



# Living Well with Dementia in Warwickshire

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# **0** Dedication

This strategy is dedicated to the memory of Marion Grimwood 1929-2010, a founder member of the Warwickshire Older Peoples Partnership Board and the Dementia Task group. Marion was a relentless and passionate campaigner for quality older people's services in Warwickshire and a leading Dementia Champion locally.





## **1** Foreword

On behalf of the Dementia Task Group and Older Adults Policy Board we are pleased to present this first Dementia Strategy for Warwickshire.

This is the first time that agencies have come together to both consult and then produce a joint strategy and is further evidence of our intention to work together on an issue that matters in Warwickshire. Dementia is a complex and perplexing condition and includes a number of complex conditions the most common of which is Alzheimer's disease.

"We must not forget that people over the age of 55 fear dementia more than any other condition, including cancer. Yet public awareness about Dementia, its symptoms, the importance of getting a diagnosis and the help available for those with the condition has been very limited." Alzheimer's Society.

This strategy is Warwickshire County Council and NHS Warwickshire's response to the National Dementia Strategy. It sets out current initiatives designed to improve the lives of people with dementia, their carers and families, enabling them to have a more fulfilled life. It is the culmination of two years of work led by the Dementia Task Group. The Dementia Task Group comprises of a group of multi-agency professionals, carers and service users. It is anticipated that the commissioning process will take five years in total to deliver and is a whole system transformation supported by collaboration of all agencies working to improve both the experience and outcomes of people with dementia and their families.

Warwickshire believes that in taking forward this strategy that:

- People's experience of having dementia and the services they receive will improve, for them personally and for those individuals and families caring.
- Levels of public awareness and understanding will improve and
- The stigma associated with dementia will reduce as people become more aware of their diagnosis, what support and services are available to them, and how they can in turn keep well and live longer supported in the community of their choice.

We would like to thank all members of the Dementia Task Group, the Dementia Project team and the Phoenix Group - a North Warwickshire Peer support group for Dementia users and their carers - who gave and continue to give their time, energy and attention to the preparation of this strategy. Without their hard work this strategy would not exist.

Cllr Jose Compton Dementia Champion Warwickshire County Council John Linnane Director of Public Health NHS Warwickshire





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## **2 Purpose of Document**

The purpose of this document is to inform all people living and working with dementia on how Warwickshire County Council and NHS Warwickshire, in partnership, are taking forward the National Dementia Strategy and other supporting papers locally. This document covers how we currently commission services and how we propose to commission in the future. Future commissioning is set in the context of well publicised financial restraints but with a focus on quality. In line with Personalisation, an emphasis on choice and control for service users and their carers will be paramount moving forward.

#### **Overall Aim of the Strategy**

By 2014, all people with dementia will have access to high quality integrated services across health and social care from highly skilled staff.





# **3 Introduction**

### **3.1 What is Dementia?**

Dementia is a long term condition with a high impact on a person's health, personal circumstances and family life. Alzheimer's disease is the most common form of Dementia and is generally diagnosed in people over 70 years of age. As well as having a profound impact on the individual, Dementia can also have high impact on family members and friends.

"Dementia results in a progressive decline in multiple areas of function, including memory, reasoning, communication skills, and those skills needed to carry out daily activities. Along side this decline, individuals may develop behavioural and psychological symptoms such as depression psychosis, aggression and wandering, which complicate care." (National Dementia Strategy 2010)

## **3.2 Why Do We Need a Dementia Strategy?**

There is considerable evidence that supporting good practice for people with dementia and their carers can better the quality of their lives and reduce care costs. Some of the key research findings are summarised below:

- Providing people with a diagnosis decreases their level of anxiety and depression. (*carpenter et al 2008*) Only around 30% of people with dementia have a formal diagnosis made (*National Audit Office* 2007)
- Early diagnosis and intervention have a positive effect on the quality of life of people with dementia (*Mittelman et al 2007*).
  People often wait up to three years before reporting symptoms of dementia to their doctor (*Alzheimer's Society 2002*)
- Early provision of support at home for people with dementia can reduce institutionalisation by 22% (*Gaugler et al 2005*). A brief program of support and counselling diagnosis alone has been demonstrated to reduce care home placement by 28% (Mittelman et al 2007)
- People with dementia in general hospitals have worse outcomes in terms of length of stay, mortality and institutionalisation, but this is not widely appreciated by clinicians, managers, or commissioners. (Royal College of Psychiatrists 2005)





# **3.3 What people with dementia and their carers** have told us

People in Warwickshire want to be well informed and to know where to go to get good quality information, advice and a timely diagnosis when they are ill. The same applies for those with Dementia.

Users and Carers tell us that services are different across the county, access to these services is not always timely and support, information and advice limited. People want confidence to know that any services provided to them or the person they care for are of the highest quality.

People have told us that once diagnosed with Dementia we needed to develop a range of services that fully meet their changing needs as both an individual and those of their carer/supporter.

Extra care housing, telecare and assistive technology are an integral part of services for people with dementia, if improving quality of care and maximising choice, independence and control are to be achieved. Housing should be based on need not the environment in which it is provided.

Users and Carers applauded the National Dementia Strategy recommendation for an informed and effective workforce.

For a full detail of what people with dementia and their carers have told us please go to Appendix 1  $\,$ 





National And Local Context





# **4 National Policy Context**

This strategy is informed by key national reports and policy documents:

The National Dementia Strategy, 'Living Well with Dementia' Dept of Health February 2009 overarching goal is for people with dementia and their carers to be helped to live well with dementia, no matter the stage of their illness or whether they are in the health and social care system. The vision to achieve this is divided in three parts:

- To encourage help-seeking and help-offering by changing public and professional attitudes, understanding and behaviour towards dementia.
- To make early diagnosis and dementia treatment the rule rather then the exception. This will be achieved by locating the responsibility for the diagnosis of mild and moderate dementia in a specifically commissioned part for the system that can make an accurate diagnosis, communicate the diagnosis sensitively to those affected and provide individuals with immediate treatment, care and peer and professional support as needed.
- To enable people with dementia and their carers to live well with dementia by the provision of good quality care for all with dementia from diagnosis to the end of life, in the community, in hospital and in care homes.

#### The **Quality Outcomes for people with dementia: building on the work of the National Dementia Strategy. Dept of Health September 2010** reinforces and builds on the strategy above and states:

**Good quality early diagnosis and intervention for all** - Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.

**Improved quality of care in general hospitals** - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; co-morbidity with general medical conditions is high, people with dementia stay longer in hospital.

**Living well with dementia in care homes** - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

**Reduced use of antipsychotic medication** - There are an estimated 180,000 people with dementia on antipsychotic drugs. In only about one third of these cases are the drugs having a beneficial effect and there are 1800 excess deaths per year as a result of their prescription.





