit for the 21<sup>st</sup> century.

1.2 The National Dementia Strategy builds on three key steps to improve the quality of life for people with dementia and their carers:

- to ensure better knowledge about dementia and to remove the stigma that still surrounds it as well as improving education and training for professionals
- to ensure that people with dementia are properly diagnosed
- to develop a range of services for people with dementia and their carers which fully meet their changing needs over time

1.3 The National Dementia Strategy identifies 17 key objectives (Appendix 1) which when implemented at a local level will result in significant improvements in the quality of services provided to people with dementia. In addition it will promote a greater understanding of the causes and consequences of dementia.

1.4 The Somerset Dementia Strategy has now been finalised following a public consultation that has taken place and reflects the feedback from stakeholders, service users and carers and members of the public.

### Background

1.4 The term 'dementia' is used to describe a syndrome which may be caused by a number of illnesses in which there is a progressive decline in multiple areas of function, including decline in memory, reasoning, communication skills and the ability to carry out daily activities. Alongside this decline, individuals may develop behavioural and psychological symptoms such as depression, psychosis, aggression and wandering, which cause problems in themselves, which complicate care, and which can occur at any stage of the illness.

1.5 The causes of these illnesses are not well understood to date but they all result in structural and chemical changes in the brain leading to the death of brain tissue. The main sub-types of dementia are: Alzheimer's disease, vascular dementia, mixtures of these two pathologies ('mixed dementia') and rarer types such as Lewy body dementia, dementia in Parkinson's disease and fronto-temporal dementia. The term 'Alzheimer's disease' is used sometimes as a shorthand term to cover all forms of dementia.

1.6 The dementias all share the same devastating impact on those affected and their family carers. Dementias affect all in society irrespective of

gender, ethnicity and class. They can affect adults of working age as well as older adults. People with learning disabilities are a group at particular risk.

- 1.7 Family members provide the majority of care for people with dementia. They are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life. However, caring can be undertaken by younger members of the family sometimes children or young people under the age of 18.
- 1.8 Dementia is a terminal disorder, although people may live with their dementia for 7 – 12 years after diagnosis.

### **Purpose of the Strategy**

- 1.9 The purpose of the strategy is to provide a framework for local services to deliver quality improvements to dementia services, addressing health inequalities relating to dementia and ensuring delivery on key ambitions and performance indicators. This strategy includes dementia of all types.
- 1.10 The strategy will ensure that people with dementia and their carers will have an improved experience of dementia services in Somerset resulting in improved health outcomes and quality of life.

### **The Somerset Vision**

- 1.11 The Somerset Health and Social Care Community comprising of NHS Somerset, Somerset County Council, Somerset Partnership NHS Foundation Trust, Somerset Community Health, Taunton and Somerset NHS Foundation Trust, Yeovil District Hospital NHS Foundation Trust, Care Focus Somerset and the Somerset branch of the Alzheimer's Society have contributed to the development of the Somerset Dementia Strategy which sets out the vision for services for dementia in Somerset with planned actions and an implementation plan to achieve this ambitious strategy. This builds on existing work that has already taken place within the county.
- 1.12 The vision in Somerset is for people with dementia and their family carers to be helped to live well and improve the quality of their life, no matter what the stage of their illness or where they are in the health and social care system. Transformation of dementia services will ensure that in the future all people with dementia have access to the appropriate care and support. In order to achieve this vision, the following needs to take place:
- the public and professionals are well informed about dementia and the fear and stigma associated with the illness has been dispelled by changing public and professional attitudes, understanding and behaviour

- families affected by dementia will know where to go for help and what services are available, and where the quality of care is exceptional
- make early diagnosis and treatment the rule rather than the exception
- enable people with dementia and their carers to live well with their condition by the provision of good quality care for all from diagnosis to the end of life, in the community, in hospitals and in care homes

1.13 Full implementation of the Somerset Dementia Strategy will ensure that all people with dementia and those that care for them will have the best possible healthcare and support. Improving health and social care outcomes in dementia in the short and medium term can have significant benefits for society both now and in the future.

1.14 The Somerset Dementia Strategy follows the National Dementia Strategy in taking an outcome focused approach and therefore is divided into three broad themes and this is replicated in this strategy:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia

## 2 NATIONAL AND LOCAL CONTEXT

- 2.1 Within the United Kingdom, there are approximately 700,000 people with dementia. In just 30 years, the number of people with dementia is expected to double to 1.4 million.
- 2.2 The national cost of dementia is about £17 billion per year. In 30 years the cost of dementia is expected to treble to over £50 billion per year.
- 2.3 Care home placements for people with dementia costs the United Kingdom £7 billion per year with two-thirds paid by social services and one-third by older people and their families.
- 2.4 Nationally there are over 500,000 family members who care for people with dementia which constitutes over £6 billion a year of unpaid care.
- 2.5 In Somerset it is currently estimated that there are 7,640 people with dementia of which 145 are aged under 65. This is expected to increase to almost 11,500 by 2021 as Table 1 below demonstrates (Source: ONS population projection 2007).

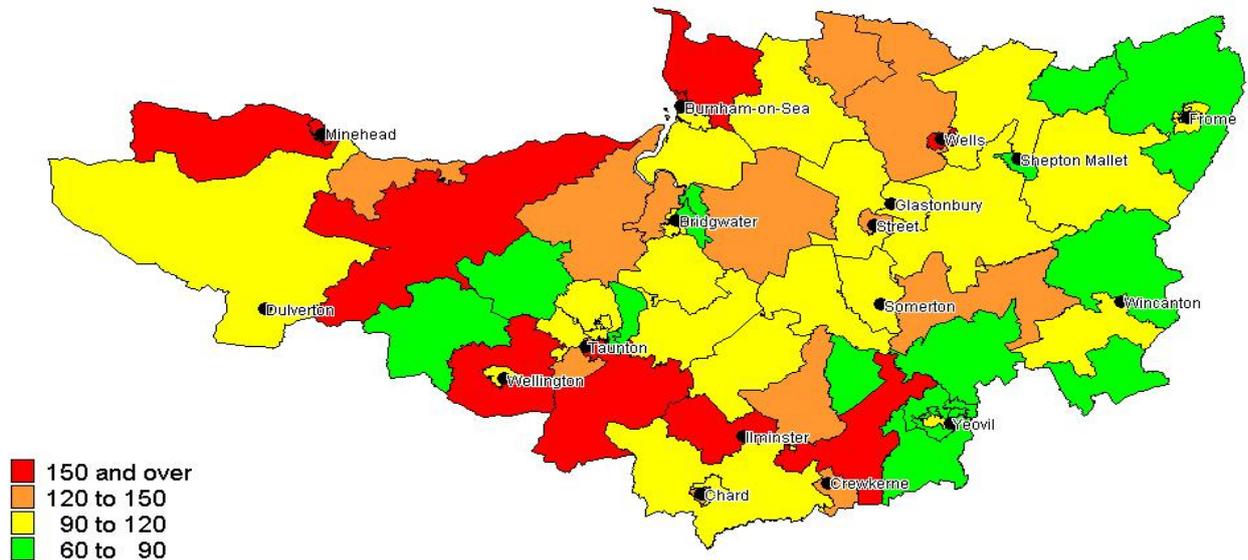
**Table 1**

	Year	30 – 64	65 – 74	75+	Total	% aged 65+ with dementia
<b>Males</b>	2007	85	525	1,952	2,562	5.60
	2017	93	773	2,965	3,831	5.87
	2021	100	784	3,482	4,365	6.17
<b>Females</b>	2007	60	427	4,592	5,078	8.74
	2017	67	637	5,719	6,422	8.41
	2021	71	653	6,407	7,130	8.63

- 2.6 The prevalence of dementia according to the primary care data of crude rates per 1,000 list size from the Quality Outcome Framework (QOF) shows that the rate of dementia in Somerset of 4.5 is higher than the national rate of 4.0.
- 2.7 It is estimated that within Somerset only 32% of 'true' dementia cases are recorded on practice registers. This means that approximately two thirds of dementia cases are undiagnosed.
- 2.8 The map in Table 2 demonstrates the projected number of people aged 65+ with dementia in 2010 geographically across the county.

**Table 2**

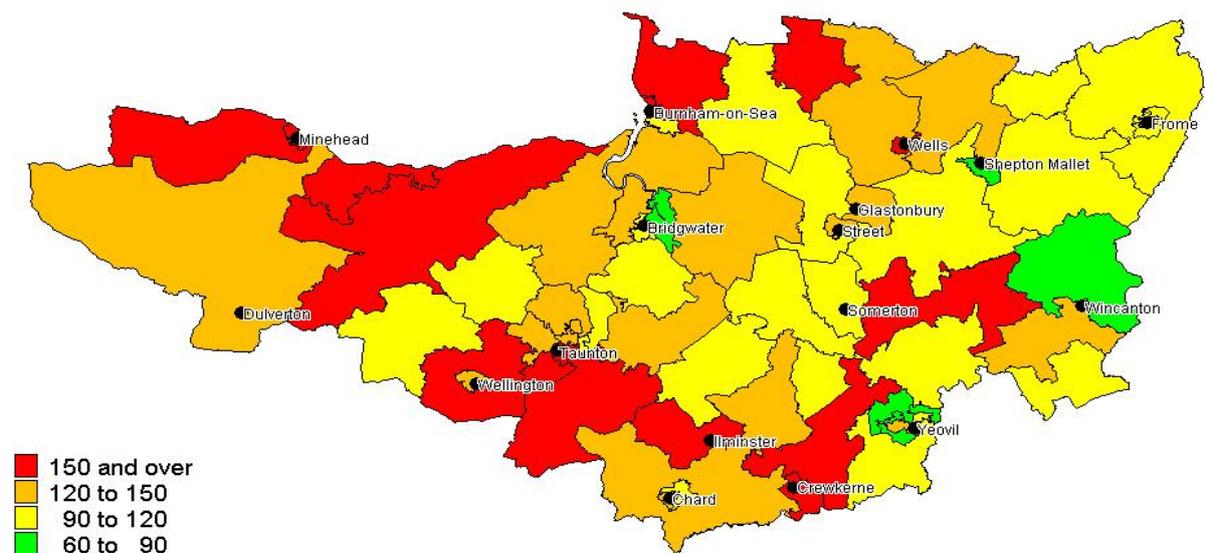
**Estimated number of people with dementia 2010 at Middle Super Output Area level**



2.9 The map in Table 3 demonstrates the projected number of people aged 65+ with dementia in 2015 geographically across the county.

**Table 3**

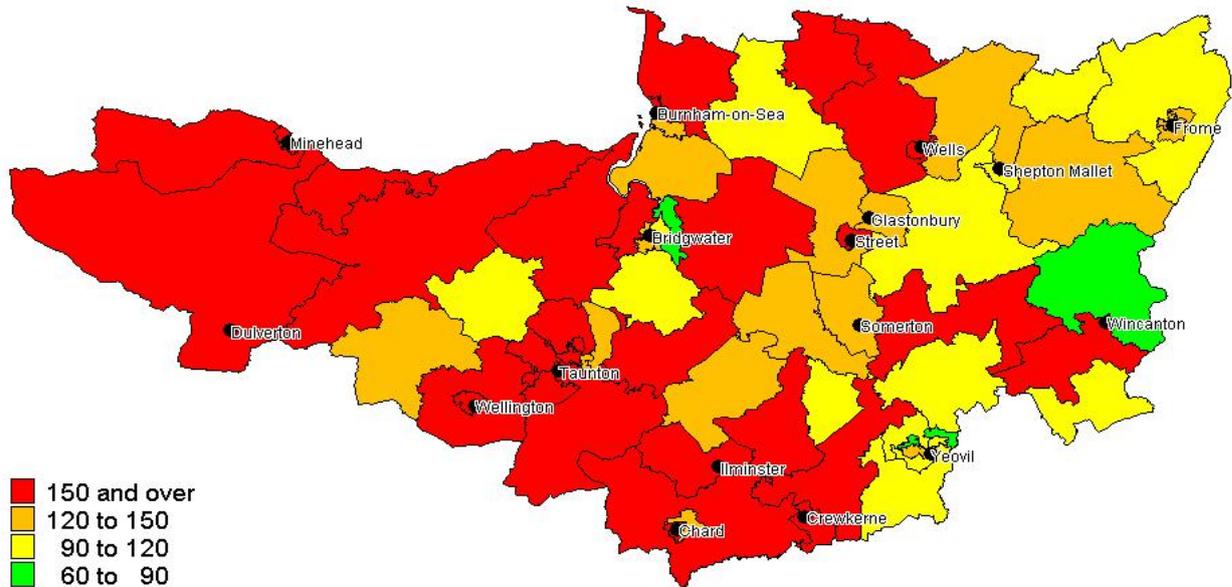
**Estimated number of people with dementia 2015 at Middle Super Output Area level**



2.10 The map in Table 4 demonstrates the projected number of people aged 65+ with dementia in 2020 geographically across the county.

