Torbay NHS
Care Trust

TORBAY CARE TRUST

DEMENTIA STRATEGY

2009-2012

"We can no longer ignore dementia, or pretend that is an inevitable part of the aging process. A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society"

(Department of Health, 2008)"

December 09

Torbay Dementia Strategy

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1.0 FORWARD

"We can no longer ignore dementia, or pretend that is an inevitable part of the aging process. A strategic, cross-cutting approach is vital if we are to deal with the challenges and consequences of dementia as a society" (Department of Health, 2008)"

"Dementia is a condition that imposes a good deal of distress on those who are living with it and for their families. It is especially important for us here in Torbay because we have a large and growing population of older people. Much can be done. Early assessment followed by support and care for carers, care in hospital settings and care in residential and nursing homes all requires development.

We are fortunate in Torbay in having good local services and some fantastic commitment from the voluntary sector. We have a large task ahead, but the National Strategy clearly sets out the direction we should take. We welcome this and are committed to improving our local services. Some of our first steps are set out in this strategy; the task will take effort and resources over a sustained period to provide to the standards which vulnerable people and their carers have every right to expect."

Acting Chief Executive,
Torbay Care Trust

2.0 Executive Summary

2.1 Recent reports and research have highlighted the shortcomings in the current provision of dementia services in the UK. Dementia presents a huge challenge for Torbay now and even more so in the future due to our higher than the national average elderly population. It is anticipated that the local incidence of dementia will increase from 2,929 in 2010 to 4,930 in 2030. Torbay Care Trust currently spends £10,312,000 on mental health services for older people. Research suggest that costs will treble over the next 30 years

2.2 Whilst the numbers and costs are daunting, the impact on those with the illness and their families is overwhelming. Dementia is a progressive disease, resulting in a decline in memory and reasoning functioning, communication skills and skills need to carry out activities of daily living. The needs of such individuals are complex and often can not be provided by one agency alone.

2.3 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 living with dementia and should promote a greater understanding of the consequences of dementia.

2.4 This strategy has been developed following extensive consultation with users, carers and other key stakeholders. The strategy builds on the National Dementia Strategy: Living Well with dementia (DoH 2009) and the findings of the Strategic Health Authority Peer Review (summer 09).

2.5 The Torbay Dementia Strategy aims to provide a framework to implement improved responsiveness and quality services for people living with dementia and their carers across Torbay and improved health outcomes. The implementation of this strategy will be phased over the next 3 years as it is recognised that within Torbay, dementia is a key priority for improvement.

2.6 The focus of the Torbay Dementia Strategy is:

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

2.7 This strategy will be a catalyst for change in the way people living with dementia are viewed and cared for within Torbay. 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

3.0 INTRODUCTION

Impact of dementia

3.1 It is estimated that currently there are 700,000 people living with dementia in England 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 per year, with the costs in the next 30 years rising to £50 billion a year. In cost of illness studies, the direct costs of Alzheimer's disease alone exceed the combined cost of stroke, cancer and heart disease. In addition the prevalence of dementia is linked to increasing age (Everybody's Business). The number of people aged over 65 will increase by 15% and the number of people over the age of 85 will increase by 27% hence, as the number of older people in the population continues to rise, it is likely that the future costs of dementia care will increase considerably.

3.2 All types of dementia are progressive, involving physical and mental deterioration, usually over the course of several years, and culminate in the person's death, either directly or indirectly.

3.3 Few would dispute that any form of dementia can be deeply distressing for both the person living with the condition as well as their family and friends. However, it is also clear that there is a vast amount that can be done to improve and maintain quality of life in dementia.

Definition of dementia

3.4 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.

3.5 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.

3.6 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

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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

3.8 Dementia is a terminal disorder, although people may live with their dementia for 7 – 12 years after diagnosis.

The National Dementia Strategy – Living well with dementia

3.9 The first national dementia strategy was published in February 2009 – Living well with dementia – A National Dementia Strategy, (Department of Health). The National Dementia Strategy identified 17 key objectives (Appendix 1) which when implemented will result in significant improvements in the quality of services provided to people living with dementia and their carers and should promote a greater understanding of the consequences of dementia.

3.10 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 meets their changing needs over time

Torbay Dementia Strategy

3.11 The Torbay Dementia Strategy aims to provide a framework to implement the Nation Dementia Strategy and to implement improved, responsive and quality service, improved health and well being related outcomes, for people living with dementia and their carers across Torbay. The strategy has been developed following extensive consultation with people living with dementia, carers and other key stakeholders (Torbay care trust, Devon Partnership Trust, Aged Concern, Alzheimer's Society, Independent Providers) and been informed by the Strategic Health Authority Peer review which took place on the 30th June and 1st July 2009.

3.12 The focus of the Torbay Dementia Strategy is:

- To raise awareness and understanding of dementia with the general public
- To ensure there is early diagnosis, support and intervention for people living with dementia and their carers
- To provide a higher quality of care to enable people to live well with dementia
- To ensure appropriate support is available for carers
- To implement the National Dementia Strategy

Purpose of the Torbay Dementia Strategy

3.13 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.

3.14 This strategy will be a catalyst for change in the way that people living with dementia are viewed and cared for within Torbay. The implementation of this strategy will ensure that people living with dementia and their carers are supported throughout and receive the highest possible standard of care resulting in improved health outcomes and quality of life. We acknowledge this can only be achieved by transcending existing boundaries and partnership working between statutory providers, commissioners, the third sector and users and carers.

The Torbay vision

3.15 The vision in Torbay 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

3.16 Full implementation of the Torbay 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.

3.17 The Torbay 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

4.0 Key Drivers

4.1 With the publication of Forget me not, the Audit Commission's report on older people's mental health services (Audit Commission, 2000) and the National Service Framework for Older People (Department of Health, 2001) dementia began to become a priority for public policy in the UK. More recently the profile has risen significantly in both media and policy terms, particularly as a result of the publication of several key reports and guidance, including:

- Everybody's Business, (DoH 2005)
- Forget me not (Audit Commission 2002)
- Sainsbury Centre for Mental Health reviewed older people's mental health services in Devon and Torbay (2005)
- Twilight period (J. Delves 2002)
- Death by Indifference (DoH 2007)
- Supporting people with dementia and their carers (National Institute for Health and Clinical Excellence and the Social Care Institute for Excellence, 2006)
- NICE guidance
- Dementia UK (Alzheimer's Society, 2007a)
- Improving services and support for people with dementia (National Audit Office,2207)
- Home from home (Alzheimer's Society, 2007b)
- See me, not just the dementia (Commission for Social Care Inspection, 2008)
- Always a last resort (All Party Group on Dementia, 2008)
- Dementia – Out of the shadows (Alzheimer's Society, 2008)
- Living well with dementia: A national Dementia Strategy (DH 2009)

4.2 Messages from the above give consistent messages which includes the increasing challenge that dementia poses to health and social services because of the rising number of people affected, the importance of overcoming existing obstacles to early diagnosis and intervention, and the need to improve the consistency and quality of care and support for people with dementia and their carers.

4.3 In February 2009 the DoH published the first Nation strategy – Living well with dementia: A National Dementia Strategy. The strategy contains three key themes:

- Improving public and professional awareness of dementia
- Better early diagnosis and intervention
- Ensuring high care and support.

4.4 Few people who are involved in the field of dementia would challenge the importance of these objectives. Torbay Care Trust's dementia strategy build on these aims and expand how they will be implemented in such a way at a local level to ensure we really make a difference to those with dementia and their families who live in Torbay.

4.5 The NDS sets out a wide range of services that should be available to every person with dementia and their carers. The recommended services are based on:

- Evidence-based interventions
- Services that people living with dementia and their carers told us during the NDS consultation
- Recommendations form the SHA Peer review

5.0 National and Local Context

Background information

5.1 Torbay is a seaside resort area in a beautiful part of Devon. It has a population of approximately 140,000 which is growing due to inward migration. The forecasts are that the growth will continue at a rate of 1,200 each year. Torbay is made up of three towns; Torquay, Paignton and Brixham, Torquay is the largest with a population of around 64,000, Paignton has a population of around 49,000 and Brixham is far smaller with just under 18,000. Torbay is a popular place for retirement therefore accelerating the rate of increase of the older population constantly. There is also a high incidence of "fragmented families" – i.e. following the loss of a partner the individual is left living alone with family members living out of the area.

5.2 According to the 2001 census figures, Torbay has 28.6% of it population over the age of 60yrs, this compares with a national average for England and Wales of 20.9%. This means that there are approximately 37,900 people over the age of 60 yrs living in Torbay.

5.3 Torbay Key Facts:

- Torbay covers an areas of just 64 square Kilometers (25 square miles)
- Torbay has approximately 45 Kilometers (27 miles) of coast line with 20 public beaches
- The average age of residents in Torbay is 43.7 years; higher than the England & Wales average of 39.2
- Over 15,000 of Torbay's resident population live with an area in the top 10% most deprived in England
- Torbay resident population has a higher prevalence of alcohol related deaths compared to the England & Wales. This may suggest a higher rate of people with alcohol-related dementia in the future.
- Torbay is the 10th most populated authority in the South West while at the same time being the 8th smallest in area.

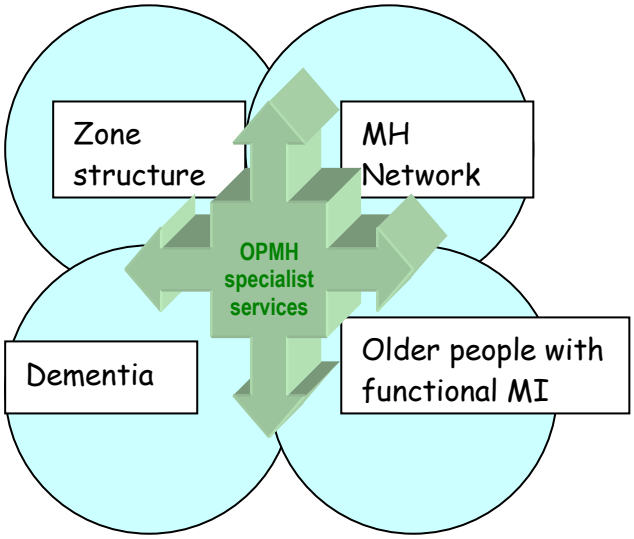
5.4 Torbay Care Trust delivers both social care and health services across a geographic area that is divided into 5 zoned area teams. The teams are multi-disciplinary and are based on GP surgeries in Torquay (north and south), Paignton (north and south) and Brixham.

5.5 Adult mental health services are provided by MH Networks: mental health networks have been developed and provide services with three component functions:

Wellbeing and access
Urgent care
Recovery and independent living

5.6 OPMH specialist services (integrated health and social care team), deliver and support services for two main categories of older people and their carers, dementia (organic) & functional mental health problems, recognising that people do not necessarily fit these categories neatly and that flexibility (an aim for both networks & zones) will be required to meet individuals' needs.

5.7 Older people with mental health problems have complex needs which can only be met by Specialist Older people's mental health teams and generic health and social care teams. TCT aims to develop stronger links between generic zone teams by co-locating OPMH team members, the zone teams and primary care. A specialist hub will be retained at Chadwell.