It is underpinned by **The Vision for Adult Social Care:** *Capable Communities and Active Citizens* sets out the Government's ambition for personalisation and states that:

' The Government's values of freedom, fairness and responsibility, shifting power from central to local, from state to citizen, from provider to people who use services. Our ambition is to foster the conditions in which communities... and others can develop a diverse range of preventative and other support that will help to reduce isolation, improve health and wellbeing and, by doing so, better manage the demand for formal health and care.'

The paper goes on to state that:

'Better use of existing community-based services, for example step-down re-ablement or home improvement and adaptations, can also reduce demand for nursing and residential care. We expect councils to look closely at how they can reduce the proportion of spending on residential care through such improvements to their community-based provision.'

#### The NHS Operating Framework 2010-2011(Revised)

The Dept of Health, in the Quality Outcomes for people with Dementia report, identified, through the Strategic Health Authority monitoring process, that dementia was not given sufficient attention by PCTs. In the revised NHS Operating Framework it now states:

'NHS organisations should be working with partners on implementing the National Dementia Strategy. People with dementia and their families need information that helps them understand their local services, and the level of quality and outcomes that they can expect. Localities should publish how they are implementing the National Dementia Strategy to increase local accountability for prioritisation.<sup>1</sup>

NHS Warwickshire has identified Dementia as one of its key priorities for 2011/2012.

Combined, these national strategy documents confirm that because of the projected increase of dementia and its associated costs there needs to be better joint provision which enables people to prepare and plan for their care that supports them to live well with dementia.

It is also worth noting that this strategy will be implemented during a difficult and well documented financial climate. More than ever investments will need to demonstrate that key outcomes are being delivered in an effective and efficient manner.

<sup>&</sup>lt;sup>1</sup> Quality outcome for people with dementia: building on the work of the National Dementia Strategy 2010.



## **6.1 Local Policy Context**

The Adult Social Care Transformation Programme underpins the development of this strategy. This whole systems transformation incorporates:

- Self directed support to become mainstream ensuring people have maximum choice and control
- Access to universal information, advice and signposting for all people irrespective of their eligibility for public funding.
- Personal budget for everyone who is eligible for public funded support
- An increase in the take up of Direct Payments
- Family carers treated as experts through experience and support to mainstream their caring role and to have a life outside of caring.
- o A skilled and informed workforce
- Commissioning that stimulated and incentivises high quality services that provides high quality services.





# **5 Population Profile and Future Demand**

### **5.1** The prevalence of Dementia nationally

Dementia presents a huge challenge to society both now and increasingly in the future. The Alzheimer's Society statistics tells us there are currently 750,000 people living with dementia in the UK<sup>2</sup>. This represents one person in every 88 (1.1%) of the entire UK population. By 2021 there will be over 940,000 people living with dementia and this is predicted to soar to 1.7 million by 2050, this represents a 125% increase in the number of people living with dementia between 2010 and 2050, or 3% per year. Oldest age is the largest risk factor for dementia. Around 68% of people with dementia are over 80 years of age, but there are over 16,000 people (2%) under the age of 65 who have the illness.

It is estimated that there are currently 735,000 people are currently living with late onset dementia in the UK. The table below show the prevalence rates for late onset dementia (aged 65 and over) per 100,000 of the population<sup>3</sup>. It shows that the prevalence of dementia rises substantially with increased age, on average almost doubling every 5 years between the ages of 65 and 94. There is a higher prevalence of late onset dementia for females aged over 75, population statistics tell us that the life expectancy of women is longer than men meaning there will be more women than men living with dementia. Overall The Alzheimer's Society estimates that approximately two women for every man living with dementia<sup>4</sup>.

		Female	Male	Total
	65-69	1,000	1,500	1,300
<u>ہ</u> ہ	70-74	2,400	3,100	2,900
nset ntia	75-79	6,500	5,100	5,900
O	80-84	13,300	10,200	12,200
Late Den	85-89	22,200	16,700	20,300
	90-94	29,600	27,500	28,600
	95+	34,400	30,000	32,500

#### Prevalence of Late Onset Dementia – per 100,000 Population

#### Early on set Dementia in younger adults

The table below show the prevalence rates for early onset dementia (aged between 30 and 64) per 100,000 of the population<sup>5</sup>. Young onset dementia is comparatively rare, accounting for 2.2% of all people with dementia in the UK, the Alzheimer's Society estimate that there are now

Dementia Strategy V1.00.doc





<sup>&</sup>lt;sup>2</sup> Alzheimer's Society (<u>http://www.alzheimers.org.uk</u>)

<sup>&</sup>lt;sup>3</sup> 'Dementia UK', 2007 - Alzheimer's Society

<sup>&</sup>lt;sup>4</sup> Alzheimer's Society (<u>http://www.alzheimers.org.uk</u>)

<sup>&</sup>lt;sup>5</sup> 'Dementia UK', 2007 - Alzheimer's Society

16,000 people with young onset dementia in the UK. However, given that data on the numbers of young onset cases are based on referrals to services, this number is likely to be an underestimate, the true figure may be up to three times higher. The prevalence of early onset dementia is higher in men than in women for those aged 50-65. There is a higher prevalence of early onset dementia for people from Black and Minority Ethnic (BME) groups. It is estimated that 6.1% of people from BME groups with dementia have early onset dementia, compared with 2.2% in the wider population of people living with dementia<sup>6</sup>. This means there is likely to be a demand for specialist early onset dementia services tailored to those from BME groups. Additionally people with learning disabilities, particularly those with Down Syndrome, have a greater propensity to acquire early on set dementia. Combined, this raises issues for appropriate provision of support to suit the needs of this particular group.

				•
		Female	Male	Total
	30-34	9.5	8.9	9.4
_ ۲	35-39	9.3	6.3	7.7
nse Itia	40-44	19.6	8.1	14
Early O Demen	45-49	27.3	31.8	30.4
	50-54	55.1	62.7	58.3
	55-59	97.1	179.5	136.8
	60-64	118	198.9	155.7

This chart shows the projected increase in the number of people living with late onset dementia in the UK between 2005 and  $2051.^7$ 



Projected number of people with late-onset dementia by age group (UK)

<sup>7</sup> 'Dementia UK', 2007 - Alzheimer's Society







<sup>&</sup>lt;sup>6</sup> 'Dementia UK', 2007 - Alzheimer's Society

#### **5.1.1 Economic burden of illness nationally**

The Alzheimers Society estimate that in 2007 the total cost of dementia in the UK was £17 billion per annum or on average £25,472 per person with late onset dementia<sup>8</sup>. Accommodation accounted for 41% and informal care inputs from family members and unpaid carers accounted for 36% of this £17 billion. The chart below show the distribution of dementia service costs



The table and chart below shows the average total annual cost per person based on the severity of their dementia and their setting and the breakdown of who is meeting those  $costs^9$ . It shows that the most expensive scenario is a person with severe dementia living in the community, however 72% of this cost is the estimated value of unpaid informal care provided by family and friends. 28% of the cost (£10,500 per person per annum) is provided by Social Services or NHS. The largest single cost is accommodation costs in residential care, representing 92% of the cost of people with dementia in care homes and is the responsibility of Social Services or NHS to fund if the person cannot fund their own care.