**Table 4**

**Estimated number of people with dementia 2020 at Middle Super Output Area level**



2.11 2010 populations for Middle Layer Super Output Areas (MSOAs) were estimated locally using the numbers on the Exeter system of GP registered patients constrained to sum to the ONS projected population of Somerset (by quinary age and gender). MSOA populations in 2015 and 2020 were increased in line with the ONS projected district populations for those years (using the relevant district of each MSOA).

2.12 The Projecting Older People Population Information (POPPI) website provides estimates of the proportion of the population aged 65 and over that have dementia:

- for men: 1.5% of 65-69 year olds; 3.1% of 70-74 year olds; 5.1% of 75-79 year olds; 10.2% of 80-84 year olds; 19.7% of men aged 85 and over are predicted to have dementia
- for women: 1% of 65-69 year olds; 2.4% of 70-74 year olds; 6.5% of 75-79 year olds; 13.3% of 80-84 year olds; 25.2% of women aged 85 and over are predicted to have dementia

2.13 The above graphs were produced by applying these rates to the MSOA projected populations aged 65 and over to give the estimated number of people with dementia in this age group.

2.14 These projections do not include estimates for people with early onset dementia and people with a learning disability and dementia as this is more reliable when projected over larger geographical areas.

### 3 EXISTING SERVICES AND BENCHMARKING

#### Existing Services

- 3.1 Statutory services for people with dementia are commissioned by NHS Somerset and Somerset County Council.
- 3.2 Joint commissioning is in place between Somerset County Council and NHS Somerset for the following services:
- 3.2.1 **Specialised Residential Care (SRC):** Specialist care development nurses work within designated specialised residential care homes to provide access to specialist services, advice, training and support to ensure people with dementia receive quality services. An independent review of SRC was completed in early 2009 and areas for development highlighted in the final report will be addressed as part of an action plan aligned with the wider Somerset Dementia Strategy.
- 3.2.2 **Specialist In-reach Liaison to Acute and Community Hospitals:** Somerset Partnership provides psychiatric liaison services to Acute and Community Hospitals. This enables better treatment for patients and prompt appropriate discharge arrangements.
- 3.2.3 **Carer Assessment Workers:** Carer Assessment Workers provide support and information to the unpaid carers of all people with a mental illness. These workers link with staff throughout Somerset Partnership NHS Foundation Trust, Somerset County Council and NHS Somerset, including Carer Support Workers employed by Somerset County Council and based in GP practices.
- 3.2.4 **Active Living Centres:** Somerset County Council and NHS Somerset are investing in the further development of Active Living Centres across Somerset (initially funded through the Department of Health funding through Partnerships for Older Peoples Projects), working with a range of other key stakeholders. Active Living Centres are supported by local groups and volunteers and provide a café style environment and diverse programme of activities which promote wellbeing through activity for older people. The Active Living Centres are all very different depending on the needs of the local community and with the predicted increase in older population in Somerset over the next few years, will provide an important vehicle for promoting a positive healthy living message to our aging population, and to address the needs of specific patient and carer groups including those with dementia.
- 3.3 Somerset County Council commissions a range of services from the private, voluntary and community sector. These include:
- 3.3.1 **Residential Care and Nursing Care:** A quality premium scheme has been launched to improve the quality of residential care and nursing care in Somerset.

- 3.3.2 **Care at Home:** This small pilot service for people with dementia adopted a person centred approach in providing individual support at home. The service aimed to maximize independence and establish individual daily routines, with any ongoing care package provided by the home care provider.
- 3.3.3 **Housing-Related Floating Support Service:** Mental health charity Rethink is commissioned to provide this service to help younger people with dementia and older people with memory problems or dementia, continue to live independently. The service offers individuals around five to ten hours of support per week, including guidance on maintaining a safe and secure home, finances and paying bills, and staying healthy.
- 3.3.4 **Assessment and Care Management:** Somerset County Council Adult Social Care Services routinely assess and care manage a significant proportion of service users with dementia living in the community, in consultation with staff from Somerset Partnership NHS Foundation Trust.
- 3.4 NHS Somerset commissions Somerset Partnership NHS Foundation Trust to provide specialist mental health services for Older People, including illnesses such as severe depression, severe anxiety, schizophrenia and dementia. These services are aligned with tier 1 and 2 services commissioned by both NHS Somerset and Somerset County Council. Arrangements are in place to ensure that the planning and commissioning of services are considered jointly by the NHS and the Local Authority. A Recovery Care Plan Approach has been adopted which emphasises the involvement of people receiving services and the promotion of recovery towards wellbeing, rather than concentrating solely on diagnosis and treatment of identified problems. These services include:
- 3.4.1 **Community Mental Health Teams:** Multidisciplinary teams, co-working with Somerset County Council and Somerset Community Health staff, operate throughout Somerset. Community Mental Health Teams provide information and advice to people using services, support to other agencies (including the third sector), carry out initial assessments, establish treatment plans and arrange appropriate care packages for those with severe mental health problems as well as care management/care coordination, which includes ongoing complex casework and review.
- 3.4.2 **Community Teams for Adults with Learning Disabilities:** Four multidisciplinary community teams, comprising specialist health and social services professionals, operate throughout Somerset. They offer a service to adults aged 18 and over, with a learning disability. Their remit is similar to that of the Community Mental Health Teams and to older adult teams, with a focus on meeting the particular mental health and critical social care needs of people with learning disabilities.

- 3.4.3 **Inpatient Assessment and Treatment Wards:** Specialist inpatient treatment is provided in wards located in Taunton, Wells and Yeovil. People with dementia are treated in separate areas to those with severe depression and other illnesses. They undertake assessment, treatment and care planning, with follow up in the community provided by Community Mental Health Teams.
- 3.4.4 **Specialist Day Hospitals and Day Services:** Specialist day hospitals and day centres, located throughout Somerset, work to promote good mental health and provide support to the most severely ill patients, thereby avoiding the need for unnecessary hospital admissions. The day hospitals provide assessment, treatment programs and ongoing care planning. People with dementia are usually accepted into different groups from those with illnesses such as severe depression or schizophrenia. Specialist day centres provide ongoing social day care for people who need specialist day care to maintain their independence in the community and provide relief for informal carers.
- 3.4.5 **Memory Clinic Services/Early Interventions:** Memory Clinic Services for early diagnosis, treatment and provision of information for service users and carers are located throughout Somerset.
- 3.5 NHS Somerset also commissions Somerset Community Health which is the provider arm of the Primary Care Trust to provide:
- 3.5.1 **Community Matrons:** Community Matrons act as case managers for people with complex health needs. The role aims to keep people out of hospital by actively managing care and empowering people to manage conditions themselves. Community Matrons provide care to people with dementia and work with Community Mental Health Teams to develop skills and expertise for this group.
- 3.6 NHS Somerset has commissioned a new Emotional Health and Wellbeing Service in partnership with WyvernHealth.Com and Somerset County Council for adults of all ages in Somerset. The service is in line with Department of Health guidance on Improving Access to Psychological Therapies (IAPT) that is a national initiative which aims to ensure that all adults with common mild to moderate mental health problems such as anxiety and depression can access therapy, in particular talking therapy, close to where they live. The service commenced in October 2009.
- 3.7 There is a wide provider market consisting of organisations providing services for people with dementia and their carers.
- 3.8 Care Focus Somerset is commissioned by Somerset County Council to share best practice and offer advice and guidance around workforce planning and development to all independent care providers in Somerset, supporting them to deliver high standards of care to their residents. This includes care homes providing services to people with dementia.

## **Healthcare Market Analysis: Dementia Fast Track**

3.9 NHS Somerset has participated in a dementia fast track project looking at healthcare market analysis along with other Primary Care Trusts in the South West region. Four key areas of patient need were identified:

- early, sensitive and accurate diagnosis
- appropriate dementia care in hospitals
- patient-centric care and case management and system brokering
- physical health care in care homes and domiciliary care

3.10 These needs sit in three markets:

- identification market
- acute care market
- community care market

3.11 Two strategies were developed for harnessing market forces in the identification market:

- incentivised case finding: awareness campaigns with payment based on outcomes
- case finding with support: funded support provision for all needs and levels to encourage case finding

3.12 Four strategies were developed for harnessing market forces in the community care market:

- admission avoidance and rapid discharge services: community based teams awarded on performance and created by reallocating secondary funding into the community
- dementia specialist agencies: specialist residential care paid at a premium with in-reaching dementia specialist practitioner commissioned by care home provider
- integrated hub-based community care providers: vertically integrated community care with bundling of health and social care facilities and services
- long-term condition management organisations: integrated providers with pooled funding to manage populations of service users

3.13 Some of the strategies outlined above are particularly relevant to the special needs of Somerset's population and the Fast Track project is providing a mechanism to support the development of a meaningful long term strategy for market development of dementia services.

## World Class Commissioning

3.14 World Class Commissioning is about delivering better health and well being for the population; ‘adding years to life and life to years’. The outcomes element of the World Class Commissioning Assurance process required Primary Care Trusts to select eight priority outcomes that will be assessed as part of the assurance process; these outcomes reflect local strategic priorities and the selected outcomes are consistent with the Primary Care Trust’s longer term ambitions and aspirations for Somerset and those agreed with partners i.e:

- to improve health and reduce health inequalities
- to eliminate waiting
- to improve health services

3.15 One of the eight outcomes selected focuses on early identification of patients with dementia as follows:

<b>Metric</b>
Number of patients with Dementia on Practice Registers compared to expected prevalence

3.16 The key priority actions relating to this metric within the NHS Somerset Strategic Framework for Improving Health in Somerset 2009/10 to 2013/14 are as follows:

- to increase the number of patients with dementia on Quality and Outcomes Framework registers from current baseline (in line with expected baseline)
- to ensure all people diagnosed with dementia have a care plan, which includes access to health checks every 15 months, within four weeks of their diagnosis by 31 March 2010

3.17 All 75 general practices in Somerset were able to produce a register of patients with dementia, as at 31 January 2009 and the practice registers identified a total of 2,524 people with dementia (per Quality and Outcomes Framework indicator DEMI). Data indicates that the number of people identified with dementia in Somerset equates to around 32% of the estimated prevalence (national average 38%).

3.18 Specialist NHS dementia care in Somerset is delivered mainly through general practice, and the specialist mental health trust. Improving awareness and early identification of people with dementia is a quality marker within the National Dementia Strategy. Early diagnosis is important to enable appropriate interventions and strategies to be commenced to delay progression of the disease and to support people at home for as long as possible.

3.19 Early intervention is demonstrated to enable people to continue at home with family for an additional six to nine months.

3.20 A detailed action plan to support delivery on these priorities is being developed.

### **Examples of Good Practice Nationally**

3.21 A review of good practice across the country has highlighted some areas of good practice relating to the delivery of dementia services. These include:

#### **Awareness Raising of Dementia**

##### **North Somerset Forget-Me-Not**

The Forget-Me-Not is a service for people who are concerned about their memory but do not have a formal diagnosis of dementia, or for those who have recently been diagnosed with dementia, or for the carers and families of people with memory problems. Forget-Me-Not is promoted through the practice itself, either by people reading information about the service in the waiting room and self-referring or by being referred to the Forget-Me-Not service by their GP. The service is run by members of staff from the Alzheimer's Society and focuses on information and support at the earliest stages. Forget-Me-Not does not provide any form of diagnosis and works in partnership with the GP and memory services to refer onwards if appropriate.