National context

5.8 Dementia is one of the most severe and devastating disorder we can face. It is also very common. Key data illustrate the impact of dementia as follows:

- There are approximately 700,000 people with dementia in England
- In just 30 years, the number of people with dementia is expected to double to 1.4 million
- The national cost of dementia is about £17 billion per year
- In the same 30 years, the cost will treble to over £50 billion per year
- Dementia is predominantly a disorder of later life, but there are at least 15,000 people under the age of 65 who have the illness
- Its incidence and prevalence rise exponentially with age
- It affects men and women in all social groups
- People from all ethnic groups are affected by dementia
- The level of UK diagnosis and treatment of people with dementia is generally low, with a 24-fold variation in activity between highest and lowest activity by PCT
- Care home placements for people with dementia costs the UK £& billion per year with two-thirds paid by social services and one-third by older people and their families
- Nationally there are over 500,00 family members who care for people with dementia which constitutes over £6 billion a year of unpaid care.

- International comparisons suggest that the UK is in the bottom third of European performance in terms of diagnosis and treatment, with less than half the activity of France, Sweden, Ireland and Spain

Local context

5.9 The Torbay GP registered population for Torbay, as at October 08, was 145,686. As incidence of dementia is directly related to the age profile of the population it is vital we consider the age profile of the zone in order to ensure services are developed to meet the need of the local zone population

5.10 The table below demonstrates the projected number of people aged 65+ with dementia in 2008 geographically across Torbay. The table illustrates that *26.3%* of the population in Brixham is over 65 where as in South Torquay *16.7%* of the population is over 65.

Zone	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
Total Pop	21,796	25,386	26,341	25,975	46,188	145,686
Pop aged 65+	5,732	5,678	5,874	5,580	7,709	30,573
Pop aged 40 to 64	8,039	8,820	9,118	9,148	15,807	50,932
Pop aged 65 to 69	1,615	1,470	1,398	1,444	2,155	8,082
Pop aged 70 to 74	1,358	1,255	1,308	1,324	1,788	7,033
Pop aged 75 to 79	1,067	1,121	1,138	1,114	1,408	5,848
Pop aged 80 to 84	866	897	1,012	832	1,177	4,784
Pop aged 85+	826	935	1,018	866	1,181	4,826

Zone	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
Total Pop	21,796	25,386	26,341	25,975	46,188	145,686
Pop aged 65+	26.3%	22.4%	22.3%	21.5%	16.7%	21.0%
Pop aged 40 to 64	36.9%	34.7%	34.6%	35.2%	34.2%	35.0%
Pop aged 65 to 69	7.4%	5.8%	5.3%	5.6%	4.7%	5.5%
Pop aged 70 to 74	6.2%	4.9%	5.0%	5.1%	3.9%	4.8%
Pop aged 75 to 79	4.9%	4.4%	4.3%	4.3%	3.0%	4.0%
Pop aged 80 to 84	4.0%	3.5%	3.8%	3.2%	2.5%	3.3%
Pop aged 85+	3.8%	3.7%	3.9%	3.3%	2.6%	3.3%

5.11 Zone population – April 2008

FEMALES	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
65 to 69	799	754	727	748	1,092	4,120
70 to 74	714	675	695	691	927	3,702
75 to 79	556	637	633	599	795	3,220
80 to 84	537	569	616	526	703	2,951
85+	567	651	716	612	821	3,367

MALES	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
65 to 69	816	716	671	696	1,063	3,962
70 to 74	644	580	613	633	861	3,331
75 to 79	511	484	505	515	613	2,628
80 to 84	329	328	396	306	474	1,833
85+	259	284	302	254	360	1,459

5.12 Estimated local prevalence

The following prevalence rates have been applied to estimate local prevalence data (source: POPPI):

Estimated Prevalence (%)	**Female**	**Male**
65-69	1	1.5
70-74	2.4	3.1
75-79	6.5	5.1
80-84	13.3	10.2
85+	25.2	19.7

5.13 The table below was produced by applying ONS sub national population by Sex and quinary age groups for 20008

Estimated Zonal Prevalence

FEMALES	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
65 to 69	8	8	7	7	11	41
70 to 74	17	16	17	17	22	89
75 to 79	36	41	41	39	52	209
80 to 84	71	76	82	70	93	392
85+	143	164	180	154	207	848
TOTAL	276	305	327	287	385	1,580

MALES	Brixham	North Paignton	North Torquay	South Paignton	South Torquay	Grand Total
65 to 69	12	11	10	10	16	59
70 to 74	20	18	19	20	27	103
75 to 79	26	25	26	26	31	134
80 to 84	34	33	40	31	48	187
85+	51	56	59	50	71	287

TOTAL	143	143	155	138	193	771
Overall Total	418	448	482	425	578	2,351

5.14 The above table suggests that as at April 2008 we should have expected there to be **2351** people living in Torbay with a diagnosis of dementia. However data from Torbay GP Dementia register identified **853** people with dementia (Quality Outcome Framework 06/07).

5.15 It is estimated that within Torbay only 36% of "true" dementia cases are recorded on practice registers. This means that approximately two thirds of dementia cases are undiagnosed.

5.16 Expected incidence of dementia in Torbay over the next 30 years:

Age Group	Prevalence	2008 Practice based profile of need	2007 MYE based profile of need	2010	2015	2020	2030
				2006 Based, 2008 Sub National Population Projections			
40 to 64	1 in 1,000	51	46	48	48	48	50
65 to 69	1 in 50	162	157	176	208	192	240
70 to 74	1 in 20	352	338	370	420	500	505
75 to 79	1 in 20	292	293	295	340	390	435
80 to 84	1 in 5	957	959	960	1,000	1,180	1,680
85+	1 in 5	965	1,036	1,080	1,180	1,340	2,020
TOTAL				**2,929**	**3,196**	**3,650**	**4,930**

The table above show the incidence of dementia is anticipated to more than double by 2030.
The table was produced by applying projected increases form ONS sub national population projections by sex and quinary age groups for 2010, 2015, 2020, 2030 (source: POPPI) to Mid-2007 Population Estimates for 2007 zones in England and Wales (Source ONS). Prevalence rates have been applied as described in 5.12

5.16 These zone level projections do not include projections for people with early onset dementia and people with a learning disability.

5.17 It has been reported that the learning disability community can experience a prevalence of approximately 4% above the general population. (Cooper 1997) with those who have Down 's syndrome at particular risk of developing dementia:

- 30-39 years 2%
- 40-49 years 9.4%
- 50-59 years 36.1%
- 60-69 years 54.5%

(Currently there are approximately 570 people with a known learning disability in Torbay)

6.0 Existing services, resources and benchmarking data

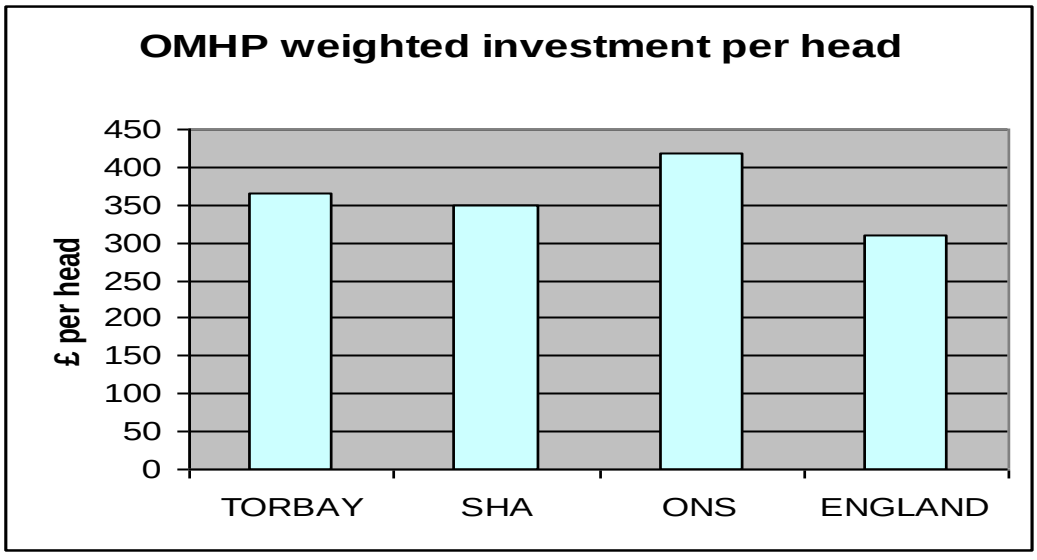
Financial data

6.1 For the first time in 2005, the Department of Health supported service financial mapping for specialist older people's mental health services. It has proved invaluable for local providers and commissioners to benchmark local services against national provision.

6.2 The 07/08 service and financial mapping information, along with local data, will be used to map current services and to ascertain current spend. However the data shown is for the spend on OPMH services and not just dementia services.

6.3 Overview of OPMHS investment

SERVICE CATEGORY	TORBAY	TORBAY	This SHA	THIS ONS	ENGLISH LITs
Direct Costs	£9,597	93%	85%	86%	83%
Indirect costs	£450	4%	6%	6%	7%
Overheads	£71	1%	7%	6%	8%
Capital Charge	£194	2%	3%	2%	3%
Total OPMHS	**£10,312,000**				

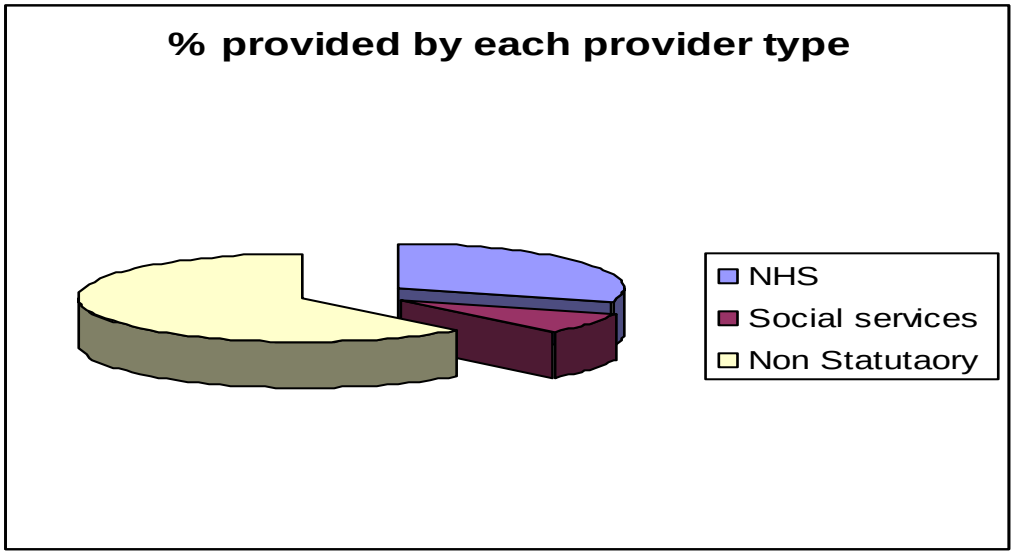


Torbay weighted investment in OPMH services per head - £365 (£15 per than the SHA average)

6.4 Torbay Investment in older people mental health services 07-08 (health and social care)

Breakdown of spend (direct costs):

SPECIALIST SERVICE	EXPENDITURE
Specialist OPMH (health and social care)	£5,264,000
Day care services	£229,000
Home care	£94,000
Residential care	£3,727,000
Special housing	£141,000
Special groups (e.g. LD)	£142,000
TOTAL SPEND	**£9,597,000**



6.5 Of the total annual spend 30% within the NHS, 8% social services and 62% within the independent/third sector.

Existing services

6.6 Health and social care services for people with dementia and their carers are commissioned by Torbay Care Trust.

6.6 **Specialist Older Mental Health Team.** Torbay has a community health and a social care team for Older People with mental health problems (CMHT) which are currently co-located under a single integrated manager. The "team" includes community psychiatric nurses, occupational therapists, consultant psychiatrists, administration staff, community support workers, psychologists (all employed by DPT) and social workers, admin staff,

community support staff (employed by TCT) and AMHP's (employed by TCT). CMHT 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. The total staffing is 11.47 wte per 10,000 populations.