Setting	Total Annual Cost Per Person
People in community with mild dementia	£16,689
People in the community with moderate dementia	£25,877
People in the community with severe dementia	£37,473
People in care homes	£31,296

<sup>&</sup>lt;sup>9</sup> 'Dementia UK', 2007 - Alzheimer's Society





<sup>&</sup>lt;sup>8</sup> Dementia UK', 2007 - Alzheimer's Society

#### Living Well with Dementia in Warwickshire



### 5.2 The prevalence of Dementia locally

The total population of Warwickshire is 535,000 of which 95,000 people were aged 65 and over<sup>10</sup>. Taking into account Warwickshire population estimates and the Alzheimer's Society prevalence rates set out above it is estimated that there are currently 7,100 people in Warwickshire living with dementia. Using the population projections for Warwickshire it is estimated that by 2021 9,500 people in Warwickshire living with dementia, an increase of 34%. The projected increase in the number of people in Warwickshire living with dementia is a reflection of the projected 'demographic drift' where we will see people living longer and therefore more older people, particularly those living beyond the age of 85. As the prevalence rates showed the older a person becomes the more likely they will have dementia.

The graph below show the dramatic increase in older people's population compared to the 2011 baseline, especially in the 85 and over age group. The number of people aged over 85 is predicted to double between 2011 and 2028.

<sup>&</sup>lt;sup>10</sup> 2009 Mid Year Population Estimate – Office of National Statistics







Percentage increase in Older People Population, 2010 Baseline

When the projected population increases are combined with the dementia prevalence rates it shows the large projected increase in the numbers of people in Warwickshire living with dementia in the next 20 years.







The chart below illustrates that based on prevalence rates and population projections there will be significantly more women than men living with dementia in Warwickshire. However the proportion of men and women with dementia will be changing over the next 20 years. Currently 63% of people with dementia in Warwickshire are women, this is predicted to fall to 59% by 2028.



The chart below shows that effect of the 'demographic drift' on the predicted numbers of people with dementia is a particular issue for Warwickshire. Warwickshire is predicted to have the 3<sup>rd</sup> highest number of people living with dementia by 2028 in comparison to the rest of the PCTs in the West Midlands. Additionally Warwickshire is predicted to be amongst the largest proportional rise, a trend that is prevalent in all rural areas (i.e. Worcestershire, Staffordshire, Shropshire and Herefordshire)







The following table shows the current numbers of patients registered as having dementia within the local population by District rather than by proposed GP Consortium, against the expected prevalence. This will enable local targets to be identified in order to narrow the gap by 25% between the recorded incidence and expected prevalence by 2013.

Area	Recorded Incidence	Expected Prevalence	Percentage	Difference
Warwick	522	1492	35%	970
Leamington	420	1440	29%	1020
Rugby	219	580	38%	361
North Warwickshire	726	2218	33%	1492
Nuneaton	286	1073	27%	787
Bedworth	333	852	39%	519
Stratford	207	414	50%	207
Grand Total	3535	10747	33%	7212





# 6. Having an Assured Care Pathway for people with dementia living in Warwickshire

Warwickshire County Council and NHS Warwickshire, have, over a period of time, developed the Warwickshire Assured Care Pathway for people with Dementia and their Carer. Attached as a separate paper entitled, 'Warwickshire Assured Care Pathway for people with Dementia and their Carer.' This document illustrates the journey a patient and any carers should take once a diagnosis of dementia has been confirmed across the health and social care economy. Summarised below, the pathway also



Care Planning Process for Users and Carers defined to include -Dementia Advisors ( signposting for Users, Carers and Family) -Carers Support ( Carers needs and assessment) -Community Psychiatric Nurse for user to remain across pathway -Primary Care Liaison Worker to support GP in making a diagnos

> defines the type of services people should expect as their illness progresses. The Dementia has four key stages; Early Stage, Middle Stage, Later Stage and End of Life. Each stage is interdependent and requires transactional and transformational ownership across all partner organisations to ensure that the person with dementia and their carers receives high quality care.





## 7 Market Analysis

The National Dementia Strategy, in its development, was clear that Local Authorities and Primary Care Trust's should take a radical approach to whole system transformation to meet the twin aims of better outcomes at lower cost.

The national strategy has set a clear direction of travel. Using 17 objectives set within 4 broad themes:

- Raising awareness and understanding
- o Early diagnosis and support and
- o Living well within dementia
- Making the change

And defined within the care pathway, as illustrated below:



#### **Current Map of Services**

A market analysis has been undertaken to assist in building a picture of existing local services as well as a wider picture of the market and an assessment of current gaps in services availability. Using these objectives to establish a baseline of current provision, it provides health and social care with an evidence base of gaps in provision which will inform the future joint commissioning intentions for Dementia services within Warwickshire.





# 7.1 Raising Awareness and Understanding

**Objective 1 - Improved 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. Individuals should informed of the benefits of timely diagnosis and care, promote the prevention of dementia and reduce social exclusion and discrimination. It should encourage changes in behaviour in terms of appropriate help-seeking and help provision.

Dementia is increasingly becoming one of the most important causes of disability in older people. A key part of understanding mental ill health is to promote positive mental health and keeping a well 'mind and body', this includes people being aware of what they eat, drink and the exercise they take and how excess can contribute to long term conditions one of which is dementia.

As two-thirds of people with dementia live either in their own homes or with their carers, and as such, come into contact with the full range of universal services – e.g. housing, benefits agency staff and GP receptionists. A lack of understanding of dementia can lead to; a) symptoms not being recognised b) people not being encouraged to seek further information and support and c) care practices that can make the situation worse for both the person with dementia and their carer further creating an isolating and marginalised environment.

Wellbeing Exchanges, are currently provided to meet the needs of general mental health adults and older adults with functional conditions but none for Organic (Dementia). These are jointly funded through the Local Authority and NHS Warwickshire. There at seven bases across the County (5 x Mental Health Services and 2 x Local Authority) at a value of  $\pounds$ 60,000 per service.

Services report that they have provided signposting to both Age Concern and Alzheimer's society services and some drop in services for functional mental health do attract working age /early onset dementia users who do not want to access older age services.

A more rigorous public health campaign to raise general awareness of the benefits of healthy lifestyles and links to dementia, together with a better universal understanding of the impact of dementia given its potential to touch everyone's life, will underpin this strategy.

Joint training, across a range of providers and key stakeholders, including universal services, is discussed under objective 13.