The Forget-Me-Not service has been piloted in five GP practices in North Somerset and has proved to be a success with most clinics being booked. The service aims to:

- provide information and support to people who are worried about their memory or the memory of a relative
- generate awareness of dementia, the role of the Society and the help available at the earliest stages prior to or soon after formal diagnosis
- facilitate people in accessing a range of support locally, both in terms of specialist and community activities
- build relationships with general practitioners and ensure they have access to good quality information.

Each GP practice involved in Forget-Me-Not provides a consulting or therapy room for a morning or afternoon on a regular basis which is agreed at the outset. Appointments are made for each Forget-Me-Not session by practice receptionists and each appointment lasts for a maximum of 45 minutes. Patients can choose to attend on their own or with members of their family if they prefer. Alternatively, carers and families of people with memory problems can attend. Through conversation, possible next steps are explored and relevant strategies for strengthening memory function are discussed. Appropriate information is offered; often including wider issues connected with

disability and/or ageing and a personal action plan emerges.

During each appointment, the Forget-Me-Not worker makes notes which, with consent, are scanned into the patient's personal file for the GP to see. The GP is then aware of the discussions which have taken place and is able to make further enquiries if appropriate. In addition, the patient now has access to up-to-date, relevant and timely information which can enable them to make informed choices.

The Forget-Me-Not service has a range of benefits:

- it provides the opportunity to focus on needs purely from the "client" perspective;
- information can be provided to people at an early stage, thereby enabling people to make informed choices about their own care and needs – and reducing the distress caused through lack of empowerment;
- relationships are developed with practices to ensure greater awareness of dementia and the available services amongst general practitioners;
- people with memory problems can talk freely about the worries prior to deciding whether to speak to their GP
- family members can discuss their concerns in confidence.

### **NHS Cornwall and Isles of Scilly and Cornwall County Council**

Cornwall has used the Alzheimer's Society new public information campaign to raise awareness of dementia, its symptoms and the importance of getting an early diagnosis.

The "Worried about your memory" campaigns have been designed to prompt and help people to consider if their forgetfulness or that of a friend or relative is due to just poor memory or the beginning of a medical problem and encourage them to seek medical support.

Cornwall has launched "Worried about your memory" road shows throughout Cornwall. Staff who specialise in dementia care will be present as well as social care staff. These experts will be able to provide information and advice.

## **Living Well with Dementia**

### ***Early Diagnosis and Support***

#### **Admiral Nurses**

Admiral Nurses are specialist dementia nurses, working in the community, with families, carers and supporters of people with dementia. The Admiral Nurse model was established as a direct result

of the experiences of family carers. Admiral Nurses are named after Joseph Levy, who had dementia. He was known by his family as 'Admiral Joe' due to his keen interest in sailing.

Admiral Nurses:

- work with family carers as their prime focus
- provide practical advice, emotional support, information and skills
- deliver education and training in dementia care
- provide consultancy to professionals working with people with dementia
- promote best practice in person-centred dementia care

## **Leeds**

The Leeds Intermediate Care service for people with mental health problems or dementia was developed as part of a Partnership for Older Peoples Project (POPP), with several linked components.

An Intermediate Care rapid response team operates seven days per week up to 9.30pm in North West Leeds. It targets people experiencing a crisis with their mental health (all functional mental health problems and dementia) who are at risk of admission to hospital, also those in hospital who could be discharged with an advanced level of care for a short time and those who need intensive short-term rehabilitation to avoid going into residential care. The team is nurse-led and includes nurses, health support workers and an Occupational Therapist. The team offers intensive home treatment and has access to a night sitter through the mainstream Intermediate Care service of the Primary Care Trust. During the first 17 months, there were 429 referrals to the team, of which 261 were admitted to the service.

A multi-disciplinary liaison psychiatry team operates in the general hospital, including a psychiatrist, mental health nurses, an Occupational Therapist and health support workers. It provides expertise in diagnosis, treatment and management of older people with mental health problems; and training and support to hospital staff, aiming to bridge between general acute and specialist mental health services. Most referrals to date have come from the main acute hospital wards. Few have come through accident and emergency, possibly because it has been difficult to complete appropriate mental health assessments within the four-hour waiting time target, and there are no suitable facilities for undertaking these in accident and emergency.

Just over one third of those referred to the liaison service had some type of dementia, over a quarter had a functional mental health problem, over a quarter had a combination of mental health problems

and 8% had a severe and enduring mental health problem. Over half were unknown to specialist mental health services, indicating considerable under-recognition of such problems in older people. The interventions provided by the team varied widely, with only one third having more than a few contacts. Around 40% returned home, some with community support, 20% went into long term care, 10% went into an acute mental health bed and 5% to an intermediate care bed either in general Intermediate Care or one of the mental health resource centres (see below).

Three resource centres in different areas of the city each provide five intermediate care beds and active rehabilitation for people with mental health problems. They are led by social services and have support from the mainstream intermediate care team (including general and psychiatric nursing, Occupational Therapy and physiotherapy), mental health specialists, joint care managers, care staff and outreach workers to provide enabling assistance in the centre and in the transition to the person's own home. The centres also offer day care for limited periods. The service is targeted to older people with dementia who might otherwise have an unnecessarily prolonged stay in acute hospital or residential/nursing care.

The main sources of referrals to the centres to date have been the acute general hospital, social services, the Intermediate Care rapid response team, the long term joint care management team and community health services such as GPs and district nurses. Around half were previously known to mental health services. The mean length of stay was 33 days, with considerable variation, and almost one third returned home.

A mental health community support service in North West Leeds provides short-term (six to eight week) enhanced assistance from community support workers, aiming to prevent admission to hospital or institutional care. It works alongside other professionals and carers and assists with assessment, to maximise the possibility that any long term service will promote independence.

A Black and Minority Ethnic (BME) community development worker works with community groups and services working with older BME people to help them to deliver better services to those with mental health problems. A workforce development programme and a Single Assessment Process/Care Programme Approach ( facilitation programme are developing a training programme for the hospital trust, the mental health trust, the Primary Care Trust, the social services department, voluntary sector agencies, service users and carers. This aims to promote best practice in older people's mental health and to share best practice across all partner agencies.

The POPP project's end of second year report showed a significant fall in admissions of people with both primary and secondary diagnoses of

dementia to the main acute hospital, against a rising trend. It estimated that 550 admissions had been avoided, leading to a saving of £1.2m. The other acute hospital in the area also showed a fall in admissions of people with these diagnoses and estimated that 74 admissions had been avoided.

The length of stay for people with a mental health diagnosis also showed a significant reduction. The average number of 'excess' bed days for this group fell from 120 per month to 32 per month, making a saving of 1056 bed days over a year. In addition, the monthly average number of bed days due to emergency admissions for people with a primary or secondary mental health diagnosis fell significantly, leading to further savings. There were also falls in the number of placements made in residential and nursing homes for people with a mental health diagnosis and an increase in the number with mental health problems receiving home care.

### **Central Lancashire Primary Care Trust**

The service has 10 beds in a residential home for intermediate care for people with dementia, transferred from acute hospital wards. A multi-disciplinary team provides support, especially Occupational Therapy and other therapies, aiming to re-skill people to become independent. Cognitive assessment and rehabilitation is an important element.

The team also provides outreach support when people leave, linked with a community resource centre providing enhanced day care, drop-in, open access and the base for the Community Mental Health Teams (CMHT) and voluntary organisations. The model of care in the resource centre is based on dementia day care and re-skilling, including horticultural and other therapies, using a similar approach to that in the residential beds. The team also provides some training and support is provided for intermediate care home care staff, to help them to care for people with dementia.

## **Good Practice in Dementia Care and Development**

### **North Lincolnshire Primary Care Trust**

Have developed General Hospital Clinical Guidelines for Older People with Mental Health problems. These guidelines:

- support and train staff in the detection and initial management of mental health problems later in life
- proactively work with general care teams to avoid unnecessary admission
- improve the mental health care of older people while they are inpatients

The overall purpose of the guideline is to support and develop the delivery of care within a hospital setting for patients suffering from dementia, depression and delirium. The guidelines aim to improve the identification and referral of dementia, depression and delirium within the hospital setting and are hoped to reduce variations in practice thus ensuring equity of service throughout.

### **Cornwall – Older People’s Mental Health Liaison Services**

The current Older People’s Mental Health Service is provided by Cornwall Partnership NHS Trust and is designed to inject specialist mental health skills in a general medical setting.

As well as providing specialist hands-on care, the team have a key role as educators and cultural ‘change agents’. By spreading and sharing their expertise and enthusiasm, the team has led an approach which makes dementia care ‘Everybody’s Business’. Their approach is pivotal to supporting colleagues to think differently about people with dementia, encouraging greater sensitivity, thoughtfulness and empathy towards the individual.

Until now, there has been no comparable service in community hospitals, although the team see as many people with dementia as acute hospitals. The Primary Care Trust recently appointed a Lead Dementia Nurse to test whether the liaison model could work in the community. The Lead Dementia Nurse works closely with community hospitals, care homes and GPs to increase understanding of dementia. Due to the success of this, the Primary Care Trust is looking to commission a permanent expansion to the liaison service with 3 new Dementia Liaison Practitioners.

The Dementia Liaison Practitioners will be responsible for building sustainable skills, knowledge and expertise of dementia care in mainstream settings.

3.21 The following chapters focus on the three broad themes included in the National Dementia Strategy, describing the Somerset outcome focussed approach. These themes are:

- raising awareness and understanding
- early diagnosis and support
- living well with dementia

## 4 RAISING AWARENESS AND UNDERSTANDING

- 4.1 There is generally a low level of public and non-specialist professional understanding of dementia. There is also a widespread stigma attached to dementia where both the public and non-specialist professionals find it hard to talk about dementia, and seek to avoid addressing the possibility of an individual being affected. For professional groups, this can result in low priority being accorded to the development of the skills needed to identify and care for people with dementia.
- 4.2 There is also widespread mis-attribution of symptoms to 'old age', resulting in an unwillingness to seek or offer help. There is also the false view that there is little or nothing that can be done to assist people with dementia and their carers. These factors act together to delay diagnosis and access to good quality care.
- 4.3 It is therefore crucial to develop a better understanding of dementia by the public and the professionals to ensure that better information is provided on how to seek help and what help and treatment is available. This will begin to address the stigma and misunderstandings that currently exist for dementia.
- 4.4 Some examples of good practice in Somerset include:

### **Dementia Conference**

A successful dementia awareness conference was held on 17 June 2008 aimed at health and social care practitioners in Somerset caring for people with dementia. The objectives of the conference were to:

- raise awareness of dementia care and dementia services
- raise awareness of carers' perspectives
- implement mental health for older people as Everybody's Business
- focus on improving quality of care in general hospitals and community environments
- develop approaches to facilitate early discharge of dementia patients from hospital

The conference also had a strong carer perspective with Barbara Pointon, Ambassador for the Alzheimer's Society and for the Admiral Nurse charity, being the key note speaker. The carer's video was shown and local carers participated in the workshops.

Somerset Partnership NHS Foundation Trust and Social Care staff helped to develop the programme. All of the workshops were facilitated by Partnership staff who shared clinical expertise and simple approaches that can be implemented in general settings. The conference also facilitated networking between specialist mental health

staff and general staff so that links can be developed for clinical practice.

Each workshop provided key actions that could inform future service development and commissioning. Individual participants were also asked to identify three actions that they could take back to their own area of clinical expertise to improve care.

### **Somerset Direct**

A year-long pilot is beginning in April 2009 to Improve Customer Access as part of the Personalisation programme. Some social work staff will be based at Somerset Direct, the first point of contact for all Adult Social Care enquiries. They will be able to provide a fast response to requests for urgent, non-complex services. They will complete a telephone Overview assessment as part of the Single Assessment Process and order services to provide help and support for the person or their carer. This will include arranging home care or respite services such as short stays or sitting service. This will provide a fast, consistent response to people in need of urgent support, whether due to a crisis or a recent deterioration in their situation.