6.7 **Acute inpatient facilities**
(Fernworthy closed for refurbishment)

AREA	NAME	LOCATION	TYPE	SITE	OWNER	BEDS	BEDS PER 1000 65+ POP
Torbay	Harbourne	Totnes	Organic	Totnes	DPCT	10	0.62 (Devon 1.11)

6.8 Statistics below are for 06/07 rather than 07/08 as Fernworthy is currently suspended due to refurbishment.

- Admissions per 1000 population over 65yrs for Fernworthy = 4.2 (Compared to a DPT average of 6.9)(05-06)
- 18% were admitted as formal patients (detained under the Mental health Act) and 82% as informal patients (Compared to DPT average of 7% patients admitted as formal patients)
- Inpatient budget per 1000 population over 65years = £27,903 (Compared with Devon average of £44,513)
- Average bed occupancy of Fernworthy = 70% (DPT average = 78%)
- Average length of stay 39 days (DPT average = 42)
- Fernworthy audit on a weekly basis delayed discharges – the most common reason for delay, currently, is "awaiting a nursing home placement"
- Fernworthy is a mixed unit for older people with functional and organic mental health problems

6.9 Older People's mental health inpatient services are currently under review. The review is taking place under the auspices of the OPMH PEG (Professional Expert Group). This strategy will incorporate and implement the findings of the review. However the strategic context recommended in this strategy includes:

- Rebalancing OPMH service resources from hospital to integrated community based services, with more comprehensive service provision across the whole pathway, improving home based supports and services for carers.
- Needs led and not age determined services
- Providing separate inpatient facilities for older people with organic and functional mental health needs
- Average bed occupancies of 85%
- Ensuring sound governance, training and support for inpatient staff

- Appropriate facilities to ensure privacy and dignity for male and female patients
- Given age related physical facilities, sufficient staff for assistance with personal care.

Memory Clinic Services/early intervention

6.10 The CMHT has been offering a Memory clinic service in Torbay for nearly 20 years. However having recognized that it does not have the capacity to see and diagnose all Torbay clients TCT invested an extra £44,000 in 2009/2010 to double the capacity of the current service. This will be rolled out from the January 2010.

Residential care/nursing home

6.11 There is a higher that average number of residential and Nursing home beds in Torbay. There are three Nursing homes which specialize in complex mental health and dementia, and many dementia specialist residential homes. In addition to these it is recognized that most physical Nursing homes and residential care homes care for a significant number of residents who have a dementia

Intermediate Care unit

6.12 This compliments other community based intermediate care resources in Torbay. It is currently able to provide 8 residential beds. The service provides assessment and intensive reablement.

Carer support workers

6.13 The CMHT has a part time carer's support worker, offering carers assessments and support groups.

Memory Café

6.14 Established 5 years ago, and after a slow start, the memory café, run in Paignton by the Alzheimer's Society has gone from strength to strength. It currently meets weekly and welcomes up to about 50 people each time. TCT is very pleased to be working with the Department of Health and the Alzheimer's Society as a National Dementia Strategy Demonstrator site to extend the current provision over the next two years.

Community Team for Adults with Learning Disabilities

6.15 The Community Team for Adults with Learning Disabilities works closely with the CMHT for older people to support individuals with learning difficulties who are suffering from dementia

Zone health and social care teams

6.16 In Torbay the district nurses, generic adult care social workers, occupational therapists and physiotherapists sit together in 'zone teams'. These teams are

geographically based across the bay and are linked with particular GP practices. It is recognized that the vast majority of people with dementia and their carers will not be directly in touch with specialist services for most of the time they have the illness. These people are supported by their GP's and by the zone teams if required.

World Class Commissioning

6.17 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 aspiration for Torbay i.e.:

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

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7.0 Development of Torbay's dementia strategy

7.1 This strategy has been developed following extensive consultation on local services and the draft national Strategy, during the summer of 08 (see appendix 3). It has been based on the World Class Commissioning guidance.

7.2 The information gathered during the local consultation has been used to underpin this strategy and has informed our priorities for development 2009-10.

7.3 Local consultation identified there were already areas of good practice undertaken in Torbay, but there were areas for further development.

7.4 The Torbay Older People's Mental Health Local Implementation Group has become a time limited dementia implementation task and finish group. The group is chaired by TCT Acting Chief Executive. Representation includes Primary Care, Independent providers, voluntary sector, mental health professionals, zone manager, users and carers, acute trust and commissioners. (See appendix 2)

7.5 The OPMH LIG has systematically worked through the recommendations in the National Dementia Strategy (2009 DoH) and the SHA peer review (summer 09) and have mapped current provision against the recommendations. Areas for development have been identified.

7.6 This strategy highlights areas for development and investment for 09/10. Resources were secured for developments 09/10 and the improvements are being implemented.

7.7 Specific work regarding support for people who have a learning disability and dementia is planned, implemented and monitored via the Learning Disability Programme Board at Devon Partnership trust. This forms part of the Health plan monitored via Torbay's Learning Disability Partnership Board.

8.0 Raising Awareness and Understanding

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

(Living well with dementia: A National Dementia Strategy (DoH 2009)

8.1 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.

8.2 There is also a widespread mis-attribution of symptoms of "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.

Local examples of good practice

8.3 Some examples of good practice in Torbay include:

Raising awareness and understanding

- **Integration of OPMHT with in zone teams,** will bring expertise on dementia to influence and support primary care and generic services at a local level
- **Dementia consultation process,** variety of public events and post card survey
- **Memory Cafes** introduced to raise awareness, open to the public and offering initial support, advice, information and signposting for people who are concerned with memory problems and their carers. Professional expertise available. Café currently runs on a weekly basis, demand is high for this service. The memory café also facilitates peer support.
- **Older people's board** – dementia awareness raising through involvement in the consultation phase of the National Dementia Strategy
- **Open dementia consultation** events led by CSIP, and support for the SW CSIP OPMH Collaborative
- **Whole Systems Training initiatives** across statutory, independent and voluntary sectors – i.e., for the Mental Capacity Act, and Safeguarding Adults as two examples.
- **Dementia information packs -** production and distribution of a comprehensive information pack produced by the Local Alzheimer's Society with statutory sector support. (Launched March 09)

Achieving Improved Awareness amongst the Public, Service Users and Carers

8.4 To achieve improved awareness amongst the public, Service Users and Carers the following will be delivered:

- We will develop and implement a local campaign to raise awareness, involving all partners and make full use of variety of media
- We will involve public health/health promotion expertise on an alcohol/dementia campaign
- We will continue to the support the Dementia Care Pathways booklet and ensure the distribution of packs to a wide range of locations including GP practices, pharmacies, libraries, community centers, zone teams, memory clinic and memory cafes. The information will be updated on a regular basis
- We will ensure information is accessible for those living with a learning disability, sensory loss, physical disability or from a Black and Minority Ethnic group.

Achieving Improved Awareness amongst Professionals

8.5 To achieve improved awareness amongst professionals the following actions will be delivered across Torbay:

- OPMH staff will work with GP practices to increase the awareness and knowledge of dementia within primary care
- We will use existing communication channels to raise awareness e.g. TCT newsletter, Local Medical Council newsletters.
- We will identify a local GP who will act as dementia Champion.
- We will develop raising awareness initiatives using emerging integrated team and zones as hub for local activities to promote and implement the national strategy.
- Ensure an appropriate assessment tool is used to identify those with a learning disability and dementia at the Annual Health check for those with a learning disability.

Key Priorities to achieve objective 1

Areas for development	Actions	Lead	Timescale
- Develop and implement local campaign to raise awareness. Involve all partners and make full use of variety of media.	OPMH staff to work with surgeries to increase awareness	Joanna Wildgoose	12 months
- Involvement of public health/health promotion expertise on an alcohol/dementia prevention campaign.	Develop public awareness and staff training strategy	Ann Redmayne	12 months
- Finalise local dementia commissioning strategy and formal validation process	Present to SMT, TCT Board, PEC, OSC	Ann Redmayne	Dec 09
- Ensure information is available in accessible formats	Ensure information is available in accessible formats	Ann Redmayne	Feb 10

9.0 Early Diagnosis and Support

Good-quality early diagnosis and intervention for all

Objective 2: Good-quality early diagnosis and intervention for all
(Living well with dementia: A National Dementia Strategy (DoH 2009)

9.1 Nationally only one third of people with dementia receive a formal diagnosis at any time in their illness. For some people 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

9.2 Early diagnosis and intervention can improve quality of life and delay or prevent unnecessary admissions into care homes

9.3 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

9.4 Evidence suggests that a local memory café service can provide a point of contact for people with dementia and their carers; they can provide information and advice about dementia and help to signpost them to specialist help and support. A memory café service can complement existing health and social care supports that people with dementia already receive and facilitate peer support.

9.5 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

Local examples of good practice

9.6 Some examples of good practice in Torbay include:

Examples of local good practice:

- **Integrated zones teams**, with the inclusion of Older People's Mental Health teams into the generic health and social care zone structure, will bring improvements through case finding, promoting independence and care pathways with operational arrangements for effective interfaces between primary care, specialist and generic services for right interventions through the progression of need.