## **7.2 Early Diagnosis and Support**

**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 that is 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.

#### **General Practice**

Practices in Warwickshire currently record some 2000 patients with a diagnosis of Dementia against the national prevalence and research indicators.

GP Consortia	Recorded Incidence	Expected Prevalence	Percentage	Difference
Warwick	522	1492	35%	970
Leamington	420	1440	29%	1020
Rugby	219	580	38%	361
North Warwickshire	726	2218	33%	1492
Stratford	207	414	50%	207
Nuneaton	286	1073	27%	787

There are currently around 7,200 people with dementia living in Warwickshire which suggests registration is not representative of need. This is a key issue for individuals as Quality Outcome Framework registers require individuals to be registered and for their care to be reviewed every 15 months. For those individuals diagnosed early this ensures speedy referral to Memory Assessment Services (MAS) and pharmaceutical and therapeutic interventions that will help them live active lives for longer. NHS Warwickshire has asked 15 low recording GP practices to specifically improve their Dementia QOF registration over the next year.

#### Memory Assessment Clinics

NHS Warwickshire currently commission Memory Assessment Services (MAS) through Coventry and Warwickshire Partnership Trust. There are currently three memory assessment clinics, each with their own consultants, in; Rugby, North Warwickshire and South Warwickshire. Access to these services is routinely through primary care. The clinics vary in approach due to legacy funding and the services currently commissioned vary across the county but will move to a more equitable model which is based on the outcome of a key stakeholder consultation in Sept 2009. Further focussed attention needs to be given to the referral process from GPs through to the Memory Assessment Services, part of





this will be to improve the screening process and links between Coventry and Warwickshire Partnership Trust as the provider and GP practices.

This operates a two stage approach for more complex cases, people will be referred to a consultant, for less complex referrals there will be a nurse led service which will help increase and improve throughput. Importantly referral routes need to be established for vascular conditions that results in people acquiring dementia, such as stroke hypertension and coronary heart disease.

#### **Community Mental Health Teams**

The development of the Community Mental Health Teams for Older People in Coventry & Warwickshire was informed by the proposal to integrate Coventry and Warwickshire County Council and the Coventry and Warwickshire Partnership Trust resources to form integrated health and social care Community Mental Health Teams for Older People in Coventry & Warwickshire. This arrangement has been underpinned by a Section 75 agreement under the NHS Act 2006.

The aim of the integrated service is to provide seamless health and social care to older people with mental health needs and their carers and whose needs are complex and fall within the scope of the service. All older people who are referred to the community mental health team will be individuals who have eligible needs as directed by Fair Access to Care Services guidance.

The team provide comprehensive specialist assessments, appropriate therapeutic engagements and interventions to:-

- people over the age of 65 years with functional mental health problems and people with dementia
- service users previously known to working age CMHT who have now graduated into older adults psychiatry due to their presenting needs
- people under the age of sixty five who have a diagnosis of early onset dementia.

The main functions of the integrated Community Mental Health Teams for Older People are to provide:

- Co-ordinated delivery of secondary health and social care for service users who have complex and enduring mental health needs
- Appropriate assessment to diagnose, provide treatment and enable people to access support
- Assessment of carers needs and access to support
- Advice and assistance to GPs, primary care teams and others on request.
- Give individual support, advice and assistance to agencies which provide care to older people with mental health problems if the service user is already known to Community mental health teams older people





• Assessment and appropriate follow up to known service users in other hospital locations

The service is also available to support family and other informal carers, professionals and agencies seeking to meet the needs of people who meet the criteria (e.g. residential and nursing homes, acute and community hospitals, generic health and emergency services). In addition the service is also available to agencies whose role includes supporting older people with mental health conditions to live independently (i.e. primary care and social care in the statutory, voluntary and independent sectors) with advice and occasional intervention to overcome short-term difficulties.

**Objective 3 - Good quality information for those diagnosed with 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.* 

Warwickshire County Council currently spends approximately  $\pounds$ 90,000 on commissioned information services. Primarily commissioned through the Alzheimer's society, the service provides information and advice to people with dementia and their carers.

Part of this expenditure is used to develop a dementia specific website that links several other sites including; NHS Choices, Guideposts, Alzheimer's, and Sterling University. The site development is part of the dementia demonstrator site bid award and is supported by a range of organisations including; the Phoenix group, a post diagnostic support group in the North of the County. Adult Health and Community Services as part of the dementia demonstrator site work have commissioned the Phoenix group to research the type, format, source, accessibility and usefulness of advice and information available to newly diagnosed dementia users and carers.

In addition to the service provided by the Alzheimer's Society a number of other providers supply information and advice for both users of services and their carers/families. All of the material used by these providers is currently accessible through the WCC Dementia website. This is to ensure ease of access and a central gateway to services for both professionals and the public.

Community mental health teams have some publications and leaflets that are used in the assessment and care management process.

#### Advocacy

Warwickshire currently commissions its Advocacy services jointly with NHS Warwickshire from a singe voluntary sector providers.

In July 2010 NHS Warwickshire commissioned Independent Advocacy, the joint provider, to produce a report and recommendations in respect of the





needs of people with dementia. The report indicated that some 197 contacts were made by service users for support ranging from; benefit advice, housing related support legal issues, debt, finances, and appeals. Recommendations have been made to NHS Warwickshire in respect of converting part of the current service to a Dementia specific resource. There is also further work to scope future advocacy services for social care underway to ensure better commissioning of this form of support.

For those users who lack capacity to make decisions Warwickshire adult social care jointly commissions, with Coventry City council and Solihull care Trust, Independent Mental Capacity Act services. This is provided through a grant the valued £137k.

Objective 4 - 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.

#### **Dementia Advisor**

Warwickshire was successful in securing 1 of 22 national Dementia Advisor Demonstrator sites in the North of the County. A Dementia advisor has been appointed. The purpose of this role is to provide information and support to newly diagnosed patients and to signpost the journey ahead and the services and support that will be available to people with dementia and their carers. Intervention at this stage when people are first diagnosed is seen as key to enabling people with dementia and their carers to come to terms with the disease and enable them to cope better throughout their journey with dementia. A key benefit of this role is the relationship with the memory assessment service and links to people at the point of diagnosis.

National evaluation of the Department of Health Demonstrator site pilot is inbuilt into the DH programme. Locally Warwickshire have commissioned TD4H, an independent provider to develop a programme of evaluation (IPOP) with the capabilities of measuring both qualitative and quantitative information produced through contact made by the dementia advisors. Long term the programme capabilities include outcome measurement and quality of life measures for the person with dementia, types of services accessed and impact on admissions to both residential and acute care settings. Lessons learned from the pilot will inform our future joint commissioning intentions. Early responses from users tell us that the service is valued, has enabled people with Dementia to have a choice in decisions made about their future and has secured for those users a voice.