### **Adult Learning Disability Services**

Adult Learning Disability services organised a training conference for Local Authority Dementia Leads, in September 2007. Presenters were both Health and social services from the Community Team for Adults with Learning Disabilities and Health Action Planning teams. Presentations covered current practice, pathways and research findings around good practice.

Adult Learning Disability services commissioned a DVD on Growing Old with Learning Disabilities. The DVD has interviews with local service users, family and paid carers, Adult Learning Disability services and hospice professionals. It discusses the significant issues that affect people as they grow older, including retirement, loss of family, home and carers, reversal of roles, moving home, illness including dementia and the impact of all of these on the person, their carers and the services that support them. The focus is on positive life choices and on recognising the importance of different individual life histories.

### **Dementia Care and Support Conference**

The conference 'A Personal Approach to Dementia Care and Support - Practical skills for care and support workers in domiciliary care' was held

on 6<sup>th</sup> December 2007 in Taunton by Care Focus in association with Somerset County Council. The event was directed at domiciliary care providers and promoted as a 'train the trainer' event. It was aimed at managers, training managers and senior care and support workers of people with dementia being cared for in their own homes. The expected outcome from this event was that delegates would be equipped to cascade training that enable their organisations to think differently about their approach when caring and supporting people with dementia in their own homes.

### **Achieving Improved Awareness amongst the Public, Service Users and Carers**

4.5 To achieve improved awareness amongst the public, people using services and their carers the following will be delivered:

- *Improving signposting and information:*
  - \* development of early signposting and information packs with information taking into account the needs of specific groups
  - \* distribution of information packs to a wide range of locations including GP practices, pharmacies, libraries, hospitals, community centres, Active Living Networks, Age Concern and the Somerset Branch of the Alzheimer's Society.
  - \* governance arrangements will be put in place to ensure that all information produced is current, evidence based and accessible to people with a learning disability, sensory loss, physical disability, from a rural or travelling community and from black and ethnic minority groups. All information will be reviewed at least annually by an information review group to avoid duplication and ensure it remains relevant
  
- *Developing a communications and marketing plan:*
  - \* development of a comprehensive communications and marketing plan to achieve improved awareness of dementia with a view to reducing the fear and stigma attached to the condition and encouraging people to access the necessary support required to improve outcomes and quality of life
  
- *Involving Users and Carers:*
  - \* develop plans for user participation and involvement in service design.

## Achieving Improved Awareness amongst Professionals

4.6 To achieve improved awareness amongst professionals the following actions will be delivered across Somerset:

- *Identifying dementia leads/champions:*
  - \* identification of dementia leads throughout the health and social care community, including independent and voluntary sector to support the implementation of the Somerset Dementia Strategy
- *Raising awareness in community and primary care services:*
  - \* to be incorporated within the wider communication and marketing plan this will include the use of a range of communication channels including Practice Based Commissioning (PBC) newsletter and the Local Medical Council (LMC) newsletters
  - \* Partnership working with the regulators i.e. the Care Quality Commission will be implicit in all communication programmes
- *Raising awareness in hospital settings:*
  - \* to be incorporated within the wider communication and marketing plan this will include raising awareness in both acute and community hospital settings through the implementation of the 'Implementing Quality Standards for the Care of People with Dementia in General Hospital Wards' plan, coordinated by NHS Somerset

4.7 The main findings from the public consultation that took place on the priorities contained within the Somerset Dementia Strategy for raising awareness and understanding was regarding information and communication. Information should be available on any service provision, where to go to get help, and support for patients and carers when they need it. The information should be clear and easy to follow.

### KEY PRIORITIES

#### Phase One: 2009/2010

Work Programme	Planned Action	Lead Organisations
Achieving improved awareness amongst the public, service users and	Three year Communication and Marketing Plan to be developed with the following actions being taking forward in 2009/2010 including:	NHS Somerset/ Somerset County Council.
	Development of information packs	NHS Somerset/

<b>Work Programme</b>	<b>Planned Action</b>	<b>Lead Organisations</b>
carers	which will be updated annually and plans for distribution.	Somerset County Council/ Alzheimer's Society
	Plans for user participation in service design.	NHS Somerset/ Somerset County Council
Achieving improved awareness amongst professionals	Identification of dementia leads/champions across relevant statutory, voluntary and independent organisations.	NHS Somerset/ Somerset County Council
	Plans to raise awareness in community and primary care services including work programmes in GP practices to support increased awareness and good diagnosis.	NHS Somerset/ Somerset County Council
	Plans to raise awareness in hospital settings.	NHS Somerset

### **Phase Two 2010/2011**

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Achieving improved awareness amongst the public, service users and carers	To implement the communications and marketing plan.	NHS Somerset/ Somerset County Council
Achieving improved awareness amongst professionals		

### **Phase Three 2011/2012**

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Achieving improved awareness amongst the public, service users and carers	To continue implementation of the communications and marketing plan.	NHS Somerset/ Somerset County Council

Achieving improved awareness amongst professionals		
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## **5 EARLY DIAGNOSIS AND SUPPORT**

- 5.1 Nationally only about one third of people with dementia receive a formal diagnosis at any time in their illness. For some people the diagnosis is often made too late for them to make any choices about their care. For others the diagnosis can come at a time of crisis which may have been avoided if the diagnosis had been made earlier.
- 5.2 Early diagnosis and intervention can improve quality of life and delay or prevent unnecessary admissions into care homes.
- 5.3 The diagnosis of dementia, and in particular mild dementia and people with learning disabilities where the diagnosis is more complex, should be carried out by a clinician with specialist skills. This will include:
- improving how the diagnosis is made
  - giving the diagnosis in a sensitive and informative way to the person with dementia and their family, and
  - providing directly appropriate treatment, information, care and support after diagnosis
- 5.4 The importance of good quality information for patients and carers to enable them to direct their own care is essential. Every person diagnosed with dementia and their carers need to be provided with good quality, relevant, information on the illness and the local services that are available to them. Whilst different information may be required for different types of dementia or as the dementia progresses, every person diagnosed should receive a standard information pack at or soon after diagnosis, depending on when they are ready to receive it.
- 5.5 Evidence suggests that a local dementia adviser service can provide a point of contact for people with dementia and their carers; who can provide information and advice about dementia and on an ongoing basis, help to signpost them to additional help and support. A dementia adviser service can complement existing health and social care support that people with dementia already receive.
- 5.6 People with dementia and their carers can obtain continuity of care and support not only from statutory services, but also in the form of peer support. Structured models of support can incorporate advice and support from health and social care professionals and enable people living with dementia and their carers, to exchange practical advice and emotional support.
- 5.7 Somerset County Council commissioned an independent review of its advocacy services in 2008, and the review covered advocacy services jointly commissioned with NHS Somerset. During 2009 a long term strategy for the provision of advocacy services will be developed. This strategy will incorporate outcomes from work already underway

considering how advocacy can also be made available to carers, including those who care for people with dementia.

5.8 Somerset will take the learning from the dementia fast track project to harness market forces with early case finding. The overall aim of community-based awareness campaigns is to promote greater knowledge of the disease, reducing fear and stigma, with the purpose of bringing people with dementia and carers in touch with services that can support them and their condition.

5.9 As part of the commitment towards improving services locally for people with dementia and in particular supporting people with this condition, Somerset has chosen a local World Class Commissioning outcome to improve the number of people with dementia recorded on GP registers.

5.10 Some examples of good practice in Somerset include:

#### **Wincanton Memory Café**

Wincanton Memory Café has been running since September 2008 as a peer support activity for people affected by dementia. The café takes place in a memorial hall in the centre of Wincanton and runs twice per month, supporting six to eight people with dementia, plus their friends and carers, at each session. Following consultation, the café has been developed to provide a place for people to meet socially and provide support to one another, whilst enjoying a range of physical or mentally stimulating activities and gaining access to information. The café is run by a member of staff from the Alzheimer's Society with support from a number of local volunteers who organise refreshments and chat to attendees. In addition, health and social care professionals also attend in order to meet people affected by dementia on "neutral ground".

The key outcomes of the Memory Café are to:

- help prevent social isolation and encourage people to network and build contacts
- promote healthier lifestyles and general well-being through the organisation of group activities such as creative and physical activities;
- provide information and support on dementia and dementia care
- provide continuous support to people affected by dementia and access to appropriate services and contacts
- provide informal access to relevant health and social care professionals through their attendance at each café

#### **Singing for the Brain**

Singing for the Brain in Castle Cary follows a model which has been developed over many years by the Alzheimer's Society. This project

involves running structured group singing sessions on a weekly basis for people affected by dementia. Two groups have been developed – one in a residential home and one in a sheltered accommodation unit. People living in the wider community are also welcomed and up to 30 people attend each group each week. The groups are led by a trained facilitator who is supported by a number of volunteers providing singing support as well as general help. Each session includes a mix of singing, social interaction to promote well-being and gentle aerobic exercise to promote physical health.

The key outcomes of Singing for the Brain are to:

- help prevent social isolation and encourage people to network and build contacts
- provide an opportunity for people with more severe dementia to express themselves through music and singing
- provide a sense of mental well-being through being involved in a group activity
- encourage physical well-being through taking part in physical activity

### **Carers Information Day**

Taunton & West Somerset Branch of the Alzheimer's Society, in partnership with Carers UK and Somerset County Council organised a free carers information day in Taunton in September 2008. The event focused on paying for care, carers' rights, the implications of the Mental Capacity Act and continuing care and was attended by over 40 carers of people with dementia who heard presentations by former carer, Barbara Pointon, and representatives from the Alzheimer's Society and Somerset Primary Care Trust.

### **Single Assessment Process**

Assessments for people with dementia, as all adults, are person-centred and shared between appropriate professionals through the Single Assessment Process. The assessment documentation is shared electronically between agencies and professionals through a secure IT system. This reduces the risk of duplication in the assessment process for the individual and prevents the heightened anxiety that can be caused by several professionals asking a person the same or very similar questions. It also encourages multi-disciplinary and multi-agency care plans. The person can be given a copy of their assessment and care plan to keep in their home and share with anyone involved in their care.

### **Adult Learning Disability Services**

As well as a Referral and Diagnosis Pathway, agreed with GPs, the Adult Learning Disability service has an Early Recognition of Dementia Strategy. This strategy hopes to achieve early recognition through a rolling programme of Baseline Skills Assessments, carried out on everyone aged 50 and over (or aged 40 and over for people with Downs Syndrome), against which any future deterioration can be measured. The early recognition strategy has been implemented within current resources, meaning that progress in achieving it is necessarily slow.