- **Links –**there are currently good established links and relationships with the OPMH team and primary care.
- **Liaison –** established links with community hospitals
- **Memory Clinics** (with EDI functions) already in operation in Torbay, but needs to be reviewed in light national guidelines
- **Memory Service functions** delivered across Torbay by CMHS(OP)s, with other specialist staff (Psychiatrists and Clinical Psychologists)
- **'Fast Track Re-entry'** systems in CMHS(OP)s were thought to be good, however the dementia strategy consultation have brought the effectiveness into question and carers have indicated there is a lack of 'continuity of care'
- **Information –** Comprehensive information pack has been developed in partnership with the third sector. (Launched March 09)
- **Carer support worker** - DPT employ a dedicated carer support worker for carers of older people with mental health problems
- **Care Pathway** – Care pathway has been agreed (See appendix 1)

Achieving Improved Early Diagnosis and Support Services

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

- *Early diagnosis and case-finding:*
  - monitor actively the % of general practitioner registered patients with dementia diagnosis (Quality outcomes Framework).
  - Promote and monitor general practitioner uptake of awareness training offered
  - Improve case finding within Community Learning Disability Service and identify services to meet the needs of ensuring linkage to an integrated dementia pathway
- *Memory and assessment services:*
  - Commissions to lead work to establish a clear service specification for memory service, with defined outcomes and capacity to meet the need

Key priorities to achieve objective 2

Areas for development	Actions	Lead	Timescale
- Need to monitor actively the % of general practitioner registered patients with dementia diagnosis.	OPMH team to work closely with surgeries to ensure registers are accurate	Jane Batstone	12 months
- Promote and monitor general practitioner uptake of awareness training offered.	Link to training plan in Objective 1	Ann Redmayne	12 months
- Commissioners to lead work to	Write service spec based on	AR,DS,CW,JH	By Feb10

establish clear service specification for memory service, with defined outcomes and capacity.	EDI PIG and local need data. Commission expanded EDI service		
- Improve case finding within the Community Learning Disability Service and identify services to meet needs ensuring linkage to an integrated dementia pathway.	LIG to seek input from LD service and request they nominate a dementia champion (letter from AR to consultant & service manager).	AR/Nikki Henderson	By Feb 10

9.10 **Good quality information for those with diagnosed dementia and their carer**

Objective 3: Good-quality information for those with diagnosed dementia and their carer
(Living well with dementia: A National Dementia Strategy (DoH 2009)

9.11 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

Local examples of good practice

- **Dementia Care pathway booklet** for carers
- Devon Partnership Trust run **post-diagnosis groups** from the memory clinic
- **"One Stop Shop"**
- **Carer's education group**

Achieving good-quality information for those with diagnosed dementia and their carer

9.12 To achieved improved good-quality information for those with diagnosed dementia and their carer will be delivered:

- Commissioners will work with partners in health and Social Care and the third sector to monitor information available with view of improving access for *all* including those living with a learning disability, sensory difficulties or those from a Black and Ethnic Minority (BME) group
- We will commission a programme of audits to evaluate effectiveness of the information accessed by people with dementia

Key Priorities to achieve objective 3

Areas for development	Actions	Lead	Timescale
- Commissioners to work with partners in Health & Social Care and third sector to monitor information available with view to improving access	Review what is available	SLL & David Mannion	6 months
- .Undertake programme of audits to evaluate effectiveness of the information accessed by people with dementia.	Audit department	AR	6 months

9.13 Enabling easy access to care, support and advice following diagnosis

Objective 4: Enabling easy access to care, support and advice following diagnosis
(Living well with dementia: A National Dementia Strategy (DoH 2009)

9.14 One of the most clear and consistent messages emerging from discussions with people with dementia and their carers has been the desire for there to be someone who they can approach for help and advice at *any* stage of the illness. Currently health and social care services normally discharge individuals once the case is stable.

9.15 The National Dementia Strategy suggests that this support needs to be provided without removing health and social care professionals from the front line. However there is a lack of good-quality evidence to support the range of models that exist nationally. The Department of Health demonstrator sites have been established to identify best practice. Torbay Care Trust will use the learning to commission a Dementia Advisor Service for people living with dementia and there carers in Torbay.

9.16 Local examples of good practice

Local examples of good practice:

- "Days out" service.
- Carers Support Groups.
- Carers Support Workers.
- OT post diagnosis group.
- Sensory memory stimulation group.
- Need to access follow on resources possibility outside mental health expertise base.
- Memory cafe in Paignton all that is available but is appreciated and valued.
- Comprehensive cohesive working in zonal teams.
- Joint working at CMHT level – good relationships between health and social care.

Achieving easy access to care, support and advice following diagnosis

9.17 To achieve easy access to care, support and advice following diagnosis Torbay will:

- We need to use the learning to commission a Dementia Advisor Service for people living with dementia and their carers in Torbay.
- We pilot a dementia advisor service in Brixham (2010/11)
- Commission a dementia advisor service across Torbay (2011/12)

Key priorities to achieve objective 4

Areas for development	Actions	Lead	Timescale
- Learn the lessons from the Department of Health Dementia Advisors' Demonstrator sites and apply to local practice.	Apply learning, develop service specification, business case, consider pilot in one area	AR	12 months
- Memory Clinic needs to be developed to provide a variety of support and education options.	Review Clinic and medication protocol	JW, SLL	3 months
- Also needs to link with a dementia pathway.	Develop a fully commissioned comprehensive dementia pathway	AR	12 months

9.18 Peer support and learning networks for people with dementia and their carers

Objective 5: Development of structured peer support and learning networks
(Living Well with dementia: A National Dementia Strategy)

9.19 One clear message we have received from people living with dementia and their carers, who have used the memory café, is that they draw significant benefit from being able to talk to others in similar situations.

9.20 The value of peer support is that this can empower people to make choices and assist them to plan their own lives

9.21 Torbay is a Department of Health Demonstrator Site for Peer Support. The support and learning will enable us to commission an evidence based peer support service for *all* who require it across Torbay.

9.22 **Local areas of good practice**

- Host carer scheme open to people with early dementia.
- Plans to commission a Memory Café network.
- CMHT input into Memory Café.
- Dementia Café runs every week.
- Plans to develop Memory Cafés in Torquay & Brixham (Demonstrator site).
- Carer's Education Group.
- Carers' Support Group.

Achieving structured peer support and learning networks for people with dementia and their carers.

9.23 To achieve an improvement in structured peer support and learning networks for people with dementia and their carers, the following will be delivered:

- *Peer support*
  - We will fully implement the DOH peer support demonstrator project implementation plan.
  - We will work with the Department of Health to establish best practice (09-11)
  - We will develop and commission a model based on the findings of the DOH demonstrator site evaluation

Key Priorities to achieve objective 5

Areas for development	Actions	Lead	Timescale
Low intensity support (dementia adviser and peer support networks) are consistently cited by carers of people with dementia as their top priority. Support networks are generally inexpensive, and hence offer a potential early on. Opportunity to review coverage and funding arrangements and learn from national demonstrator sites	Commissioners to develop a comprehensive pathway and commission it. This may involve transfer of resources. Fully Implementation of DOH peer support demonstrator project implementation plan. Ensure sustainability (commissioning strategy)	AR AR, SO, DM	12 months 18 months

10 Living well with dementia

Objective 6: Improved community personal support services
Objective 7: Implementing the Carers' Strategy for people with dementia
Objective 8: Improved quality of care for people with dementia in general Hospitals
Objective 9: Improved intermediate care which is accessible to people living with Dementia
Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers
Objective 11: Living well with dementia in care homes
Objective 12: Improved end of life care for people with dementia
(Living well with dementia: A national Dementia Strategy 2009)

10.1 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 is probably the single most important service involved in supporting people with dementia in their own homes.

10.2 Specialist dementia home care can provide 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 Torbay there is a need to ensure the market place delivers quality services. We currently do not commission a specialist dementia domiciliary care provider.

10.3 People with dementia are known to be an 'at risk' group in terms of abuse through financial exploitation, fraud and theft with some individuals who are unable to complain. Torbay 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.

10.4 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.

10.5 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 institutionalization 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. Torbay Care Trust is a Department of Health Demonstrator site to develop innovative breaks for carers.

10.6 Up to 70% of acute hospital beds are occupied by older people and up to a half of these may be people with cognitive impairment, including those with dementia and delirium. The majority of these patients is not known to specialist mental health services and is undiagnosed. People living with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalization

10.7 Admission to hospital can be a confusing and challenging time for people with dementia and family members who may be excluded from care planning within the hospital setting and the 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 development of an explicit care pathway for the management and care of people with dementia in hospital, led by a senior clinician
- to ensure carers are actively involved in care planning and the discharge process
- commissioning a liaison psychiatry service, which includes specialist liaison older people's mental health service to work at Torbay Hospital

10.8 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.

10.9 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 contribute to their independence and safety.

10.10 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

10.11 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

10.12 **Local areas of good practice**

Local areas of good practice (as identified by the SHA Peer review process)

Objective 6:
- Host carer scheme
- Well managed, with dynamic leadership generic zonal teams
- St Edmunds Intermediate care and community support team
- Currently review of day care services
- Residential, visited by the SHA peer review were able to demonstrate they were able to provide high quality services to meet the needs of people living with dementia

Objective 7:
- Dementia Care Pathway information booklet for carers
- Carer assessment process
- Patient held record - Yellow folder system for people with complex needs
- Carers support workers in GP surgeries
- "safely Home scheme"

Objective 8:
- Commissioning of a liaison psychiatric service at Torbay Hospital
- Specialist Dementia Nurse within the DGH
- Extensive educational package
- Excellent links with Plymouth University
- Innovative work to improve care for people with dementia with in the district general hospital – lead by the Assistant Director of Nursing

Objective 9:
- Existence of intermediate care services
- St Edmunds – excellent outcomes for people living with dementia.

Objective 10:
- Telecare show flat
- Plans for extra care housing – on track for October 2010

Objective 11:

- Specialist support into residential homes
- Specialist dementia residential home

Objective 12:

- Joint advance statements which include sign up by the Local Ambulance Trust
- Non-malignancy end of life pathway being considers
- Strategy for End of Life care being developed but not yet implemented
- Gold standard framework in place but not for people living with dementia

Key priorities to achieve objective 6

10.13

Areas for development	Actions	Lead	Timescale
- Review capacity of domiciliary care to meet actual and predicted demand.	Consider specialist dom. Care service	AR	12 months
- Range and quality of day care	Review day care provision	Hannah Horrocks	18 months
- Improved choice and control for people living with dementia and their carers	Encourage individual budgets	SS, CW & Nicola Barker	

Key priorities to achieve objective 7

10.14

Areas for development	Actions	Lead	Timescale
- Promote Carers Strategy and link to programme of training amongst staff to raise awareness.	SW to link with training programme	Linda Hammett /AR	12 months
- Review systems for collecting data about carers and identify improvements.	Systems review	LH/Katie Heard	12 months
- Consider an out of hours' helpline for carers.	To be commissioned	AR	12 months
- Promote the work of the Carers Support Worker in each GP practice.	SW to work with practices to increase awareness	LH	6 months
- Range and quality of day care	Review day care provision and develop community hubs	Hannah Horrocks	By April 10
	Fully implement DOH demonstrator carer programme (dementia)	James Drummond	18 months

Key priorities to achieve objective 8

10.15

Areas for development	Actions	Lead	Timescale
- Raise profile of, and training for, DOLs and MCA to improve safeguarding.	Prioritise training for key staff ~ plan to be developed for all staff	Liz Childs/ Maggie Dunbar	6 months
- Dementia awareness training to be comprehensively rolled out.	As above	MD	6 months
- Environmental issues need attention using the Alzheimer's Society reference tool.	Staff to work with University of Stirling to review environments	MD	12 months
- Liaison service and also care/intermediate care need to be properly commissioned and service specification formalised with provider input.	Commissioner to develop service spec with DPT	AR	Fully operational by April 09

Key priorities to achieve objective 9

10.16

Areas for development	Actions	Lead	Timescale
- Undertake a training needs analysis.	Undertake analysis	David Jones & Sally Pritchard	6 months
- Regularly monitor effectiveness of intermediate care for people with dementia.	Audit care	DJ & SP	6 months

Key priorities to achieve objective 10

10.17

Areas for development	Actions	Lead	Timescale
- Telecare in St. Edmunds needs development	Sally to discuss options	SP	6 months
- Further extra care housing for people with dementia + their carers planned (e.g. Guineas Trust 65 flats ECH re-modeled from sheltered). Ensure plans linked with the local Dementia Strategy.	Strategies for housing and dementia need to link closely	AR, John Bryant, Barbara Alexander	6 months

Key priorities to achieve objective 11

10.18

Areas for development	Actions	Lead	Timescale
- Consider expanding current support to allow for training and education within care homes.	Commission care home support team	AR	6 months
- CPN and multi professional in-reach to care homes.	As above		
- Consider and develop further preferred providers.	Tender to preferred providers	AR	6 months
- Need specialist pathway for dementia and roll out yellow folder.	Develop pathway	AR & DS	6 months
- Preferred provider lists or specific homes that are contracted with.			
- Contract specifications to focus on qualitative aspects and to be taken into account alongside CQC rating.	Develop contract	Ray Hodgson	6 months
- Stimulate the role of dementia champions in care homes.	Care home link CPN	Bob Bartrum	6 months

Key priorities to achieve objective 12

10.19

Areas for development	Actions	Lead	Timescale
- Consider expanding current support to allow for training and education within care homes.	Extend current developments	AR & Maggie Clough	6 months
- Develop pathway in EOL strategy that is dementia specific.	End of Life strategy to link directly with DS	DS, AR & Reine	6 months

11.0 Framework for delivering the National Dementia Strategy

Objective 13: An informed and effective workforce for people with dementia
(Living well with dementia: a national Strategy)

Workforce

11.1 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.