The service currently is linking with the Admiral Nurse Service in the North of the County to ensure that carers are also fully supported and issues such as Advance Directives are discussed. Admiral Nurses provide support to carers of people with dementia. The Admiral Nurses are trained Community Psychiatric Nurses who:

- work with family carers as their prime focus
- provide practical advice, emotional support, information and skills





- deliver education and training in dementia care
- provide consultancy to professionals working with people with dementia
- promote best practice in person-centred dementia care

A full evaluation of this project will inform the commissioning intentions of this strategy in relation to developing future dementia advisors across the county.

**Objective 5 – 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.

#### Peer Support & Dementia Cafés

Peer support is key to living well with dementia. Peer support services have developed to give people with dementia an understanding of how other people with dementia perceive and cope with their own illness and the problems they may encounter every day. This includes the possibility of social isolation and difficulty in accepting the diagnosis, and what this means to them and their families. Peer support brings with it the emphasis that individuals with dementia and their carers are not alone in coping with the disease and encourages interaction with others who know, as far as is possible, what they are going through. The dementia cafes are designed to complement formal care and information services and are part of a wider range of psychosocial treatment, care and support, which is critical for an illness with limited medical treatment options.

The café are usually supported by a skilled facilitator and can be thought of as a type of guided self help peer support group. The service is provided for the person with dementia as the first priority. The service is available to people who have received a diagnosis of dementia who may attend either unaccompanied where appropriate, or with family, friends or carers. Cafés are generally directed at people in the earlier stages of dementia, although people at different stages of dementia are included.

Service	Location	Annual contract value	Funding Source	Evaluation
Alzheimers Society Advice and Information	Rugby, South, North	42,000	AHCS (inc one-off grants)	Low-level services review
Alzheimers Society Café	South, Warwick	10,777	AHCS (one-off grant)	Low-Level services review
Peer	North/ N+B	10,000	CWPT	Under review

#### **Current Spend on Low-level dementia services**



Dementia Strategy V1.00.doc



#### Living Well with Dementia in Warwickshire

	Gross Spend	159,750		
Dementia Advisors Project	North	103,750	Dementia Demonstrator Site (DoH)	Full review being carried out by consultancy
Dementia website	Countywide	2,000	Dementia Demonstrator (DoH)	Ongoing review as part of Demonstrator site
Joes Cafe	North/ N+B	2,000	CWPT	-
Support/ Phoenix				

Service reviews for low-level services will be considered as a high priority to ensure commissioning intentions are delivering against Objective 5.

Discussions with members of the BME Phoenix group indicate that membership is low. It is perceived that some members are not seeing the benefit of peer support. It is essential that in taking forward information and promotion for Dementia services with the BME community that advice and support to people from different cultural backgrounds and with specialist needs are included in services commissioned. Further work needs to be commissioned to understand the specific needs of people with dementia from minority communities and their ability to access mainstream services.





## **6.3 Living Well with Dementia**

#### **Objective 6 - 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.

#### **Personal Budgets**

SCIE define a personal budget as an allocation of money that is to be used to meet the individual's personal outcomes. Key to the personal budget approach is the need to give clear early understanding of the amount of money available, so that they can influence and control how it is spent, in a way that best meets their needs. Personal budgets must be implemented within the framework of self directed support which involves self directed assessment, up front allocation of money and support planning to promote choice and control.

Personal budgets are already being used across older people and physical disabilities services. Learning disability clients will begin using personal budgets from April 2011. For older people with mental health issues including people with dementia plans are at a formative stage and its anticipated that they will be implemented by September 2011.

#### **Community Fast Response Team**

NHS Warwickshire in partnership with CWPT recently de-commissioned Acute specialist MH beds at Hawthorne ward in Rugby, diverting acute resources to a community based 'fast response team' for dementia/older adult mental health clients. Early evidence shows that the new service has succeeded in reducing/diverting admissions through its assertive outreach approach. Consideration now needs to be made in rolling our both this service and to expanding the current Crisis Resolution and Home Treatment services available to functional adult mental health to all older adult provision on a 24/7 basis. This will prevent inappropriate admissions, facilitating early discharge and provide specialist home support to users, families and carers.

#### **Domiciliary Care**

Specialist domiciliary care for people with dementia is a necessary component of support to enable people with dementia to be supported to live in their own homes. Not all people with dementia necessarily require specialist dementia domiciliary care as their needs follow a continuum and many people's needs are appropriately met through standard domiciliary care where staff are appropriately trained in dementia awareness. This is





the case where a persons needs are primarily for personal care rather than mental health care.

However, there are a small number of people who needs do require specialist care. A specialist dementia service is only likely to be required where the person with dementia may be presenting with challenging behaviours.

There are currently three models of domiciliary care that caters for people with dementia. These include:

- $\circ~$  A countywide generic model of maintenance through a block contract with providers, valued at £304,333 per week with call off
- A specialist dementia spot purchase contract provided by Guideposts valued at £8988 per week, this covers 35 people per week totalling 432.32hrs.
- An in house specialist model operating in the North of the County and Stratford only, the value of this contract is  $\pounds400,000$  working with some 17 clients in total in 2009/10 clients with dementia.

#### **Specialist Domiciliary Care**

Warwickshire County Council currently operates an internal specialist dementia domiciliary care service and commission a service from a specialist external provider. The external provision has been in place since April 2008 and currently supports 33 having peaked at almost 50 customers in September 2008. In November 2009, elected members approved the establishment of a 2<sup>nd</sup> specialist dementia in house home care service in Nuneaton and Bedworth, to mirror the one that had been operating in Stratford since 2007. The internal service currently supports 25 customers, in June 2010 it was supporting 34.

The chart below show the trend in the number of customers receiving the internal and external services since January 2008. The reduction in the number of people receiving domiciliary care is mirrored in domiciliary care for personal care needs and is a result of the County Council's reablement service helping people to regain their independence and therefore not be reliant on council funded services, this is combined with a stricter application of Fair Access to Care eligibility criteria. At present reablement is for personal care needs only but the service will soon be rolled out to help people with dementia regain their independence which will likely see a reduction in demand for specialist dementia domiciliary care.





**Dementia Home Care Customers** 



Source: WCC Carefirst

This chart is taken from Adult, Health and Community Services Transformation Monitoring. It shows the total weekly cost of specialist dementia domiciliary care since January 2008 and predicts (from April 2010) what demand would have been, based on trends and demographic changes, if the Directorate did not change the way it delivered its services. It shows that the weekly cost of specialist dementia domiciliary care is predicted to rise by 40% between April 2010 and March 2014.



**Total Weekly Cost - Dementia Home Care** 







#### Living Well with Dementia in Warwickshire

The following 2 charts show the split between internal and external specialist dementia home care provision. They show that 68% of the total hours of care being provided are though external provision but this represents just 60% of the total cost. This is a reflection on internal services being more expensive to deliver than external provision. The cost per hour for external services is £21, compared to £30 for internal services.