### **Alzheimer's Society**

The Somerset Branch of the Alzheimer's Society has secured funding from Somerset County Council and The Rowse Trust to pilot an outreach service for younger people with dementia, which will begin in 2009. The pilot project will have three aims:

- to provide a specialist outreach service to younger people with dementia, their families and carers, identifying and offering relevant information and providing ongoing support. This service will be provided through a mixture of face-to-face, telephone and e-mail contact as appropriate
- to establish a series of peer group activities to enable those younger people who are affected by dementia to meet others in similar situations and develop their own support networks
- to identify opportunities where a younger person with dementia would benefit from being matched with a befriender in order to continue taking part in leisure activities. In conjunction with volunteer groups across Somerset, as well as colleagues within the Alzheimer's Society, the project will aim to identify and match potential volunteer benders with younger people with dementia

The anticipated benefits of the pilot are:

#### **For younger people with dementia:**

- people will be helped to live as independently as possible for as long as possible, through the provision of information enabling informed decisions to be made
- people will be able to enjoy social activities, tailored to their preferences
- people will retain their skills for longer and may learn new ones
- people will be able to network with others in a similar position and have the opportunity to make new friends

**For carers:**

- carers will be able to access up-to-date, high quality information to enable them to make informed choices
- carers will be able to access specialist peer support groups
- if befriending is provided, carers will receive some short-term respite
- carers will be able to network with others in a similar position and have the opportunity to make new friends

**For the statutory sector:**

- professionals will have greater choice in referring clients
- professionals will have access to specialist knowledge in working with younger people with dementia
- the statutory sector will start to address the requirement for ongoing support and information following diagnosis and the development of peer support groups as identified in the National Dementia Strategy for England

**Achieving Improved Early Diagnosis and Support Services**

5.11 To achieve improved early diagnosis and support services for people with dementia the following will be delivered:

- *Early diagnosis and case-finding:*
  - \* an action plan will be developed to support the delivery of the World Class Commissioning health outcome on the number of people with dementia recorded on GP registers will improve through the World Class Commissioning outcome for Somerset
  - \* plans will be developed to implement early case finding from the dementia fast track project to increase information provision and awareness of available services, and increased early assessment
- *Memory and assessment services:*
  - \* a review of existing services will be undertaken and, if appropriate, a revised service specification for a memory assessment service in Somerset will be developed to ensure the early detection and diagnosis of dementia whilst identifying treatable causes of cognitive impairment. Improved early intervention will help to maximise quality of life and independent functioning, and to manage risk and prevent future harm to older people with memory difficulties and their carers. A revised dementia pathway will ensure clear links between the memory assessment service and early intervention and support services

- *Care pathways and personalised care planning:*
  - \* a single care pathway for dementia (including early onset dementia) will be developed. This will include people with a learning disability who are diagnosed with dementia
  - \* personalised care plans will be widely implemented as part of the post diagnosis support for people with dementia that will record individual's values, beliefs and preferences
  
- *Community based support for users and carers:*
  - \* Implement the Somerset Dementia Care Adviser pilot. It is recognised that support will need to be ongoing and that people with dementia and their carers often have difficulty “navigating” statutory services and may sometimes be unaware of peer support groups and services provided by the third sector
  - \* people diagnosed with dementia will be signposted to local third sector and peer support services as soon as possible after diagnosis
  - \* plans will be developed to extend the Memory Café service to all areas of the County. ‘Singing for the Brain’ groups will also be developed as part of this resource
  - \* plans will be developed to widen the programmes offered through Active Living Centres to incorporate additional activities that support people with dementia and their carers including identifying dementia leads enabling information is available regarding the third sector
  - \* carers of people diagnosed with dementia will be offered education and support groups as soon as possible after diagnosis, which will include current and former carers

5.12 The main findings from the public consultation that took place on the priorities contained within the Somerset Dementia Strategy for early diagnosis and support was regarding the role of the GP who was seen as a crucial contact for obtaining help, support and the early diagnosis of dementia. Responders were also keen for GPs to use their register of dementia patients and that patients should be followed up on a regular basis to pick up any other underlying medical conditions in addition to their dementia.

5.13 Another area identified within the engagement process was support for carers. This was seen as an essential priority for carers to receive support on an ongoing basis from the very start of the diagnosis. A quote from a responder states: *“Carers, as opposed to care workers, have rarely chosen their role and they often have little experience of either the illness or the problems it will bring, or the services and benefits that are available to them”*.

## KEY PRIORITIES

### Phase One 2009/2010

<b>Work Programme</b>	<b>Planned Action</b>	<b>Lead Organisation</b>
Early diagnosis and case-finding	Develop and implement detailed action plan to support delivery on World Class Commissioning dementia outcome	NHS Somerset
	Develop options and recommendations for progressing early case finding	NHS Somerset
Memory and assessment services	Review of current memory assessment services	NHS Somerset
Care pathways and personalised care planning	Review and update current dementia care pathways in line with National Strategy.	NHS Somerset/ Somerset County Council working with other key stakeholders
	Introduce a personalised care plan for all people diagnosed with Dementia	NHS Somerset/ Somerset County Council
Community based support for users and carers	Pilot the Somerset Dementia Adviser Service which is a national Dementia Demonstration site for Dementia Care Advisers	Somerset County Council/NHS Somerset/Alzheimer's Society
	To develop plans for a phased approach to the establishment of additional Memory Cafés across Somerset	Somerset County Council/NHS Somerset/Alzheimer's Society
	To widen programmes accessible to people with dementia through the Somerset Active Living Centres and identify dementia 'champions' within each active living centre	Somerset County Council/NHS Somerset
	To incorporate with the care pathway, actions to ensure patients diagnosed with dementia and their carers are offered education and support as soon as possible after diagnosis, within the training and education plan (see Appendix 3)	

## Phase Two 2010/2011

<b>Work Programme</b>	<b>Planned Action</b>	<b>Lead Organisations</b>
Early diagnosis and case-finding	Commission early case finding service based on options and recommendations paper	NHS Somerset
Memory and assessment services:	Implement agreed recommendations resulting from the review of memory assessment services – ensuring that an equitable service is available to service users across Somerset	NHS Somerset
Care pathways and personalised care planning	Monitor implementation of revised dementia pathway	NHS Somerset/ Somerset County Council
	Monitor implementation of personalised care plans including user and carer feedback, and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council
Community based support for users and carers	Monitor and evaluate the outcomes of the Dementia Adviser pilot and ensure the results inform future commissioning of the service.	NHS Somerset/ Somerset County Council
	Implement plans for a phased approach to establishing additional Memory Cafes across Somerset	NHS Somerset/ Somerset County Council/ Alzheimer's Society
	Review and monitor effectiveness of additional services offered through Active Living Centres and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council

## Phase Three 2011/2012

<b>Work Programme</b>	<b>Planned Action</b>	<b>Lead Organisations</b>
Early diagnosis and case-finding	Ongoing monitoring of numbers of cases on GP registers and early case-finding against expected prevalence	NHS Somerset
Memory and assessment services:	Continue to work with provider organisations to ensuring that a high quality equitable service is available to service users across Somerset	NHS Somerset
Care pathways and	Ongoing monitoring of effectiveness of revised dementia	NHS Somerset/ Somerset County

<b>Work Programme</b>	<b>Planned Action</b>	<b>Lead Organisations</b>
personalised care planning	pathway	Council
	Continued monitoring of personalised care plans including user and carer feedback, and put in place actions to improve where appropriate	NHS Somerset/Somerset County Council
Community based support for users and carers	Agree and implement future commissioning arrangements for the role of Dementia Adviser based on outcomes of Demonstrator site evaluation	NHS Somerset/Somerset County Council
	Continue to implement phased approach to establishment of additional Memory Cafes across Somerset	NHS Somerset/Somerset County Council/Alzheimer's Society
	Continue to review and monitor effectiveness of additional services offered through Active Living Centres and put in place actions to improve where appropriate	NHS Somerset/Somerset County Council

## 6 LIVING WELL WITH DEMENTIA

- 6.1 Nationally two-thirds of all people with dementia live in their own homes in the community. Some of these people will be in the early stages of their dementia and some nearing the end of their lives. The right support at the right time and in the right place is especially important to give them choice and control over the decisions that affect them. Whilst the majority of care and support for people is provided by family members and friends, home care and home support is important to assist people with dementia living in their own homes.
- 6.2 Specialist dementia home care provides considerable benefits to both people with dementia and their carers with improved outcomes including reduced stress and risk of crises for the carers, and extended capacity for independent living for people with dementia. Within Somerset there is a need to ensure the market place delivers quality services.
- 6.3 People with dementia are known to be an 'at risk' group in terms of abuse through financial exploitation, fraud and theft with some individuals unable to complain. Somerset safeguarding protocols provide clear information on how to complain about poor standards of care, or report concerns about possible abuse to safeguard people with dementia and their carers, ensuring their human rights are protected. Staff in all settings should be familiar with these arrangements.
- 6.4 Most family carers want to be able to provide the support to enable the person with dementia to stay at home, although they often require more assistance than is routinely available. Residential care may be the most appropriate and effective way of meeting someone's needs and providing a service of choice. However, it should always be a choice. Often older people with dementia are admitted to long-term residential care because it appears that there are no other alternatives available, especially if the person has been admitted to hospital as the result of a crisis. This is partly due to a lack of knowledge and understanding from professionals. It is also due to home care staff and family carers not receiving adequate training and advice in dementia, so not having the skills and competencies to provide appropriate care.
- 6.5 Flexible and responsive breaks and day services are vitally important to support families in their caring role and people with dementia. These services should provide valued and enjoyable experiences for people with dementia and their carers. They can play an important role in preventing institutionalisation and keeping people with dementia in the community. Breaks can be provided in a variety of settings, including the home of the person with dementia. They also need to be on an emergency, urgent and planned basis.
- 6.6 Admission to hospital can be a confusing and challenging time for people with dementia and family members who may be excluded from discharge planning. There can also be a lack of co-ordination between hospitals

and care providers at the point of discharge, with delay in access to care packages such as home care and intermediate care that might enable successful discharge. Further improvements to hospital care include:

- the identification of a senior clinician within the general hospital to take the lead for quality improvement in dementia care
- the development of an explicit care pathway for the management and care of people with dementia in hospital, led by that senior clinician
- commissioning specialist liaison older people's mental health teams to work in general hospitals

6.7 People living with dementia should receive high quality care appropriate to their needs in general health settings. The need for robust and detailed assessment of people's abilities, previous interests and arrangement approaches for activities of daily living should be identified on admission. This needs to include a full assessment of risk for the patient's safety and promotion of independence on admission to hospital, particularly in relation to their cognitive ability.

6.8 Intermediate care is not widely available for people with dementia. There is good clinical evidence that people with mild or moderate dementia with physical rehabilitation needs do well if given the opportunity. People with severe dementia may need more specialist services to deliver their mental health needs as well as those providing general physical rehabilitation.

6.9 In order to enable people with dementia to live well with their condition, much is being done that is positive in terms of housing options and assistive technology that are part of mainstream care for people with dementia and that contributes to their independence and safety.

6.10 Improving the quality of care for people with dementia in care homes is an objective of the National Dementia Strategy with a number of recommendations being made:

- identification of a senior staff member within the care home to take the lead for quality improvement in the care of dementia in the care home
- development of a local strategy for the management and care of people with dementia in the care home, led by that senior staff member
- only appropriate use of anti-psychotic medication for people with dementia
- the commissioning of specialist in-reach services from older people's community mental health teams to work in care homes
- the specification and commissioning of other in-reach services such as primary care, pharmacy, dentistry, etc
- readily available guidance for care home staff on best practice in dementia care

- implementation of the Deprivation of Liberty Safeguards (DOLS)

- 6.11 The Deprivation of Liberty Safeguards process in Somerset is administered on behalf of Somerset County Council and NHS Somerset by a DOLS Co-ordinator. For some people with dementia whose capacity to make decisions or to keep themselves safe is very limited there may be a need to deprive them of their liberty in order to keep them safe. Wherever possible the least restrictive form of care should be put in place. Where this is not possible and the person in a care home or a hospital will need a high level of restriction for a significant period of time, the care plan may need to be authorised using the Deprivation of Liberty Safeguards process. The managers of care homes or hospitals are responsible for deciding if the care plan might require authorisation and they have received training to do this.
- 6.12 For people with dementia, end of life planning needs to take place early while they still have the sufficient mental capacity and where decisions and preferences can be recorded consistent with the principles set out in the Mental Capacity Act. This could include the use of lasting powers of attorney, advance decisions and advance statements. A working group is in place for the development and implementation of advanced care planning as part of the implementation of the end of life care strategy.
- 6.13 Somerset is part of the Marie Curie Delivering Choice programme which aims to improve and deliver better care to support all terminally ill patients, irrespective of diagnosis, in making choices over their place of care and death. The programme works in partnership with the NHS, voluntary sector, social services and other healthcare providers to improve the whole palliative care system. Somerset is currently in phase 2 of the programme which will help inform the development of services for end of life care for people with dementia. A key focus of all the work streams is to ensure that palliative care services are commissioned to meet the needs of patients with cancer and non cancer diagnoses.
- 6.14 WyvernHealth.Com the Practice Based Consortium in Somerset has approved a pilot scheme to look at enhanced clinical care for patients in residential care beds to prevent unnecessary hospital admissions through:
- ensuring all residents should have medical records that include a decision on whether they are for resuscitation. This will need to be discussed with the patient, carers, relatives and their doctor
  - developing a culture of appropriate care to provide care in the home where possible and prevent trips to hospital which may be unnecessarily frightening for the patient and not result in any improvement in quality of life
  - training homes to establish when a 999 call is needed and when an urgent doctor request may be more appropriate

6.15 Some examples of good practice in Somerset include:

#### **Somerset Care Ltd**

Somerset Care Ltd is a not-for-profit company that has 26 care homes in Somerset, eight of which provide specialist dementia care. Their approach to caring for people with dementia has two key principles:

- care should be provided in the right environment, and
- that person centred care is key to all decisions

In January 2004, Somerset Care Ltd consulted with the Iris Murdoch Centre at Stirling University on the design of their homes and now uses good practice principles for designing better homes for people with dementia as it is recognised that the homes should be specifically designed to meet the needs of their clients.