11.2 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.

11.3 Torbay Care Trust and Devon Partnership trust have both developed workforce strategies to ensure that high quality and relevant workforce developments are provided to support organisational commissioning and provider functions.

11.4 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 Torbay Care Trust and Devon Partnership Trust.

Key priorities to achieve objective 13

Areas for development	Actions	Lead	Timescale
- Workforce development strategy required to address training needs across all partners in relation to dementia.	Develop training strategy and implementation plan	AR	6 months
- Extend dementia awareness training within the SDHFT to wider range of staff.	Increase training in hospitals	Maggi Dunbar & community hospital matrons	12 months
- Improve awareness within zonal teams and with general practitioners and build confidence of staff to respond appropriately to needs of people with dementia and their carers.	Increase specialist team presence in the zones GP communication and education programme	CW JW	12 months 12 months

Joint Commissioning Strategy for Dementia

Objective 14: A joint commissioning strategy for dementia
(Living well with dementia: the National Dementia Strategy)

11.5 This strategy has been developed following extensive consultation on local services and the draft national Strategy, during the summer of 08 (see appendix 3). It has been based on the World Class Commissioning guidance.

11.6 The information gathered during the local consultation has been used to underpin this strategy and has informed our priorities for development 2009-10.

11.7 Local consultation identified there were already areas of good practice undertaken in Torbay, but there were areas for further development.

11.8 The Torbay Older People's Mental Health Local Implementation Group has become a time limited dementia implementation task and finish group. The group is chaired by TCT Acting Chief Executive. Representation includes Primary Care, Independent providers, voluntary sector, mental health professionals, zone manager, users and carers, acute trust and commissioners. (See appendix 2)

11.9 The OPMH LIG has systematically worked through the recommendations in the National Dementia Strategy (2009 DoH) and the SHA peer review (summer 09) and have mapped current provision against the recommendations. Areas for development have been identified.

11.10 This strategy highlights areas for development and investment for 09/10. Resources were secured for developments 09/10 and the improvements are being implemented.

Key priorities to achieve objective 14

Areas for development	Actions	Lead	Timescale
- Approve and publish the local Dementia Strategy. - Include milestones, target dates, lead individuals and clearly identified short and medium term priorities and investment in action plan.	Publish local strategy redraft - Present to January LIG - Communication plan	AR CW Jim Delves	6 months
- Consider how core messages from local Dementia Strategy can be reinforced to relevant staff whose main focus is not	Link with training strategy	AR	12 months

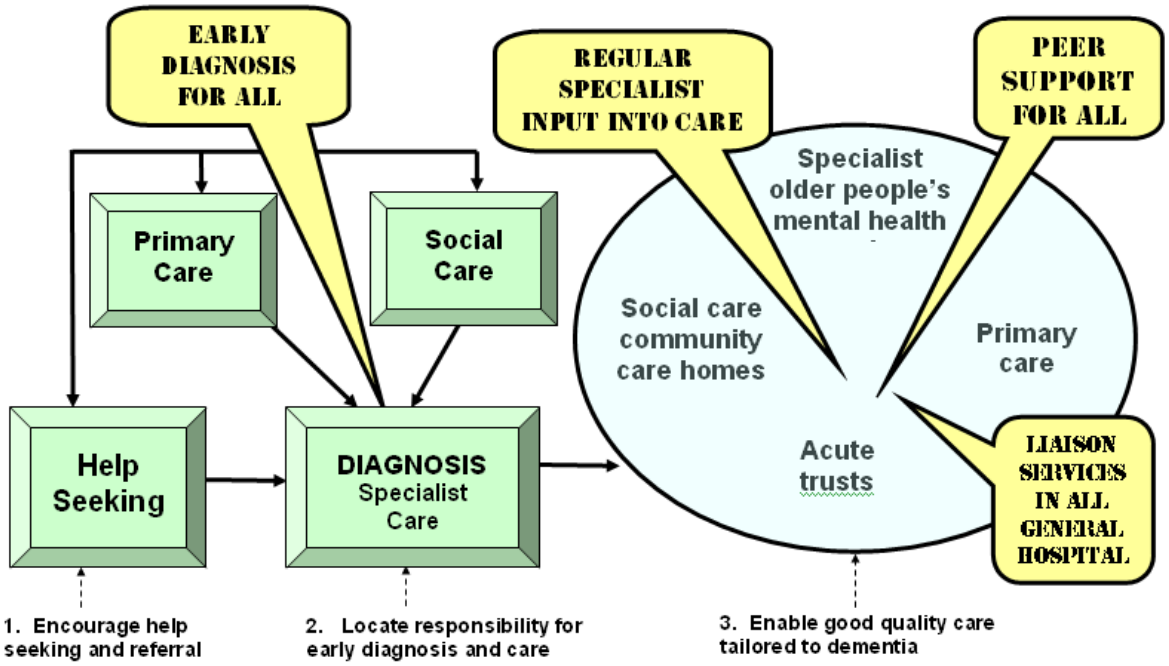
dementia. - Develop capacity planning, looking at quantifying supply of services at different points of an agreed commissioner determined dementia pathway, as well as demand in the JSNA.	Clear plan to increase capacity over 5 & 10 years	AR	12 months
- Re-clarify the lead general practitioner role for dementia.	AR to discuss and clarify with LT	AR	12 months
- Seek opportunities to involve clinicians and practitioners in a leadership role for certain work-streams.	AR & CW to identify key individuals	AR	
- Begin work to define outcomes for objectives in the local Dementia Strategy and commissioned services for monitoring and evaluation	Local strategy to include a review and evaluation process bi-annually	AR	

Governance and implementation plan

11.11 The Torbay Dementia Strategy will be monitored through the Local Implementation Group. (See appendix 1 for membership). This group will report progress to Torbay Care Trust Board and the Older People's Partnership Board

11.12 The Torbay Implementation Group will be responsible for implementing and monitoring the strategy, reviewing the quality of data for specific service areas. Task and finish Sub-groups of the LIG will be established to implement specific objectives. Performance management arrangements will be put in place to ensure the strategy is achieving the planned actions specified.

DEMENTIA CARE PATHWAY



(Based on the Sube Banerjee model 2008)

APPENDIX 2

Dementia Local Implementation Group – Membership

NAME	REPRESENTAION
Anthony Farnsworth	Chair Acting Chief Executive (TCT)
Chris Whitehead	Integrated Service Manager (DPT/TCT)
Dr David Sommerfield	Consultant Psychiatrist DPT Medical Director
Dr Liz Thomas	GP
Mike Vango	Carer
Jim Delves	Alzheimer's Society
Ann Redmayne	Mental Health Commissioner
Robin Causley	Aged Concern
Sally Pritchard	St Edmunds (intermediate care)
James Drummond	Carers Lead TCT
Liz Feller	Independent Sector (Residential Care)
Maggie Dunbar	Specialist Nurse (SDHCT)
Julie Hickie	Zone Manager (TCT)
Sue Smith	Social Worker
Cindy Stocks	Non Executive Director (TCT) Torbay Council Member
Dr Joanna Wildgoose	Consultant Psychiatrist

APPENDIX 3

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.

APPENDIX 4

CONSULTAION FEEDBACK

Views are sought on the following:

Chapter 1 – Improved Awareness

Recommendation 1: Increased public and professional awareness of dementia
Recommendation 2: An informed and effective workforce for people with dementia

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

Yes, especially "help people to understand the benefits of EARLY diagnosis". (DIC, Carer)

The Strategy talks about raising awareness of dementia but can we look at what has worked in the past in terms of awareness campaigns for mental health (and in relation to investment). Where is money best invested for the greatest impact? (OPMH Group, DPT)

Clearly these are the right goals, but how will we be measuring them? (AB, Carer)

One of the biggest problems that I have had has been the lack of understanding of the illness from staff. (JC, Carer)

My husband's care has particularly suffered in hospital as a result of lack of understanding from staff of people with dementia ~ I very much welcome this recommendation. (PS, Carer)

I think there needs to be effective media campaign to help ensure that dementia becomes part of day-to-day life. Storylines could be written in to television soaps, and generally there needs to be much more focus on dementia as being a normal part of ageing. (JC, Carer)

I feel awareness is gradually coming with the general public ~ it is needed more ~ with shopping difficulties. (JB, Carer)

2. Is there anything that has been missed to help us improve public and professional awareness of dementia?

ALL HEALTH STAFF should include All Care Homes, Day Centres and Hospital staff, and private domestic homes' care workers. (DIC, Carer)

The Stroke Society carries cards for people to show, to retail, Post Office, travel etc. This I think is a very good idea, able to show to these people, so that the worry of not being able to explain to others what is wrong. (JB, Carer)

- The campaign needs to be effective but there needs to be substance/capacity and competence within services. The timing of an awareness campaign is crucial ~ carers will not want to know about it until the Strategy is in place.
- The key questions here are about what the campaign should target/raise awareness of, and when.
- Awareness first needs to be raised among professional groups.
- The focus on prevention is minimal ~ more could be said about the available evidence for reducing particular types of dementia, eg Korsakoff's Syndrome and the links with alcohol/substance misuse, diet/cholesterol/blood pressure, and multi-infarct dementia.
- Adults below 40 years could be a useful target. (OPMH Group, DPT)

Schools/Colleges

- Education at a younger level, of dementia/Alzheimer's Disease.
- Speakers to go into schools/colleges to provide awareness.
- Positive PR
- More workshops? (Consultation Event Group)

Media/Delivering Message

- People going into businesses to raise awareness
- Alzheimer's Week/conferences ~ awareness
- Mobile caravan to visit towns, roadshows
- Positive PR on programmes ~ TV/radio
- Better advertising of Safety Home Scheme and other services such as wallet for transport services.
- Greater health promotion through the media to de-stigmatise mental health in older people. (Consultation Event Group)

I visited four carers groups across South Devon over the last three months, and generally it was felt that this was very much welcome. However, there were concerns raised by the groups about how this would be achieved, how it would be measured, etc. (Chris Whitehead)

3. What can you or your organisation do to help implement the recommendations?

This I find a difficult situation ~ my own husband cannot explain himself, by this I mean he cannot converse, so going shopping on his own is now impossible. (JB, Carer)

Encourage the media (BBC etc) to help in education ~ they already do a lot but tend to feature headline news items. (JB, Carer)

Clearly NHS organisations and Council organisations have a huge responsibility to ensure that professional awareness of people with dementia is raised and that we have an informed and effective workforce across our hospitals and community services. We also have a responsibility to work with universities, voluntary sector and others to ensure there is adequate staff training and information to help support staff to deal with the problems that people with dementia may pose.