#### Dementia Home Care - Hours per Week









#### Non-Specialist domiciliary care

In addition to the specialist dementia domiciliary care provided a number of people living with dementia have a predominant need of personal care that can be met with non-specialist domiciliary care. In November 2010 119 people identified with Dementia were receiving non-specialist domiciliary care totalling 1000 hours per week (8.4 hours per person per week on average)

#### **Voluntary sector day services**

Warwickshire County Council also commission the voluntary sector to provide day services:

Name of Org	District	Value of Contract	Users/ wk	Cost per unit	Contract Type
Alzheimers Society	Stratford/ Warwick	115,351	61	36.3	Block
Age UK	North	122,361	60	35	Block
Rugby Mind	Rugby	52,275(+25K PCT)	75	20.6	Block
	TOTAL	289,987	317		·

#### **Independent day care**

As at 2009/10 and through block and/or spot arrangements the following day care was provided specifically for people with dementia:

	Total Spend	244,721	151	
Chasewood Lodge	Nuneaton & Bedworth	8,271	3	Spot
Bentley House	North W	37,606	13	Spot
Pinnacle Care	Rugby	137,473	105	Block (voids)
Gildawood Court	Nuneaton & Bedworth	60,921	30	Block (voids)
Name	Area	Annual Value	Sessions per wk	Spot or Block contract

Day care block contracts with independent providers are currently underused with a large number of voids. It is vital that this is addressed given the financial pressures outlined on page 56 of this strategy.

All Day Care services were subject to a full Value for Money review in Sept 2009 and subsequent cabinet report in January 2010; this included dementia specific services. Day Care services are now subject to an





efficiency savings target across portfolios of Warwickshire's Transformation Programme. Mental Health specific day services, of which dementia specific services form a significant part, are expected to deliver efficiency savings totalling 25%. This is through a review of eligibility, a tightening of the eligibility criteria and a move towards a more personalised model of day opportunities, including a shift to Individual Budgets/ Direct Payments to fund day opportunities. We must remember that day care is one element of carer support and must be considered as part of the wider preventative strategy in dementia services.

#### **NHS day services**

Α range of davs services including day care and day treatment/assessment are offered across the county. Some of these incorporate memory clinic services. Coventry and Warwickshire Partnership Trust the provider of these services has developed and agreed with commissioners a pathway to these services to ensure clarity in future Again there are issues of equity across the population. A provision. review of these services is pending but in the South of the county hospital day care has already been reduced to one day a week for all attending. This reduction impacts on services being provided by social care to meet the shortfall.

Nuneaton	Mira Peripatetic Day Hospital	Various functions: assessment, treatment and respite.
Warwick	Woodloes	
Stratford	Loxley	
Rugby	Maple* (due to move to the Railings)	

Each of the three services above are being independently reviewed. However, each part of these service are interdependent including those commissioned through adult social care. Economies of scale need to be explored to developing a joint approach to day opportunities.

#### **Objective 7 - Services within 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.

Warwickshire's strategic intentions with regard to services to support carers embody the core principles of the "Vision for Adult Social Care: Capable Communities & Active Citizens" for services to be more personalised, more preventive, more outcome focused. The revised Warwickshire Carers Strategy "Carers Support Services: Transformation and Savings Plan 2011-14" also incorporates the key priorities for carers





support identified in the national refreshed Carers Strategy "Recognised, Valued & Supported: next steps for the Carers Strategy" which are:

- Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages
- Enabling those with caring responsibilities to fulfill their educational and employment potential
- Personalised support both for carers and those they support, enabling them to have a family and community life
- Supporting carers to remain mentally and physically well

Currently, generic information, advice and support services are being provided by Guideposts Trust in the north of the county and the Carers Support service in the south. These services offer support to carers of people with dementia. Rethink also provides a countywide information and support service targeting carers of people with mental ill health.

In addition to the above services there is:

Local Authority Specialist Mental Health Carers Assessment Workers. Based in localities carers assessment workers provide specialist assessment and support to adult and functional older adults with a MH diagnosis.

Carers Education Specialist Programmes CESP (through Rethink) to new carers enabling them to understand specific mental health conditions, treatment, medication and signs of deterioration/relapse and referral routes into services. One module of the current 12 CESP modules is a dementia module.

Dementia UK Admiral Nurses: Warwickshire has 2 Admiral Nurses commissioned by CWPT. Admiral Nurses are specialist mental health nurses specialising in dementia. Admiral Nurses work with family carers and people with dementia, in the community and other settings. Working collaboratively with other professionals, Admiral Nurses seek to improve the quality of life for people with dementia and their carers. They use a range of interventions that help people live positively with the condition and develop skills to improve communication and maintain relationships. Carers report that the support of these specialist nurses particularly at key changes in the cared for life, (admission to residential care, end of life/palliative care) is invaluable.

#### New strategic developments in carers services:

A new approach to carers' information, advice and support is being commissioned and is due to begin in July 2011. The new service will be offer a consistent, county-wide, frontline open door for all Adult carers and will reach out to identify carers earlier in their caring role. It will ensure that carers are better informed about their individual caring role and provide or enable access to specialist advice and support.





There is currently no carer education and training programme available countywide for carers of people with dementia and this is a service which is clearly needed. Evidence nationally supports the development of these programmes as a way of delaying institutional care.

Respite care is a significant support service to people who use services and their carers and families. As the spending profile of internal and external respite provision across the County, attached as appendix 2 illustrates, cost of bed based respite provision fluctuates. It is important to note that external provision costs vary with usage from £65 to £76 per day whilst internal provision is fixed at a rate of £92.86 per day whether it is used or not. A review of respite provision will form part of the delivery plan. This will provide the opportunity to look at more innovative cost beneficial types of respite, such as the use of assistive technology.

The provision of carer replacement services for people with Dementia in Warwickshire is small. Community based carer support is provided by Carers Short Break services. This is predominantly from Carers Short Break block contracts totalling £362K per year, provided through the carers grant. However, these contracts are not dementia specific. In addition, dementia Day Care and 1:1 community support can be considered as carers support services, as a dual purpose is providing the carer with a break.

Crucially and as partnership with NHS Warwickshire and Coventry and Warwickshire Partnership Trust we need to review the usage and type of future respite and Carer Support facilities.

**Objective 8 - Good quality care within 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.

The Royal College of Psychiatrists report 'Who Carers Wins'(2005), on improving outcomes for older people with mental health needs in acute general hospitals estimates that up to a quarter of people in general hospitals at any one time have dementia. They indicate that this places the responsibility on commissioners of acute services to commission high quality care for people with dementia.