Somerset Care Ltd is also undertaking research on dementia care with Exeter University.

#### **Somerset Active Living Network**

In Somerset we have an infrastructure of 94 very local Active Living Centres, which serve communities by improving local access to both primary and secondary prevention. Active Living Centres have become the 'hub' for delivering a range of preventative and well-being services which are provided by partner agencies. The concept of 'Active Living' is used to engage 'younger' older people (typically 50 plus) and to promote the benefits of keeping active and healthy.

A key success of the Active Living Service is its partnership with statutory, voluntary and community groups. The service is governed through a board with representation from NHS Somerset, Somerset County Council, District Councils, Disability Federation, Age Concern Somerset and Older people. One of the key priorities of Active Living is to ensure that older people have a voice in the development and delivery of local services. In the last year 14,480 older people have accessed Active Living opportunities. Planned developments for the Active Living service in 2009 include working in partnership with the Somerset Alzheimer's Service to support the development of additional Memory cafés. And the development of five intergenerational projects bringing younger and older people together through local projects.

## **Specialised Residential Care**

In order to improve the quality of residential care for people with dementia Specialised Residential Care (SRC) was established in 2002 as a joint project between Somerset County Council, NHS Somerset and Somerset Partnership NHS Foundation Trust.

SRC provides 24-hour personal care in a residential environment for people with dementia, with skilled support from Specialist Care Development Nurses (SCDN's) employed by Somerset Partnership NHS Foundation Trust and funded by NHS Somerset. SCDN's are members of Older Person's Community Mental Health Teams (CMHT's) and support and assist with admissions, care planning and individual care programmes and provide the link to the expertise of the Older Person's CMHT, which includes access to Psychiatry and Psychological support.

A total of 213 placements, including six available for respite, are currently commissioned at 10 residential homes across Somerset from five providers. Provision includes a mix of dedicated sites and units attached to larger homes, in both purpose built and pre-existing environments, with the aim of placing each person with dementia in the environment which best suits their needs. All 10 homes providing SRC are rated as good or excellent by the Commission for Social Care Inspection (CSCI), and planning is in progress to ensure that there is sufficient capacity available to meet future demographic demand.

An independent review of SRC was completed in early 2009 which found that SRC is unique in how it uses dedicated SCDN time in conjunction with traditional contracting measures, which makes it both effective and different to anything else identified elsewhere regionally or nationally. The review concluded that SRC delivered high quality, personalised, services for people with dementia at an affordable cost. Areas for development highlighted in the final report will be addressed as part of an action plan aligned with the wider dementia strategy.

## **Alzheimer's Society**

The Alzheimer's Society is the leading care and research charity in the UK for people with dementia and those who care for them. The Society has been active in Somerset for more than ten years, providing services and support through its local branch network. Services vary around the county but include:

- telephone information and support for carers
- a carers group
- a reminiscence group for people with dementia
- an outreach service
- memory cafés
- Singing for the Brain groups

- information provision and awareness raising
- discussion and social groups for younger people with dementia and their carers

The branches and their services, which rely heavily on volunteer support, are currently funded through voluntary income and a small amount of grant funding.

### **Specialist Home Care Service**

The specialist Home Care Service was piloted in 2007/08 in part of Sedgemoor. The aim of the service was to provide support to people with dementia or other mental health needs to enable them to remain living in their own homes. The Service used a person centered planning approach to the provision of the home care support. This meant working closely with the individual; their families, and their support network to provide a home care service that fully met their needs. For example, an individual with no insight into their memory loss may be reluctant to acknowledge or accept support. In the past these individuals may have refused all assistance until the home care was cancelled. The Specialist Home Care Service was able to work closely with the individual, offering assistance in a way they would find acceptable, increasing the level of input as the relationship of trust developed.

During the pilot period Brunelcare, the Domiciliary Care Provider, seconded one of their initial support workers into the role of Dementia Support Worker. This worker was supported by the Somerset Partnership Older Persons Team, and met regularly with them to obtain advice and support.

Whilst the day-to-day care delivery was provided by Brunelcare's home care staff the Dementia Support worker:

- looked at all new care orders to assess if they required the service.
- identified individual needs
- provided oversight/monitoring of the care plan
- offered advice and support on the needs of the individual and ensured that all the care staff involved were trained to meet the needs
- fed back any concerns/changes of behaviour to the relevant team or care manager
- worked closely with the care manager to implement any changes to the care planning
- attended regular meetings with Somerset Partnership to discuss the Service and any concerns about individual service users

The learning from this pilot will be used to inform the future design of home care delivery for people with dementia.

### **Privacy and Dignity Project**

In order to improve the quality of care provided for people with dementia in general hospital settings, NHS Somerset has developed a Privacy and Dignity project with the support of the Care Services Improvement Partnership. The aim of the project is to improve the care of people with dementia in general hospital settings by focusing on privacy and dignity in relation to dementia care.

Initial work has been undertaken to develop quality standards for the care of people with dementia in general hospital settings with the involvement of Barbara Pointon dementia carer and ambassador for the Alzheimer's Society. The Privacy and Dignity project will focus on three standards that relate specifically to the needs of people with dementia:

- communication
- assessment and risk management
- administration of medicines

Taunton and Somerset NHS Foundation Trust and Yeovil District Hospital NHS Foundation Trust, Somerset Community Health and Somerset Partnership NHS Foundation Trust are involved in the pilot project.

Pilot sites have been identified on elderly care wards in both Taunton and Somerset NHS Foundation Trust and Yeovil District Hospital NHS Foundation Trust and from two community hospitals in Somerset Community Health.

The pilot project will support the development of dementia leads in each of the pilot sites. The dementia leads will comprise of a registered nurse, therapist and health care assistant who will undertake training and development to act as a specialist resource for the care of people with dementia in their clinical area. The dementia leads will act as part of a clinical network for dementia leads in each Trust.

This network will be coordinated by the Psychiatric Liaison Nurse for Older People with Mental Health needs from Somerset Partnership NHS Foundation Trust.

The aim will be to role this model out across each Trust to replicate the skills and expertise across relevant clinical areas and to act as a resource for surgical units for example.

An initial workshop for the dementia leads has taken place which

provided training and skills development for the dementia leads together with time for action planning for their Trust.

### **Wander Guardian**

A project is taking place in Somerset around a device call the "Wander Guardian". This has been devised through NHS Innovations and is based on mobile technology. The device is like a small mobile phone that has a GPRS and a GPS card capacity and can either be worn around the neck or put into a pocket. The proposal has received ethical approval through Somerset Partnership NHS Foundation Trust who are trialling the use of the device.

The person has to agree to wear the device and agree to be monitored therefore they have to give consent and have capacity to understand what it is for. The idea is not to constantly watch someone but allow them the freedom and mobility to carry on going out, and still go out on walks. This will allow the family to check on them if they haven't returned at the usual time.

Checking is done via a secure internet site and access is only allowed via a secure log on. Patients are only identified as Mr A or Mrs B and only staff who have registered the person on the system know who is who, they do not even have to have their full name and address on the system so it is perfectly secure. The person can then see where the patient is via a GPRS/GPS mapping service and call for assistance if required.

The idea is to allow a very mobile person with the early stages of confusion to carry on their life as normally as possible. Service users have it for a trial period to see if it is beneficial for them. Early trials have shown some limitations due to network coverage but have also been successful for some patients.

### **The Adult Learning Disability Service**

The Adult Learning Disability Service, through the psychology services, have a link with the University of Plymouth and the Developmental Disabilities Research Group (DDREG). This group is concerned with research on Downs Syndrome and Dementia and achieving best practice. As a result of this link we assess everyone with dementia annually using the People with Intellectual Disabilities (DLD), so that we are in line with national practice and our information could potentially be used in a national study on profiling the progress of dementia in people with Downs Syndrome.

### **Specialist Mental Health In-Reach Liaison Services**

Somerset Partnership NHS Foundation Trust provides specialist mental health in-reach liaison services to Yeovil District Hospital, Taunton and Somerset Hospital and some Community Hospitals.

The Team is based within the local Community Mental Health Services. The aim is to work with inpatients and their carers, and in support of hospital staff, to assist with assessment, risk assessment, and discharge care planning to maximise independence and assist in avoiding unnecessarily prolonged hospital stays.

The service provides enhanced mental health skills, treatment and care planning to hospital staff. The Trust is seeking to increase and develop the service so that it can be provided at all community hospitals.

### **Improving the Quality of Life for People with Dementia**

6.16 To achieve an improvement in quality of life and support people with dementia to 'live well', the following will be delivered:

- *Commissioning for quality:*
  - \* commissioning strategies will include specific requirements around commissioning quality residential and nursing care services
  - \* commissioning strategies will include specific requirements around commissioning for 'quality' home care services as it is recognised that home care is vital to enable people with dementia to remain in the familiar surrounding of their home whilst receiving care and support
  - \* all staff employed by home care providers will be required to have a minimum level of training in providing care to people with dementia
  - \* learning from the Specialist Home Care pilot (see p37) will be used to inform the future design of home care delivery for people with dementia
  - \* information sharing protocols will be established whereby information will be routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia
  - \* options will be produced for enabling people with dementia and their carers to access an improved range of short break options in their own home, day care and residential settings. These options will include flexibility in terms of both timing, location, personalised telecare services and mechanisms for emergency access
  - \* all people with dementia will be able to secure quality services with the right level of care and support irrespective of their funding streams

- \* continue to improve the quality of care for people with dementia in General Hospital settings through continued support of the role of dementia champions/leads through the development of a Somerset dementia clinical champion network
- *Support for carers:*
  - \* a review of existing services for carers will take place with a view to identifying gaps, and developing and consulting on plans for improving these services
- *Intermediate care services:*
  - \* a review will be undertaken to identify options for an intermediate service that includes both “step up” and “step down” facilities and which incorporates a rapid response to people with dementia in their own home.
  - \* plans currently being developed and implemented to improve day opportunities include a varied programme for people with dementia

6.17 The main findings from the public consultation that took place on the priorities contained within the Somerset Dementia Strategy for living well with dementia was regarding care services and day care. Responders identified the need for care services to be of excellent quality and available to carers when they need it and for day care and residential services to continue the work done in the memory cafes, for example ‘singing for the brain’ classes.

6.18 Other areas identified within the engagement process were regarding information and communication. Responders thought there should be an effective mechanism for updating information that is developed, particularly across several agencies, third sector and service users and carers. In addition that there is a culture developed between agencies about sharing of information for the benefit of the patients and their carers.

6.19 Another key area identified within the feedback received was regarding support for carers and being offered regular breaks. Carers would be confident that their loved ones were being cared for in the right setting by people who were trained in the care of dementia.