Some of the ideas raised by the communications we have had with users and carers over the last couple of months will help us with this process. We think we can also use things like Alzheimer's Awareness Week and media campaigns locally to help improve awareness and access to services locally.

(Torbay Care Trust)

Chapter 2 – Early diagnosis and intervention

Recommendation 3: Good quality early diagnosis and intervention for all
Recommendation 4: Good quality information for those with dementia and their carers.
Recommendation 5: Continuity of support and advice

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

- The impact of early diagnosis ~ what/where is the capacity to follow this through?
- What does this role really mean? Who would do it?
- There are links to NICE/Everybody's Business ~ but these links need to be overt.
- This should be clearly stated to be a new role and about restructuring services ~ not about duplication ~ but where does it leave case management and cost funding management? How do we avoid confusion? (OPMH Group, DPT)

On reflection, early diagnosis might have been helpful, but my husband was very happy gradually dementing, and I had a good idea what was happening. I am not sure how early diagnosis would have changed anything. (SS, Carer)

Early diagnosis was really effective in helping me plan my future. (DD, Client)

Recommendation 3 ~ Early diagnosis!!! I only found this out when a friend said: "is S……. alright?" ~ therefore detection cannot always be found in the early stages. Looking back I now think [my husband] should have been diagnosed two years earlier. (JB, Carer)

Early diagnosis was fine and helpful because it helped me know where I was with my husband, who had been diagnosed with dementia. However the problem was after that, as we were given the diagnosis and then left, and our next appointment at Chadwell was a year later. (AP, Carer)

Carer's right to carer's assessment and care plan must be reinforced.
(Consultation Event Group)

2. Is there anything that has been missed to help enable early diagnosis and intervention?

My doctor told me that my husband "did not respond to questions as expected" about 18 months before I felt there was a problem ~ I had thought it was his hearing. A suggestion by the doctor of his suspicions and a hint of his "diagnosis may have meant an earlier referral and decision. (DIC, Carer)

- Where is the leadership for GPs in this area?
- Should GPs be the gatekeepers for early diagnosis/intervention? But currently GPs are seen as a barrier.
- There needs to be a direct access for memory services in the context of primary care triage.
- But then how do you control the floodgate issue? (OPMH Group, DPT)

There was a general welcoming around the groups of early diagnosis as being a productive tool which helped people have genuine choices and dignity within the illness. However there was concern that this was not for everybody and also that it would need education amongst GPs and other health care professionals to ensure that early referral happened. Referral systems need to be open to ensure easy access to specialist services. (JC, Staff)

My husband was young when he developed dementia. Staff in younger people's mental health services had no understanding of the illness and therefore it was a very difficult time for both of us as we struggled to understand what was going on for him. Anything that can be done to help earlier diagnosis would have been a help for me. (CB, Carer)

- A lot of concern about GP response to carers.
- A lack of understanding at professional level with people with dementia.
- Carers need opportunity to speak freely to professionals away from the patient without feeling guilty.
- Early diagnosis important ~ every surgery should have expertise in the practice to refer to specialist diagnosis.
- More cohesive local approach ~ pockets of excellent practice but difficult to get information.
- Avoid "assumptions" ~ build relationship with patient
- GP surgeries need to have a "specialist" for early recognition and disseminate information.
- Where the patient accepts they have a problem and will access health advice its OK, but family/carer need to be able to go to the GP or other health professional if they are worried about the relatives condition when the patient doesn't accept it.
- GP's may not pick up early stages of dementia. Need to recognise that planning for the future takes time so we should not be leaving it until the illness is critical. GP's need training in early diagnosis.
- Early diagnosis (warning signs) could be improved by ensuring people over 50 are offered an annual health check, but that this must incorporate screening on mental health to identify possible dementia. Currently some practices in Torbay offer an enhanced health check which includes social care issues, but does not cover relevant mental health e.g. memory. To work such a scheme must be offered pro actively.
- Too often carers feel they have to push hard to get someone seen, and this then requires levels of assertiveness which not everyone has.
- It is crucial to get early information/diagnosis services organised and available in the community. Too many people are leaving it until it is too late.
- Need to provide support and advice at earlier age to people with learning disability and their families/carers on issue around dementia. (Consultation Event Group)

Is there anything that has been missed to help enable early diagnosis and intervention? *Continued ….. 2*

I wish there was early diagnosis; my life and I'm sure other carers would wish for this.
(JB, Carer)

Recommendation 4: More information given by doctors, usually the first point of contact. In my case it took a long time to get information and support, one does not know which questions to ask at the start. (DB, Carer)

3. Do you agree that the diagnosis of dementia should be made by a specialist?

Yes DIC, Carer)
Yes! Most definitely ~ but how? (JB, Carer)

4. How open should referral systems to a memory service be? Should people be able to refer themselves, or should they have to go to a GP first?

People should be able to refer themselves when they recognise what the problem is ~ IF they recognise the problem! Otherwise through the GP. (DIC, Carer)

The trouble with memory services is that they focus on memory. My husband's memory was not a problem. There were other areas of his character which were failing. Eventually they were diagnosed as dementia. If we had been able to refer direct to a memory service I would not have done so as memory was not the main issue. (BC, Carer)

My wife was referred to the Memory Service which was extremely good. However, following diagnosis nothing happened and we were left to fend for ourselves. (DA, Carer)

The Memory Service at Chadwell was extraordinarily good and comprehensive. I would recommend it to anybody. (JC, Carer)

I do not think my husband would have referred himself ~ in fact I know he wouldn't. Partners (like myself) we've been married 55 years and just thought it was old age creeping on.
(JB, Carer)

- "Beginners or Idiots Guide" to what next, ie Enduring Power of Attorney.
- Keep as many options open as possible, ie flow chart of options, contact numbers etc ~ where to go next if not satisfied ~ self-referral.
- Essential: **one** point of contact or **team** to manage individual patients so that support is available regardless of holidays or sickness.
- Transparent open discussion across professionals and with carers.

(Consultation Event Group)

5. How would the dementia advisers be able to ensure continuity of care?

By treating the condition as a disease and treat as a medical condition, which it is. By NOT just treating it as a "social" problem ~ It is called a "disease". (DIC, Carer)

GP surgery support staff already do this function ~ that is, if they exist! (DB, Carer)

Like belonging to a helpful group such as ours in Paignton, "Chadwell", who look after the carers as well as the patients. (JB, Carer)

There is a minimal resource in health so there needs to be caution about shifting any funding to social care. Do we mean shifting the balance (of funding) or working in partnership ~ it should not be about drawing territory. (OPMH Group, DPT)

- Right from **day one**, where to get information? what is it? practical help; financial support; what next? etc
- Information on what is available for ongoing home care
- Importance of "life story" so that people not connected to patient have ideas for conversation and understanding of person's life and interests.
- All "professionals" or those potentially dealing with dementia **must** receive training at national level, ie nurses, GPs etc.
- Access to day care with "carers" **not** with other mentally ill patients. Important for stimulation of patient.
- Help carers use the internet to access information (i.e. more than just giving address).
- Health Professionals need to know what is available so they can signpost people to good information and support, particularly at early stages. This must be at local level.
- More promotion of local low key support and access e.g. Memory Café..
- Some people find existing day services very difficult because they have lost their ability to communicate (and so feel left out) or the service is snot tailored to their interest/ability/personality etc. One size does not fit all.
- Specific dementias need tailored services that address the individual needs.
- Explore the possibility of ex carers being befrienders/mentors as part of support.

(Consultation Event Group)

There was almost universal welcoming across all the groups and the people I spoke to for the idea of a worker for the individual and family to support the person with dementia right through the period of time they have dementia. What is not clear is what form this worker's role will take, where they will be based, who they will link with, and what contact they will have with clients. (Chris Whitehead)

6. What can you or your organisation do to help implement the recommendations?

Push for more help and keep putting dementia more to the forefront of the NHS. (JB, Carer)

Clearly Devon Partnership Trust and Torbay Care Trust, and other organisations, need to work together to implement some of these changes, to give all people with dementia a named worker throughout the period of their illness, which can be many, many years, is a huge challenge for organisations.

Locally we feel we need to work with partner organisations in the statutory and voluntary sector, and users and carers to develop these recommendations. We will very much welcome the idea of early diagnosis, good quality information and continuity of support and advice. Through our work during the consultation process we now have many ideas as to how we might be able to put these proposals into action. (Torbay Care Trust)

Chapter 3 – High-quality care and support

Recommendation 6: Improved quality of care in general hospitals
Recommendation 7: Improved home care for people with dementia
Recommendation 8: Improved short breaks for people with dementia and their carers
Recommendation 9: A joint commissioning strategy for dementia
Recommendation 10: Intermediate care for people with dementia
Recommendation 11: Improved dementia care in homes
Recommendation 12: Improved registration and inspection of care homes

1. Are these the outcomes, recommendations and suggested means of achieving them the right ones?

Yes, plus Recommendation 12 ~ add: "Inspection and testing of care home staff" to ensure they understand the problems of the person with dementia. (DIC, Carer)

- Is there funding?
- All partners/organisations need to understand the whole pathway successfully to enable the balance of care to be shifted appropriately in line with the PWD needs ~ this should not be about drawing lines around services but based on PWD need. This work would need to be clearly defined.
- Is there an agreed pathway available to share anywhere?
- There is a minimal resource in health so there needs to be caution about shifting any funding to social care. Do we mean shifting the balance (of funding) or working in partnership ~ it should not be about drawing territory.
- A key success of the Strategy will be the ability for staff to draw on the appropriate skills and an empathic nature.
- But care home staff are poorly paid ~ what is the incentive for them? How do they take on the vocation of this care?
- How do you recruit people? Training and person-centred care are important, but recruiting the right people with the right skills is essential, especially with choice, individual budgets and the propensity for PWD to recruit their own carers. (OPMH Group, DPT)

The most difficult time by far for me as a carer was when my husband was in hospital. Staff had no understanding of his illness, and made me feel awful that he was being difficult. (AP, Carer)

People in hospital are at their most vulnerable. My wife caused the surgical ward extreme problems when she had a small operation, creating havoc around the ward as she wandered all over the place. She was more confused than ever, difficult with staff, and did not like being encouraged to stay in one place. Measures to address this would have been extremely helpful. I can only describe the period of time as a nightmare. (CJ, Carer)

When my husband went into hospital to have an operation to remove his infected wisdom teeth, the hospital worked extremely well with me. They allowed me to stay in the hospital with him during all waking hours. I arrived at 7 o'clock in the morning, spent all day with him, and left about 8 o'clock in the evening. He had been very difficult leading up to the time, presumably because his infected abscesses in his teeth were causing him so much pain. The hospital admission caused me loads of worry, but actually went extremely smoothly. The staff were very supportive; because I was around my husband at all times he was relatively relaxed and in fact became increasingly less difficult, presumably because he was in less pain. (FT, Carer)

Are these the outcomes, recommendations and suggested means of achieving them the right ones? *Continued ….. 2*

Recommendation 6 ~

- Treatment on general wards of dementia patients not adequate. Essential more staff training ~ at least one member of staff with specialist awareness ~ more at basic nurse training (common sense?)
- Appropriate awareness training and education for all staff working at the DGH, particularly around behaviour management and medication.
- Carers involvement in the admission process ~ "life books"
- Carers contribution being valued
- Flexible visiting times and ability of involvement in providing care by carers, eg at mealtimes.
- Observation and safety of people with dementia ~ need for 24-hour observation ~ use of beds near the nurses station and not side rooms.
- Reduce length of stay to a minimum ~ use of alternative to hospital and intermediate care.
- "Discharge" planning should commence on admission.
- Need for information and advocacy for patient with dementia and carer/family at point of admission to hospital for general treatment.
- Carer needs to continue to be involved (if they wish) in care of person when they go into hospital or care and services should promote this and make flexible arrangements.