The National Dementia Strategy suggests improving care for people with dementia in general hospitals by providing:

- A nominated senior clinician to provide leadership,
- Developing a care pathway for people with dementia supported by a specialist liaison service.
- $\circ~$  Evidence based commissioning, this should include number of delayed transfers of care.





- $\circ~$  Ensuring the acute trust has a place on the locality commissioning board for Dementia
- Ensuring staff are dementia trained
- Ensuring that the needs of users and carers are included in all commissioning contracts with acute trusts through adoption of the Dignity in Care campaign and Essence of Care standards.

NHS Warwickshire have already taken to steps to address some of these issues. Through the CQUINN, a quality initiative, the Acute hospitals within Warwickshire have been incentivised to reduce the use of anti psychotic drugs. In addition, a target of 50% of staff trained in the management of dementia was also used to improve the experience of people with dementia in an acute setting.

NHS Warwickshire confirm that avoiding or preventing admission is a key focus for the coming year. A joint approach is required to avoid admissions and to reduce discharge to residential care, both of which are significant financial pressure points that deliver poor outcomes for the person with dementia and their family. Part of this reduction in admissions, which generally become complex cases to discharge, is a better understanding within community services, including adult social care of the management of dementia. Creating an oversight of community teams by a psycho-geriatrician is being pursued as a model to reduce avoidable admissions of people with dementia and supporting discharge to home or intermediate care as a first option.

**Objectives 9 – Intermediate Care for people with Dementia** Intermediate care which is accessible to people with dementia and which meets their needs.

In its review of Intermediate Care the Department of Health (DoH) anticipates that commissioners will ensure that people with dementia will have full access to intermediate care services.

To support commissioners the DH offer three models none of which are exclusive:

- Expanding existing services to include dementia, this would require specialist input from mental health services/teams and a review of workforce skills.
- Commissioning a specialist MH intermediate care service that would cover all mental health needs, rather than just dementia.
- Commission specialist MH intermediate care beds

NHS Warwickshire currently commission a generic intermediate care service, this excludes people with a diagnosis of dementia although inevitably some individuals referred have subsequently been diagnosed. Discussions have begun to jointly commission these services in the future.




# **Objective 11 – Good housing, housing related and telecare support.**

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.

### **Extra Care Housing**

Although the national evidence base regarding people living in an extra care housing is in its infancy, a recent review funded by the Joseph Rowntree Foundation suggests there is mounting evidence that people with dementia living in extra care housing generally have a good quality of life. The review suggests that older people moving into extra care housing have much less physical and mental impairment than those moving into the various models of residential care, including nursing homes, whilst research studies by market leaders, including housing21 - one of WCC's Framework partners - suggest that around 25% of extra care housing residents have some level of dementia.

Specialist programmes of work have now developed that shows more positive results through better engagement with individuals and their families, utilising what can be seen as a common sense approach to dealing with people with dementia. The support proposed through the 'Equal Opportunities programme' of working includes:

- **Specialist dementia expertise** embedded within the staff base of the Extra care housing team to work with individuals and the team to ensure residents reach their full potential for wellbeing.
- **Individual Assessment and case work** that is personalised to enable individuals to achieve their goals identify types of interventions, occupations and activities that are most likely to unlock the potential for wellbeing and help people to achieve goals. Case work interventions also enable issues to be dealt with promptly before problems arise.
- **Staff Training**, any staff who have face to face contact with residents receive a 1 day training course ( as a minimum) in person centred care and mental health awareness. For senior staff this should increase to a three day course in enabling residents specifically with MH issues to work within the 'Enriched Care Planning Approach', the dementia Lead mentoring these staff to ensure skills are utilised and retained.
- **Management and Leadership**, the site management team are additionally supported externally to ensure all of the above are in place and actively used to better the experience for the service user and their family.





There is a cost to this programme which will be embedded into contracts at the point of commissioning. The programme delivered fits well with personalisation, person centred planning and recovery, re-ablement and retention of independent living skills.

### Housing Related Support

A Strategic Review of Supporting People services for older people has been carried out with the recommendations being consulted upon. There are no Supporting People services specifically for people with dementia, however, it is recognised that current services do accommodate and provide support to people with low and sometimes medium level dementia. However, the review highlighted the predicted growth in the numbers of people with dementia in Warwickshire and recommends that housing related support services commissioned in the future for older people should ensure that those providing support should receive appropriate training in safeguarding older people and awareness raising and basic training in dementia.

### **Housing Options**

Warwickshire was awarded £193,000 funding from central government for 2 years to pilot a specialist housing and care options for older people. This service comprises a countywide telephone service through a national provider and a local visiting service for those who require it with a Warwickshire written guide for older people living in Warwickshire, their families and carers and professionals. The visiting service can also provide support to those older people who wish to move to more appropriate accommodation. The pilot service is a partnership between a telephone housing options provider, the County Council and District and Boroughs. The service will be evaluated and is due to end in March 2012.

The service provides information and advice about:

- Services which enable people to continue to live in their home. This can include handyperson services, home safety check schemes, community equipment, adaptations and equity release schemes
- Alternative housing options including: moving to more suitable, often smaller accommodation, moving to accommodation where care can be provided or moving to a care home.
- Advice to people who would like to buy or part buy a smaller, more manageable home.

A Housing Options service is a proactive approach to meet the prevention and early intervention agenda, for example through falls prevention, as well as improve hospital discharge. A Housing Options service also enables and supports people to maintain their independence either through moving to more appropriate accommodation or remaining in their own home safely. The preventative outcomes anticipated from a Housing Options service are that:

• More people will live independently in their home through options that enables this or through support to move to more appropriate independent living.





### Living Well with Dementia in Warwickshire

- Falls reduction and improved hospital discharge.
- Reduced crime through making properties more secure.
- Improved health and reduced heating expenses with reduced numbers of older people with flu and pneumonia through making properties warmer or downsizing to more economical properties.
- Improved quality of life of older people.
- Improved information available on housing and care options to enable more people to make appropriate choices at the right time.
- Delayed transfer of older people to care in residential homes as they are enabled to live at home for longer safely or by finding a more appropriate accommodation option.
- Reduced concerns and burden for carers and family members.
- Prevention of future more costly home repairs which can result in an individual deciding to move to less independent accommodation or living in poor quality housing.
- Reach those people not linked in with any other services and provide preventative information.
- Release family homes by supporting those who make the choice to downsize their property so enabling districts to meet more family housing need.

### Telecare

Telecare is a key element of both national and local strategies and cuts across health, social care and housing. The national vision in Lifetime Homes, Lifetime Neighbourhoods and the local vision for the transformation of housing support services in Warwickshire both see telecare and assistive technology as an integral part in the range of housing options as part of a wider and more joined up approach to meeting housing need in order to support people to live independently.