## KEY PRIORITIES

### Phase One: 2009/2010

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Commissioning for quality	Produce an interim policy on commissioning for high quality in home care services	Somerset County Council

	Produce a policy on commissioning for quality for continuing healthcare	NHS Somerset
	Commissioning strategies to include requirements for achieving high quality residential and nursing care services	Somerset County Council
	Review patient pathway to ensure all people with dementia will be able to secure quality services with the right level of care and support irrespective of their funding streams.	Somerset County Council
	Information sharing protocols will be developed whereby information will be routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia.	Somerset County Council/ Provider Organisations
Support for carers	Existing services that are available to carers will be reviewed, gaps identified and recommendations made for improving services where appropriate.	Somerset County Council/NHS Somerset
Intermediate care services	A review will be undertaken to identify options for an intermediate service with view to development of an intermediate care strategy and implementation plan	NHS Somerset/ Somerset County Council
	Review current access to short breaks with a view to improving range of short break options within home, day care and residential settings.	NHS Somerset/Somerset County Council
	Extension of day opportunities to include a varied programme for people with dementia.	NHS Somerset/ Somerset County Council

### Phase Two: 2010/2011

Work programme	Planned action	Lead organisations
Commissioning for quality	Monitor performance against quality dementia requirements within provider contracts for both residential and nursing care and home care	Somerset County Council NHS Somerset
	Monitor patient pathway implementation to ensure all	Somerset County Council

	people with dementia are successfully accessing quality services with the right level of care and support irrespective of their funding streams.	
	Implement systems and processes to embed information sharing protocols ensuring information is routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia.	Somerset County Council, Provider Organisations
Support for carers	To implement plans for improving support available to carers of people with dementia.	Somerset County Council/NHS Somerset
Intermediate care services	To implement agreed actions for an intermediate service to address the needs of people with dementia.	NHS Somerset/ Somerset County Council
	To monitor the availability of short breaks and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/Somerset County Council
	To monitor enhanced day opportunities for people with dementia and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/ Somerset County Council

### Phase Three: 2011/2012

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Commissioning for quality	Continue to monitor performance against quality dementia requirements within provider contracts for residential and nursing care and home care	Somerset County Council
	Monitor implementation of protocols, systems and processes for ensuring information is routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia. Utilise user and carer feedback to inform further improvements where appropriate.	Somerset County Council/ Provider Organisations

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Support for carers	To monitor on an ongoing basis effectiveness of support available to carers of people with dementia.	Somerset County Council/NHS Somerset
Intermediate care services	To work with providers to ensure intermediate service effectively meets the needs of service users, and prevents unnecessary hospital admissions.	NHS Somerset/ Somerset County Council
	To continue to monitor the availability of short breaks and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/ Somerset County Council
	To continue to monitor enhanced day opportunities for people with dementia and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/ Somerset County Council

## **7 FRAMEWORK FOR DELIVERING THE DEMENTIA STRATEGY**

### **Workforce**

- 7.1 People with dementia and their carers need to be supported and cared for by a trained workforce, with the right knowledge, skills and understanding of dementia to offer the best quality care and support. Awareness and skills are therefore needed in all sections of the workforce and society, not just those involved with dementia care.
- 7.2 Training should also cover the principles of the Mental Capacity Act 2005 to ensure that all decisions made on behalf of people with dementia, where they lack capacity, are in the best interests and take their wishes and desires into account.
- 7.3 NHS Somerset and Somerset County Council have both developed workforce strategies to ensure that high quality and relevant workforce developments are provided to support organisational commissioning and provider functions.
- 7.4 NHS Somerset's Workforce Strategy has been developed in the context of current government policy, as outlined in the NHS Next Stage Review and in particular 'A High Quality Workforce', published alongside the main report. The Strategy also takes into account the specific workforce priorities within the Primary and Community Care Strategy and the NHS Constitution, together with those contained within the White Paper 'Our health, our care, our say'.
- 7.5 In order to ensure effective plans for the delivery of dementia services in the community and in line with the current workforce strategies, a review of future workforce requirements will be taken forward jointly by NHS Somerset and Somerset County Council.

### **Partnership Working**

- 7.6 In order to meet the changing needs and expectations of people with dementia and make best use of resources, organisations across Somerset need to work together to agree a joint approach.
- 7.7 The Somerset Dementia Strategy was developed in partnership and through wide stakeholder involvement. The Somerset Dementia Strategy Group, comprising NHS Somerset, Somerset County Council, Somerset Partnership NHS Foundation Trust, Somerset Community Health, Taunton and Somerset NHS Foundation Trust, Yeovil District Hospital NHS Foundation Trust, South West Development Centre, Alzheimer's Society, Somerset Skills and Learning and Care Focus Somerset, contributed to the development of the strategy and implementation plan. In addition links were made where appropriate with the Registered Care Providers Association and the Carers Strategy Group.

## **Governance**

- 7.8 The Somerset Dementia Strategy will be monitored through the Somerset Dementia Strategy Group. This group will report progress to the Adult Services Partnership Board, the Older Peoples Local Implementation Team and the Mental Health Local Implementation Team.
- 7.9 The Somerset Dementia Strategy Group will be responsible for implementing and monitoring the strategy, and reviewing the quality of data for specific service areas. Performance management arrangements will be put in place to ensure the strategy is achieving the planned actions specified.
- 7.10 Some examples of good practice in Somerset include:

### **Adult Services Partnership Board**

NHS Somerset and Somerset County Council have established a joint Adult Services Partnership Board to achieve a cohesive partnership approach to strategic planning and service design and the commissioning of adult services in Somerset. The Board oversees existing key planning and commissioning work-streams including dementia, ensuring that organisational objectives are aligned and partnership priorities agreed.

The Joint Strategic Needs Assessment underpins all commissioning priorities and decisions and the Board will oversee the implementation of the Somerset Dementia Strategy, with a strong performance management function.

### **Draft Dementia Learning and Development Plan**

Somerset County Council and NHS Somerset, working with key partners have developed a Draft Dementia Learning and Development Plan. The draft plan provides a comprehensive approach to improving dementia skills and knowledge across all sectors. The draft strategy focuses on:

- development programme for dementia learning needs
- roll out of learning and development
- professional development and qualifications

### **Adult Learning Disability services**

In 2002, Adult Learning Disability services set up a multi-agency working group, comprising Local Authority, Health (Adult Learning Disability and Older Adult services) and voluntary bodies (Alzheimer's Society, Age Concern, Downs Syndrome Association) to plan a strategy for people with learning disabilities and dementia. It was recognised at that time that there is an increased prevalence of dementia in this population and in particular an increased prevalence of early onset dementia in people with Downs Syndrome. Moreover, there are no population norms for cognitive functioning against which deterioration can be measured, unlike the general population, making the diagnosis of dementia complex and needing to be based on individual baseline levels of functioning and change. It was also realised that the numbers of people with learning disabilities living into old age was increasing due to improvements in health and social care, therefore increasing the numbers and proportion of people with dementia in the Adult Learning Disability population. Services needed to be prepared to work better with this growing group of people. In response to all these factors and taking national guidance into account from a variety of sources, the working group produced the Learning Disabilities and Dementia Good Practice Guide (2003), with recommendations for Somerset Adult Learning Disability services on achieving early diagnosis, assessment practices, referral pathways, continuing care issues, service and training outcomes. A five-year action plan was drawn up, covering the period 2004-2009. This plan continues to guide the service, and has been implemented as far as is possible within current resources.

### **Learning and Development**

- 7.11 Somerset Partnership NHS Foundation Trust staff provides a significant amount of training and workshops around the county for staff and carers to support increased skills for dementia.
- 7.12 To support learning and development to achieve improved care to people with dementia the following will be delivered:
- a draft dementia learning and development strategic plan has been developed to ensure:
    - \* a development programme is established for the learning leads on how to cascade information and support colleagues
    - \* roll out of learning and development which will be cascaded within care settings by learning leads
    - \* professional development and qualifications
- 7.13 The dementia learning and development strategy sets out the following commissioning intentions:

- a programme of training will be available for staff directly employed within the statutory sector. Providers, including those from the voluntary and community sector, will be given the opportunity to access the same training resources as the statutory sector and evidence will be required through performance management of contracts to demonstrate that their workforce also meets this requirement
- the statutory sector will collaborate with local further and higher education institutions to develop training opportunities that are open to directly employed and provider employed staff
- that the skills of all staff and volunteers working in generic and non-specialist areas will be enhanced to better meet the requirements of people with dementia. All staff working with older people including social workers, home carers, community matrons, care home workers, staff working on care of the elderly and general hospital wards and accident and emergency will receive more in-depth training and ongoing development tailored to their roles
- the 10 essential shared capabilities will be incorporated into pre and post registration education and training for all mental health staff
- to investigate further workforce training tools for dementia
- each provider to identify a 'Dementia Lead' for their organisation. This person will take responsibility for ensuring the workforce within their organisation has the appropriate learning and development opportunities in relation to dementia care with contact details held on a database by Care Focus to ensure up-to-date information is issued to the lead contact. Governance arrangements to be established
- all volunteers working with older people have access to specialist dementia training

7.14 People responding to the public consultation that took place on the priorities contained within the Somerset Dementia Strategy were very clear that it is essential to improve training in dementia care for all individuals who deal with dementia patients so they are treated as individuals, with interesting past lives. A comment received from one responder states: *"Gold rule could be: treat ME and all other sufferers as not just another patient. I do feel isolated by my condition. Thank you for the opportunity to voice my ideas. One of the side effects to this complaint is depression. It is the big enemy. Thank you very much for asking for my feelings and ideas it is nice to know you are there"*.

## KEY PRIORITIES

### Phase One: 2009/2010

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Workforce	Review of future workforce requirements for dementia to be developed	NHS Somerset/ Somerset County Council

Learning and development	Draft Dementia learning and development strategic plan to be developed	NHS Somerset/ Somerset County Council.
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**Phase Two: 2010/2011 & Phase Three 2011/12**

<b>Work programme</b>	<b>Planned action</b>	<b>Lead organisations</b>
Workforce	Review of future workforce requirements for dementia to be implemented	NHS Somerset/ Somerset County Council
Learning and development	Dementia learning and development strategic plan to be approved and implemented	NHS Somerset/ Somerset County Council.

## **8 IMPLEMENTATION PLAN**

- 8.1 To implement the Somerset Dementia Strategy within the next three years, there are a number of actions that need to take place within a specified timescale. Appendix 2 offers a summary of all the proposed actions that will take place from the strategy outlined above.
- 8.2 The draft Somerset Dementia Strategy went out to public consultation during the summer of 2009 to give the opportunity for people to express their opinions on the implementation of the dementia strategy in Somerset. This included key stakeholders and user/carer focus groups. One comment included: *“At last something is being done for people suffering ‘dementia’ or other serious mental problems. I wish the committee and other people involved all the best in ‘building’ on these enclosed ideas, as far too many people suffer, for far too long”*.
- 8.3 The summary of the feedback from the information and engagement process has been incorporated into the strategy and is attached at Appendix 3.
- 8.4 The outcome and feedback from the Review of Dementia Services in Somerset that took place in July 2009 has strengthened the strategy where appropriate.
- 8.5 Detailed underpinning action plans for each phase of the Strategy are being developed to ensure all the priorities identified are implemented effectively.
- 8.6 The detailed action plans will also incorporate any outstanding actions from Everybody’s Business Action Plan and the National Service Framework for Older People.

## NATIONAL DEMENTIA STRATEGY OBJECTIVES

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

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

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

All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis, sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have the capacity to see all new cases of dementia in the area.

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

Providing people with dementia and their carers with good-quality information on the illness and on the services available, both at diagnosis and throughout the course of their care.

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

A dementia adviser to facilitate easy access to appropriate care, support and advice for those diagnosed with dementia and their carers.

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

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

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

Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

### **Objective 7: Implementing the Carers' Strategy.**

Family carers are the most important resource available for people with dementia. Active work is needed to ensure that the provisions of the Carers' Strategy are available for carers of people with dementia. Carers have a right to an assessment of

their needs and can be supported through an agreed plan to support the important role they play in the care of the person with dementia. This will include good-quality, personalised breaks. Action should also be taken to strengthen support for children who are in caring roles, ensuring that their particular needs as children are protected.

**Objective 8: Improved quality of care for people with dementia in general hospitals.** Identifying leadership for dementia in general hospitals, defining the care pathway for dementia there and the commissioning of specialist liaison older people's mental health teams to work in general hospitals.

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

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

The needs of people with dementia and their carers should be included in the development of housing options, assistive technology and telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

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

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

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

People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of Health End of Life Care Strategy. Local work on the End of Life Care Strategy to consider dementia.

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

Health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

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

Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs. These commissioning plans should be informed by the World Class Commissioning guidance for dementia developed to support this Strategy and set out in Annex 1.