(Consultation Event Group)

This must be made more aware ~ hospitals need people to feed people with dementia.

(JB, Carer)

Recommendation 7 ~ Issues identified at a local level

- Domiciliary care ~ capacity issues have led to delayed discharge from hospital.
- Lack of continuity ~ different people providing the care from day to day.
- Lack of reliability
- Lack of a "specialist" domiciliary care service.
- Clearer structure for medication on discharge. (Consultation Event Group)

I myself feel very lucky to have found "Levanto" [day care home] in Paignton ~ [my husband] is happy going there ~ would be nice if everyone had this chance. (JB, Carer)

~ Feedback on the Strategy

- Promotion of direct payments which enables carers to purchase services which meet individual needs, eg sitting service
- Care at home should be maintained wherever possible to enhance user and carer experience

Recommendation 8 ~ Issues identified at a local level

- Lack of a night "sitting service"
- No access to a crisis resolution and home treatment service
- Ongoing training and education programme for carers
- Lack of information on services available and how to access them
- Continuity issues
- Lack of specialist day, with a structured programme, leading to a positive experience for the person with dementia.
- More "care" in the person's own home. (Consultation Event Group)

My first short break in 8 years starts 5th September ~ it's been awkward doing this, but the staff have been so helpful. (JB, Carer)

~ Feedback on the Strategy

- Stress that dementia is "everybody's business"
- Need for 24-hour community support for carers.

Are these the outcomes, recommendations and suggested means of achieving them the right ones? *Continued …..3*

Recommendation 10 ~ Issues identified at a local level

- Need for a crisis helpline
- Lack of information
- Emergency "sitting service"
- Carers to be involved in discharge process as soon as possible
- Improved services to prevent admission and facilitate early discharge.

(Consultation Event Group)

I think to make them feel wanted!! Such as give them musical exercises, or singing of the old songs. (JB, Carer)

Recommendation 11 ~ Issues identified at a local level

- Robust monitoring processes which involve carers
- Ability of carers to remain as "carers" whilst the person with dementia is in residential care
- Lack of structured day programmes.
- Why can there not be an advice service to help people choose between providers when they are looking for residential/nursing care?

General Hospital Care

- Designated ward to people with dementia?
- Specialist dementia link nurse?
- Need for more awareness/understanding of hospital staff towards people with dementia
- Immediate involvement of family/carers in person's care plan for admission.

(Consultation Event Group)

2. Is there anything that has been missed that would help to ensure high-quality care and support for people with dementia and their families?

A great deal more training in dementia for <u>all staff involved</u>; To be treated as a *disease* ~ not a "social" problem. (DIC, Carer)

If carers had more confidence in the care standards in care homes, they would take more short breaks. I personally have not had any short breaks for several years ~ twice the family have taken on my role to give me a day off. (DB, Carer)

- Has it missed an opportunity to really focus on the needs of PWD and their carers?
- Does it present an opportunity for changed practice / to do things differently?
- Does it have the right ingredients to meet the projected needs for PWD in the context of demographic factors and the ageing population?
- The Strategy does not go far enough to focus on the impact of ageing populations and the decrease in working-age adults and funding.
- There is no reference to the role of community hospitals.
- What is their role and to what extent will CH be reshaped as part of the care pathway to meet mental health needs?
- There is no reference to specialist mental health inpatient beds for older people. "Everybody's Business" saw the need to segment care for PWD and PWF illnesses/co-morbidity, yet there are still many services providing integrated care. (OPMH Group, DPT)

3. What more could be done in acute care, home care and care homes?

Ensure staff have good ~ really good training and a really good understanding of the way people with dementia think. Funding by Government as a medical condition ~ after all, it is a disease. (DIC, Carer)

The inspection should be more rigorous, unannounced visits to check a random sample of clients for lack of hygiene, proper nutrition etc. (DB, Carer)

Hospitals

- More awareness of hospital staff and it would be a good idea for a nominated member of staff, ie specialist nurse, to be responsible for advising all concerned with the clients' care to be notified of their condition and what it entails.
- Hospital is not a "secure unit" so security must be improved for people with Alzheimer's.
- Mental health nurses who understand the condition rather than general nursing.
- Life-Book would explain dementia/Alzheimer's Disease to both the carer and cared-for.
- Admission policy ~ fast-tracking A&C (as children)
- Stays ~ ability to remain with patient
- Discharge ~ medication arrangements. (Consultation Event Group)

Acute Care

More acute care beds provided locally to patient. (Consultation Event Group)

Community

- More awareness of surgery staff and GPs ~ education on how to recognise carers.
- More services, ie support group, "out-of-hours" contact (specialist).
- More media awareness, especially in "twilight" stage. If not under Chadwell (Community Mental Health Centre), no support available.

More "Memory Cafés". Carer needs to continue to be involved (if they wish) in care of person when they go into hospital or care and services should promote this and make flexible arrangements.

Care Homes

- Awareness of care staff ~ better training. Some homes **will not** take Alzheimer's/ dementia sufferers. Carers need to know that **all** homes are registered to take "sufferers".
- More inspections ~ ensure family involved/included.
- How do inspectors assess night care?
- Ensure structures of home meet needs of patients rather than needs of staff ~ example of home staff getting patients up at 5.30am by night staff, because easiest time for care home staff.
- Need for range of meaningful activities for patient in a care home.
- Training strategy for all staff at care homes. (Consultation Event Group)

Care Plans

- Insufficient for carers
- Staff don't appear to disseminate to colleagues to seek communality of need.
- Individualised care plans that carers/family jointly agree.
- Care homes often seem to cater for the "lowest common denominator", ie all residents given luke warm tea because someone might scald themselves.
- Link community nurses for individual care homes as resource for homes.
- More therapists ~ holistic. (Consultation Event Group)

4. What could be done to make the personalisation of care agenda (including individual budgets) work for people with dementia and their family carers?

We've had our monies looked into, and a pleasant surprise awaited us. Thanks to Cheryl Bowden MBE ~ not may OAPs know of this, or are too proud to be assessed. (JB, Carer)

In Torbay there is an implement group for individualised budgets for people with mental health problems, including people with dementia, to ensure that this way of delivering care is available to this client group. We would expect the process to evolve and become available to users and carers over the next six to nine months. (Torbay Care Trust)

5. What can you or your organisation do to help implement the recommendations?

Fill in forms like this for the Government to see how we as carers manage (with the help of our families). (JB, Carer)

Give the benefit of my experience when asked ~ generally I am not able to attend meetings. (DB, Carer)

Once again the Care Trust, in line with Devon Partnership Trust and South Devon Healthcare Trust have a huge role in implementing the recommendations suggested. We already have a Psychiatric Liaison Team in the planning, to be based in South Devon Healthcare, to support the quality of care for people with all mental health problems in the District General Hospital. We clearly need to support the development of this team and ensure that we give equivalent support and education to staff working in general hospitals.

With respect to home care for people with dementia, following this consultation it has become more clear that we need to work locally to develop a service specifically for those people with dementia.

In Torbay short breaks are available for people with dementia and their carers, however what has become really apparent through the consultation process is that not enough people know about these services and what they can offer them. We clearly need to work with our teams to ensure that our users and carers are well informed about what is on offer, and how they can access it.

As a Care Trust we already have a joint commissioning strategy for people with dementia, which also includes older people with functional mental health problems, and is developed through our local implementation group for standard 7 of the older people's NSF.

We are about to launch a residential service for people with dementia for intermediate care. We are also developing intermediate care services in the community across Torbay (which are already in existence) to include those people with dementia.

Through our Commissioning Department with the private sector we can monitor and improve dementia care in homes. We can also do this in line with our Safeguarding Adults Team and our colleagues at CSCI.

(Torbay Care Trust)

Recommendation 13 Clear information on the delivery of the strategy
Recommendation 14: A clear picture of research evidence and needs
Recommendation 15 effective support for implementation

General comments

Do you have any other comments you would like to make in relation to this consultation?

Home care workers who get the person up, wash and dress them, give them breakfast etc, need MORE TIME to do this work. The demented person can be rushed, hassled and left in a totally exhausted state when the care worker has left after a very short time. (DIC, Carer)

I feel sure there are quite a lot more people who are suffering, who have no idea that there is help out there. (JB, Carer)

I found that in my early days of caring, there was a lack of information on how to care and what appropriate support existed. Training courses are offered on handling, hygiene, continence, institution, but are of little use when you are a full-time carer. In my experience a visit from an expert is very much more valuable. (DB, Carer)

- National –v- Local interpretation ~ while a prescriptive approach is not wanted (ie targets), there is concern that locally nothing will happen (eg there was an example from one organisation where no-one locally is owning up to taking the lead on dementia.
- There needs to be greater emphasis in commissioning frameworks.
- Is there funding? (OPMH Group, DPT)

Improving short-breaks

- Host day carers scheme to include people with continence difficulties
- Ensure people/families aware of all available options for short-breaks
- Allow people to trial options to make choices
- Need for appropriate homes and services for younger adults with dementia
- Engage churches/voluntary organisations to provide respite opportunities
- **More** intermediate care appropriate to the person's needs.
- Ensure all patients given all available options and criteria.
- Better integration of services to ensure everyone knows what everyone does.

(Consultation Event Group)

General Comments ~

- The Strategy is weak on outcome measures and monitoring processes
- The value of carer involvement in monitoring and commissioning of services is not stressed
- Medication ~ hardly mentioned and no mention of value of medication.
- Carers highlighted important need to have co-ordinated services delivered by professionals and carers with good understanding of dementia from beginning to end of disease journey.
- Carers want to remain in person's life in caring role even if patient now in care home.
- Carers often feel very isolated from care plan once person is in care home.
- Need for better support to bereaved family members.
- How to meet the needs of carers and individuals once they are in longer-term residential/ nursing homes, ie
    - Accessing health professionals
    - Being involved in care plans
    - Still being the carer!