**Objective 15: Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers.**

Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

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

**Objective 17: Effective national and regional support for implementation of the Strategy.**

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

SUMMARY OF KEY PRIORITIES

RAISING AWARENESS AND UNDERSTANDING

PHASE	PLANNED ACTION	LEAD ORGANISATIONS
Phase 1: 2009/10	Three year Communication and Marketing Plan to be developed with the following actions being taking forward in 2009/2010 including:	NHS Somerset/ Somerset County Council.
	Development of information packs which will be updated annually and plans for distribution.	NHS Somerset/ Somerset County Council/ Alzheimer's Society
	Plans for user participation in service design	NHS Somerset/ Somerset County Council
	Identification of dementia leads/champions across relevant statutory, voluntary and independent organisations	NHS Somerset/ Somerset County Council
	Plans to raise awareness in community and primary care services including work programmes in GP practices to support increased awareness and good diagnosis.	NHS Somerset/ Somerset County Council
	Plans to raise awareness in hospital settings	NHS Somerset
Phase 2: 2010/11	To implement the communications and marketing plan	NHS Somerset/ Somerset County Council.
Phase 3: 2011/12	To continue implementation of the communications and marketing plan	NHS Somerset/ Somerset County Council.

## EARLY DIAGNOSIS AND SUPPORT

PHASE	PLANNED ACTION	LEAD ORGANISATION/S
Phase 1: 2009/10	Develop and implement detailed action plan to support delivery on World Class Commissioning dementia outcome	NHS Somerset
	Develop options and recommendations for progressing early case finding	NHS Somerset
	Review of current memory assessment services	NHS Somerset
	Review and update current dementia care pathways in line with National Strategy.	NHS Somerset/ Somerset County Council working with other key stakeholders
	Introduce a personalised care plan for all people diagnosed with Dementia	NHS Somerset/Somerset County Council
	To submit a bid to become a Dementia Demonstration site, for Dementia Care Advisers and implement the project if successful	NHS Somerset/ Somerset County Council
	To develop plans for a phased approach to the establishment of additional Memory Cafés across Somerset	Somerset County Council/NHS Somerset/Alzheimer's Society
	To widen programmes accessible to people with dementia through the Somerset Active Living Centres and identify dementia 'champions' within each Active Living Centre	Somerset County Council/NHS Somerset
	To incorporate with the care pathway, actions to ensure patients diagnosed with dementia and their carers are offered education and support as soon as possible after diagnosis, within the training and education plan	
Phase 2: 2010/11	Commission early case finding service based on options and recommendations paper	NHS Somerset
	Implement agreed recommendations resulting from the review of memory assessment services – ensuring that an equitable service is available to service users across Somerset	NHS Somerset
	Monitor implementation of revised dementia pathway	NHS Somerset/

PHASE	PLANNED ACTION	LEAD ORGANISATION/S
		Somerset County Council
	Monitor implementation of personalised care plans including user and carer feedback, and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council
	Monitor and evaluate the outcomes of the Dementia Adviser pilot (if identified as a Demonstrator site) and ensure the results inform future commissioning of the service.	NHS Somerset/ Somerset County Council
	Implement plans for a phased approach to establishing additional Memory Cafes across Somerset	NHS Somerset/ Somerset County Council/ Alzheimer's Society
	Review and monitor effectiveness of additional services offered through Active Living Centres and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council
Phase 3: 2011/12	Ongoing monitoring of numbers of cases on GP registers and early case-finding against expected prevalence	NHS Somerset
	Continue to work with provider organisations to ensuring that a high quality equitable service is available to service users across Somerset	NHS Somerset
	Ongoing monitoring of effectiveness of revised dementia pathway	NHS Somerset/ Somerset County Council
	Continued monitoring of personalised care plans including user and carer feedback, and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council
	Agree and implement future commissioning arrangements for the role of Dementia Adviser based on outcomes of Demonstrator site evaluation (if not identified as a demonstrator site, evidence from sites chosen will be used to inform future commissioning plans)	NHS Somerset/ Somerset County Council
	Continue to implement phased approach to establishment of additional Memory Cafes across Somerset	NHS Somerset/ Somerset County Council/ Alzheimer's

<b>PHASE</b>	<b>PLANNED ACTION</b>	<b>LEAD ORGANISATION/S</b>
	Continue to review and monitor effectiveness of additional services offered through Active Living Centres and put in place actions to improve where appropriate	Society NHS Somerset/ Somerset County Council

## LIVING WELL WITH DEMENTIA

PHASE	PLANNED ACTION	LEAD ORGANISATION/S
Phase 1: 2009/10	Produce an interim policy on commissioning for high quality in home care services	Somerset County Council
	Produce a policy on commissioning for quality for continuing healthcare	NHS Somerset
	Commissioning strategies to include requirements for achieving high quality residential and nursing care services	Somerset County Council
	Review patient pathway to ensure all people with dementia will be able to secure quality services with the right level of care and support irrespective of their funding streams.	Somerset County Council
	Information sharing protocols will be developed whereby information will be routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia.	Somerset County Council/Provider Organisations
	Existing services that are available to carers will be reviewed, gaps identified and recommendations made for improving services where appropriate	Somerset County Council/NHS Somerset
	A review will be undertaken to identify options for an intermediate care service with view to development of an intermediate care strategy and implementation plan	NHS Somerset/ Somerset County Council
	Review current access to short breaks with a view to improving range of short break options within home, day care and residential settings.	NHS Somerset/ Somerset County Council
	Extension of day opportunities to include a varied programme for people with dementia.	NHS Somerset/ Somerset County Council
Phase 2: 2010/11	Monitor performance against quality dementia requirements within provider contracts for residential and nursing care and home care	Somerset County Council / NHS Somerset
	Monitor patient pathway implementation to ensure all people with dementia are successfully accessing quality services with the right level of care and support irrespective of their funding streams.	Somerset County Council
	Implement systems and processes to embed information sharing protocols ensuring information is routinely shared between all partners involved in the provision of home	Somerset County Council,

PHASE	PLANNED ACTION	LEAD ORGANISATION/S
	care and housing related support services to a person with dementia.	Provider Organisations
	To implement plans for improving support and coordination available to carers of people with dementia	Somerset County Council/NHS Somerset
	To implement agreed actions for an intermediate service to address the needs of people with dementia	NHS Somerset/ Somerset County Council
	To monitor the availability of short breaks and utilise user and carer feedback to improve services where appropriate	NHS Somerset/ Somerset County Council
	To monitor enhanced day opportunities for people with dementia and utilise user and carer feedback to improve services where appropriate	NHS Somerset/ Somerset County Council
Phase 3: 2011/12	Continue to monitor performance against quality dementia requirements within provider contracts for residential and nursing care and home care	Somerset County Council
	Monitor implementation of protocols, systems and processes for ensuring information is routinely shared between all partners involved in the provision of home care and housing related support services to a person with dementia. Utilise user and carer feedback to inform further improvements where appropriate.	Somerset County Council, Provider Organisations
	To monitor on an ongoing basis effectiveness of support available to carers of people with dementia.	Somerset County Council/NHS Somerset
	To work with providers to ensure intermediate service effectively meets the needs of service users, and prevents unnecessary hospital admissions.	NHS Somerset/ Somerset County Council
	To continue to monitor the availability of short breaks and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/Somerset County Council
	To continue to monitor enhanced day opportunities for people with dementia and utilise user and carer feedback to improve services where appropriate.	NHS Somerset/ Somerset County Council
	Continue to review and monitor effectiveness of additional services offered through Active Living Centres and put in place actions to improve where appropriate	NHS Somerset/ Somerset County Council

## FRAMEWORK FOR DELIVERING THE DEMENTIA STRATEGY

PHASE	PLANNED ACTION	LEAD ORGANISATION/S
Phase 1: 2009/10	Review of future workforce requirements for dementia to be developed	NHS Somerset/ Somerset County Council.
	Draft Dementia learning and development strategic plan to be developed	NHS Somerset/ Somerset County Council.
Phase 2: 2010/11 and Phase 3: 2011/12	Review of future workforce requirements for dementia to be implemented	NHS Somerset/ Somerset County Council.
	Dementia learning and development strategic plan to be approved and implemented	NHS Somerset/ Somerset County Council.

## SUMMARY OF THE FEEDBACK FROM THE INFORMATION AND ENGAGEMENT PROCESS

### 1 INTRODUCTION

- 1.1 This summary report shows the main themes which came out of the process and feedback NHS Somerset used to seek the views of people with dementia, their relatives, carers, members of the public, healthcare professionals and key stakeholder organisations on improving Dementia Services in Somerset. The feedback focussed on the priorities described in the draft Somerset Dementia Strategy. The engagement process took place over six weeks between the 24 August and 12 October 2009.

### 2 SOMERSET DEMENTIA STRATEGY

- 2.1 The Somerset Dementia Strategy aims to provide a framework to implement improved, responsive and quality services for people with dementia and their carers across Somerset and improve health related outcomes. The strategy is a partnership approach to ensure that a seamless service is provided. The implementation of this strategy will be phased in over the next three years as it is recognised that within Somerset, dementia is a key priority for all agencies concerned.
- 2.2 The Somerset Dementia Strategy is a joint venture between NHS Somerset, Somerset County Council and other organisations.
- 2.3 The Somerset Dementia Strategy information and engagement process aimed to find out the views of people on the three main priority areas in the draft Somerset Dementia Strategy:
- raising awareness and understanding
  - early diagnosis and support
  - living well with dementia

### 3 MAIN THEMES

- 3.1 The Main themes which came out of the community engagement process are detailed below.

#### **Information and Communication**

- 3.2 That information should be available on any service provision, where to go to get help, and support for patients and their carers when they need it. The information should be clear and easy to follow.

- 3.3 There should be an effective mechanism for updating information that is developed, particularly across several agencies, third sector and service users and carers.
- 3.4 That there is a culture developed between agencies about sharing of information for the benefit of the patients and their carers.

### **Support for Carers**

- 3.5 This was seen as an essential priority for carers to receive support on an ongoing basis from the very start of the diagnosis.
- 3.6 This would mean being offered regular breaks and carers feel confident that their loved ones were being cared for in the right setting by people who were trained in the care of dementia.

### **Education**

- 3.7 For all healthcare staff, carers, carer support workers and anyone dealing with patients who have dementia to be trained in dementia care.
- 3.8 For any assessments on patients either to be diagnosed with dementia, or patients who have a diagnosis, to be completed by correctly trained staff at the right time and carried out on a regular basis.

### **Care Services**

- 3.9 There needs to be care services which are of excellent quality and available to carers when they need it.
- 3.10 For day care and residential services to continue the work done in the memory cafe's, for example "singing for the brain" classes.

### **General Practitioners**

- 3.11 For General Practitioners to be trained in raising the awareness of dementia. This will then mean that an early diagnosis is made and the appropriate treatment and support offered.
- 3.12 It was also suggested that General Practitioners contact the family to ensure they are aware of everything that is available to them to help the patient and their family.
- 3.13 Responders were also keen for General Practitioners to use their register of dementia patients.
- 3.14 There was a request that patients should be followed up on a regular basis not just on the basis of the underlying dementia but to do a thorough health assessment to pick up any other underlying medical conditions.

## **4 RESPONSE TO FINDINGS**

- 4.1 Feedback of the engagement process has been compiled by the Patient and Public Involvement Lead and the Patient Experience Team. The draft report has been checked by the NSF Development Manager and the Deputy Director of Strategic Development.
- 4.2 The initial findings from the engagement process have been presented at the Somerset Dementia Strategy Group, Older Peoples Local Implementation Team, Mental Health Local Implementation Team and the Adult Services Partnership Board.
- 4.3 The report has been revised to reflect the feedback received from these groups where appropriate.

## **5 NEXT STEPS**

- 5.1 The key themes from the feedback report will be incorporated into the Somerset Dementia Strategy.
- 5.2 There are action plans being developed for four work streams to deliver the Somerset Dementia Strategy. They are:
- Raising Awareness and Understanding
  - Early Diagnosis and Support
  - Living Well with Dementia
  - Workforce and Training
- 5.3 A follow up event will be planned in eighteen months time to review the progress of the Somerset Dementia Strategy.