(Consultation Event Meeting)

Key observations and areas for development against 14 objectives in the National Dementia Strategy for Torbay Care Trust

Objective	Observations	Areas for development	Actions	Lead	Timescale
Objective 1: Improving public and professional awareness and understanding of dementia	- Limited strategy or plan in place to raise awareness amongst general public. - Dementia Care Pathways booklet ~ 2,000 published currently.	- Develop and implement local campaign to raise awareness. Involve all partners and make full use of variety of media. - Involvement of public health/health promotion expertise on an alcohol/dementia prevention campaign. - Finalise local dementia commissioning strategy and formal validation process - Costed business case for 2010-11	OPMH staff to work with surgeries to increase awareness Develop public awareness and staff training strategy Present to SMT, TCT Board, PEC, OSC Finalise priorities and develop costed business case for 2010-11	Joanna Wildgoose Ann Redmayne Ann Redmayne Ann Redmayne	12 months 12 months Dec 09 Feb 10
Objective 2: Good-quality early diagnosis and intervention for all	- ↓% of expected dementia prevalence registered with general practitioners. - Good assessment and diagnosis from Devon Partnership Trust. - Memory clinics operating - EDI Policy Implementation Guide developed by the professional expert group.	- Need to monitor actively the % of general practitioner registered patients with dementia diagnosis. - Promote and monitor general practitioner uptake of awareness training offered. - Commissioners to lead work to establish clear service specification for memory service, with defined outcomes and capacity. - Improve case finding within the Community Learning Disability Service and identify services to meet needs ensuring linkage to an integrated dementia pathway.	OPMH team to work closely with surgeries to ensure registers are accurate Link to training plan in Objective 1 Write service spec based on EDI PIG and local need data. Commission expanded EDI service LIG to seek input from LD service and request they nominate a dementia champion (letter from AR to consultant & service manager).	Jane Batstone Ann Redmayne AR,DS,CW,JH AR/Nikki Henderson	12 months 12 months By Feb10 By Feb 10

Objective	Observations	Areas for development	Actions	Lead	Timescale
Objective 3: Good-quality information for those with diagnosed dementia and their carers	- Dementia Care Pathway booklet for carers. - DPT run post-diagnostic groups from memory clinic. - "One Stop Shop" - Carer's education sessions. - Memory clinic feedback interview. - Carer's education group. - Dementia pathway – Alzheimer's Society. - No leaflets from Alzheimer's Society about Alzheimer's Society Café.	- Commissioners to work with partners in Health & Social Care and third sector to monitor information available with view to improving access. - Undertake programme of audits to evaluate effectiveness of the information accessed by people with dementia.	Review what is available Audit department	SLL & David Mannion AR	6 months 6 months
Objective 4: Enabling easy access to care, support and advice following diagnosis	- "Days out" service. - Carers Support Groups. - Carers Support Workers. - OT post diagnosis group. - Sensory memory stimulation group. - Need to access follow on resources possibility outside mental health expertise base. - Memory cafe in Paignton all that is available but is appreciated and valued. - Comprehensive cohesive working in zonal teams. - Joint working at CMHT level – good relationships between health and social care.	- Learn the lessons from the Department of Health Dementia Advisors' Demonstrator sites and apply to local practice. - Memory Clinic needs to be developed to provide a variety of support and education options. - Also needs to link with a dementia pathway.	Apply learning, develop service specification, business case, consider pilot in one area Review Clinic and medication protocol Develop a fully commissioned comprehensive dementia pathway	AR JW, SLL AR	12 months 3 months 12 months

Objective	Observations	Areas for development	Actions	Lead	Timescale
Objective 5: Development of structured peer support and learning networks	- Host carer scheme open to people with early dementia. - Plans to commission a Memory Café network. - CMHT input into Memory Café. - Dementia Café runs every week. - Memory Cafés in Torquay & Brixham. - Carer's Education Group. - Carers' Support Group. - Memory Café well established (45-50 per week). CPN input weekly - Memory Café entirely volunteer run (sustainability) may be issue but very good model.	- Low intensity support (dementia adviser and peer support networks) are consistently cited by carers of people with dementia as their top priority. Support networks are generally inexpensive, and hence offer a potential early on. Opportunity to review coverage and funding arrangements and learn from national demonstrator sites.	Commissioners to develop a comprehensive pathway and commission it. This may involve transfer of resources. Fully Implementation of DOH peer support demonstrator project implementation plan. Ensure sustainability (commissioning strategy)	AR AR, SO, DM	12 months 18 months
Objective 6: Improved community personal support services **Objective 6 continued:**	- Host carer service innovative. - "Days out" service Age Concern limited to early stages (+ personal care element). - Host families – alternative day service. - Parkview Trust – flexible person centre day. - Self funders appear left very much to own devices. - Well managed dynamic leadership in zonal teams. - SWAP, host families. - St. Edmunds Residential Intermediate care and community support team. - Currently reviewing day services. - Joined up commissioning plans voiced by John Bryant.	- Review capacity of domiciliary care to meet actual and predicted demand. - Range and quality of day care	Consider specialist dom. Care service Review day care provision Encourage individual budgets	AR Hannah Horrocks SS, CW & Nicola Barker	12 months 6 months 6 months

Objective	Observations	Areas for development	Actions	Lead	Timescale
	- Eclipse lodge residential home.				
Objective 7: Implementing the carers strategy	- Dementia Care Pathway for carers. - Carers assessment completed by social worker at CMHT base. - Carer's assessment not universal. - "Yellow folder system for complex cases (travels with the patient). Carers support workers in GP surgeries.	- Promote Carers Strategy and link to programme of training amongst staff to raise awareness. - Review systems for collecting data about carers and identify improvements. - Consider an out of hours' helpline for carers. - Promote the work of the Carers Support Worker in each GP practice. - Range and quality of day care	SW to link with training programme Systems review To be commissioned SW to work with practices to increase awareness Review day care provision and develop community hubs Fully implement DOH demonstrator carer programme (dementia)	Linda Hammett /AR LH/Katie Heard AR LH Hannah Horrocks James Drummond	12 months 12 months 12 months 6 months By April 10 18 months
Objective 8: Improved quality of care for people with dementia in general hospitals	- Commissioning of a liaison service. - Have a dementia specialist acute/lead clinician in place. - Lots of innovative work in wards/departments. - Staff highly motivated. - Educational package very extensive.	- Raise profile of, and training for, DOLs and MCA to improve safeguarding. - Dementia awareness training to be comprehensively rolled out. - Environmental issues need attention using the Alzheimer's Society reference tool. - Liaison service and also care/intermediate care need to be properly commissioned and service specification formalised with provider input.	Prioritise training for key staff ~ plan to be developed for all staff As above Staff to work with University of Stirling to review environments Commissioner to develop service spec with DPT	Liz Childs/ Maggie Dunbar MD AR	6 months 6 months Fully operational by April 09

Objective	Observations	Areas for development	Actions	Lead	Timescale
Objective 9: Improved intermediate care for people with dementia	- Existence of intermediate care not age rigid - Excellent. - St. Edmunds Rehab Unit 9 beds for PwD-design friendly environment.	- Undertake a training needs analysis. - Regularly monitor effectiveness of intermediate care for people with dementia.	Undertake analysis Audit care	David Jones & Sally Pritchard DJ & SP	6 months 6 months
Objective 10: Considering the potential for housing support, housing-related services and telecare to support people with dementia and their carers	- Telecare show flat – clients known to CMHT have access to telecare via community alarm providers. - Designated team for equipment provision, including occupational therapist. - Several moves in and out of family homes to supported lodgings all broken down due to dementia symptoms (undiagnosed at time). - 45 flat ECH (John Boyne site) on track Oct 2010 with some designated dementia flats. - RSLs developing community hubs in sheltered and ECH.	- Telecare in St. Edmunds needs development - Further extra care housing for people with dementia + their carers planned (e.g. Guineas Trust 65 flats ECH remodelled from sheltered). Ensure plans linked with the local Dementia Strategy.	Sally to discuss options Strategies for housing and dementia need to link closely	SP AR, John Bryant, Barbara Alexander	6 months 6 months
Objective 11: Living well with dementia in care homes	- One nurse providing support/advice into care homes with additional support from CMHT. - Although homes mainly rated 'good' or 'excellent' by CQC, engagement with people with dementia in care homes could be improved. - Referrals into CMHT from nursing homes for fairly routine advice. - Fee level may tend to reduce quality. - Initial placement broke down	- Consider expanding current support to allow for training and education within care homes. - CPN and multi professional in-reach to care homes. - Consider and develop further preferred providers. - Need specialist pathway for dementia and roll out yellow folder. - Preferred provider lists or specific homes that are contracted with. - Contract specifications to focus on qualitative aspects and to be taken	Commission care home support team As above Tender to preferred providers Develop pathway Develop contract	AR AR AR & DS Ray Hodgson	6 months 6 months 6 months 6 months

Objective	Observations	Areas for development	Actions	Lead	Timescale
	after 6/12 (carer) . - Eclipse lodge private residential home– excellent model incl. outreach to local community.	into account alongside CQC rating. - Stimulate the role of dementia champions in care homes.	Care home link CPN	Bob Bartrum	6 months
Objective 12: Improved end of life care for people with dementia	- Joint advance statements which include sign up by Ambulance Trust. - Non-malignancy EOL pathway being considered. - Joint EOL care training available. - Auditing, care home admissions including DGH. - EOL strategy group not fully established. - Strategy for EoL care being developed but not yet implemented. - EOL care possible at St. Edmunds with input from Palliative Care Team. - Gold standard framework in place but not for dementia	- Consider expanding current support to allow for training and education within care homes. - Develop pathway in EOL strategy that is dementia specific.	Extend current developments End of Life strategy to link directly with DS	AR & Maggie Clough DS, AR & Reine	6 months 6 months
Objective 13: An informed and effective workforce for people with dementia	- Co-located CMHTs but 2 record systems can increase duplication. - Degree- level modules in University of Plymouth. - Eclipse lodge residential home excellent training and support for staff.	- Workforce development strategy required to address training needs across all partners in relation to dementia. - Extend dementia awareness training within the SDHFT to wider range of staff. - Improve awareness within zonal teams and with general practitioners and build confidence of staff to respond appropriately to needs of people with dementia and their carers.	Develop training strategy and implementation plan Increase training in hospitals Increase specialist team presence in the zones GP communication and education programme	AR Maggi Dunbar & community hospital matrons CW JW	6 months 12 months 12 months 12 months

Objective	Observations	Areas for development	Actions	Lead	Timescale
Objective 14: A joint commissioning strategy for dementia	- Dementia Strategy in draft form.	- Approve and publish the local Dementia Strategy. - Include milestones, target dates, lead individuals and clearly identified short and medium term priorities and investment in action plan.	Publish local strategy redraft - Present to January LIG - Communication plan	AR CW Jim Delves	Feb 2010
Objective 14 continued:		- Consider how core messages from local Dementia Strategy can be reinforced to relevant staff whose main focus is not dementia.	Link with training strategy	AR	6 months
		- Develop capacity planning, looking at quantifying supply of services at different points of an agreed commissioner determined dementia pathway, as well as demand in the JSNA.	Clear plan to increase capacity over 5 & 10 years	AR	6 months
		- Re-clarify the lead general practitioner role for dementia.	AR to discuss and clarify with LT	AR	3 months
		- Seek opportunities to involve clinicians and practitioners in a leadership role for certain work-streams.	AR & CW to identify key individuals	AR	6 months
		- Begin work to define outcomes for objectives in the local Dementia Strategy and commissioned services for monitoring and evaluation.	Local strategy to include a review and evaluation process bi-annually	AR	6 months