Assistive technology is defined by the Audit Commission as 'any item, piece of equipment, product or system that is used to increase, maintain or improve the functional capabilities and independence of people with cognitive, physical or communication difficulties.' It can help individuals maintain independence, increase safety and confidence and support carers alongside traditional healthcare, social care and housing initiatives.

Whilst the numbers of people using telecare in Warwickshire with a diagnosis of dementia was not available (due to the way Districts record data) the promotion of equipment and its use has progressed.

People, including those with dementia and their carers, will have access, via community mental health teams, to a range of equipment that can support their independence at home. This can include; discreet GPS watches allowing users more freedom and mobility, memo minders, flood detectors, IPads to enable users to actively participate in their care planning and completing and compiling life story work, carbon monoxide detectors, gas shut off valves, fire detectors, lamp modules and pill dispensers.





It is also our intention to utilise capital funding to develop 'Smart Suites' in each locality enabling users and their carers, with staff support to look at what this type of equipment and support can offer before they buy, ensuring familiarity with the product and effective usage to support independent living.

By supplying a range of equipment to the teams and training teams in its use we hope to ensure that telecare is an integral part of every assessment otherwise it is unlikely that the benefits, including the cost benefits, of using telecare will be realised.

### Just Checking System

Just Checking is assistive technology and can be used to enable professionals to build a more detailed picture of how a person with dementia is going about their daily life, during the day and night. It is useful at times when the person themselves may not be able to provide or recall much information and is a valuable tool in demonstrating what skills remain to enable the person to stay at home for as long as possible. There is compelling national evidence that the system can:

- Reduce home care calls by 50%
- provide evidence to tailor packages of support more effectively
- give objective information to concerned relatives

Just checking is a simple web based activity monitoring system. Small wireless sensors in the home generate a chart of activity which is accessed via a secure website. Health and social care professionals and family members can see when the person:

- got up and went to bed and whether they have had a disturbed night
- visited the kitchen to prepare meals and drinks
- left the house and for how long
- and generally, their daily patterns and how they are responding to care services

Understanding the day and night time patterns of a person with dementia will allow care to be targeted to best effect and can help gauge the effectiveness of services which are being provided.

2 of these systems are available to each community mental health team and there are plans to commission 6 more for wider use. An evaluation of the cost benefits of this approach (which has already been proven elsewhere) will be completed in the summer of 2011.

A care package of 2 home care visits a day, plus Just Checking instead of residential care saves £383.00 a week, an annual saving of £19,916 The cost of purchasing and running a Just Checking system for a year is covered if residential care is postponed for just 10 days.





### **Objective 11 - High quality services within care homes**

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

The Council has direct control over 19 care homes (686 places) for older people, of which 9 are operated on its behalf by Warwickshire Care Services, an independent not-for-profit organisation. Approximately another 400 places are purchased from the independent care home market and approximately one quarter of these include a top-up payment from relatives in addition to the standard fee rate funded by WCC.

The split between ordinary (or 'higher dependency') residential care and specialist dementia care has shifted considerably over the last few years. A recent independent survey highlighted that in the proportion of dementia care in the residential care market had risen from 9% to 52% over the last 10 years (6% within WCC homes). In the independent sector, many homes are now dual-registered for both forms of care so that if demand for dementia placements was to increase proportionately then availability could adapt accordingly.

The council is planning to retender its block contract currently being provided by WCS for 11 care homes across the County and this will provide an opportunity to introduce some of the future plans for dementia. Although the details of this contract are exempt from public discussion it is clear that the proportion of dementia residential care beds will increase and the overall strategy will include the focusing of one care home in each of the 5 districts on specialist dementia provision before the end of 2012.

### **Nursing Care**

The number of places provided by the county's 33 nursing homes for older people is over 1,600. Nursing care is commissioned jointly with the PCT but the level of dementia care within this provision is far more difficult to define than in residential care because of the range and interdependencies of health conditions. Although a number of local authorities offer a higher fee rate for dementia nursing care (as opposed to standard nursing care), The Care Quality Commission is not isolating this service as frequently as in the past and WCC have no plans to introduce this as a distinct category. However, the council is working closely with the PCT to improve overall provision and quality within nursing homes with particular attention to meeting customers' needs in relation to dementia care e.g. awareness and training.

### **Sustaining Quality**

Quality is a key issue for existing and potential residents and their families. To enable us to be proactive in the provision of good quality care we need to be aware of what quality means to older people:

> Keeping clean and comfortable





- > Enjoying a clean and orderly environment
- > Being safe
- > Having company and social contact
- > Being active, having something interesting to do.

Reference: Qureshi and Henwood 2001

These quality expectations will be built into our overall strategic vision and As identified in the recent report performance monitoring process. "Commissioning Driving up Performance" one of the key challenges facing Directorate's ability to improve performance through the the commissioning process will be the future needs of the Warwickshire population set against the financial constraints over the next 3 years. The Directorate's vision of ensuring that people's choice and voice are accurately represented in the delivery of services through focussing more on outcomes (rather than outputs) will face a reduction of 9% in baseline resources during this period. At a time of major change in both commissioning and performance frameworks, the Directorate must therefore be able to forge much stronger links than ever before between commissioning and performance if it is to ensure continuous improvement.

One strategy being developed to tackle poorly functioning services is to apply differential fee rates that reflect contract performance particularly where dignity, safeguarding or overall quality standards are not being delivered. And Warwickshire County Council will provide assistance in the form of targeted training to help lift standards with poorly performing providers.

### **Objective 12 - Good end of life care**

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.

In the West Midlands 60% of dementia patients die in care homes which is contrary to the research that suggests that most people want to die in their own homes. The vision for all future End of Life Care services developed and delivered by NHS Warwickshire are as follows:

All people in Warwickshire at the end of life will be supported and cared for, feel safe and listened to and will be enabled to die with dignity and respect.

The population of Warwickshire will have the opportunity to access an equitable, comprehensive and high quality, range of end of life care and services. These will be person and family focused, promote choice, provide symptom control, respite, psychological, social and spiritual support. They





# will be sensitive to the individual's needs and wishes and delivered in a timely, integrated and coordinated manner.

There is a Warwickshire wide End of Life strategy which has been developed after consultation and in partnership with varied stakeholders which included Coventry and Warwickshire Primary Care Trust's, Warwickshire County Council and providers of End of Life Care including acute trusts, hospices and community services and patients and carers.

Historically End of Life Care and palliative care services have been primarily focused on care and the needs of people with cancer. The needs of individuals with other conditions such as dementia, chronic heart disease, chronic obstructive pulmonary disease, progressive neurological conditions i.e. dementia and Huntington's disease, stroke, progressive organ failure and AIDS have often been overlooked. The End of Life strategy sets out a five-year plan for the development and implementation of End of Life Care services for the people of Warwickshire in their last 12 months of life, applying to people of all ages, states of health and clinical condition and diagnosis

There are a range of pathways and frameworks that are used to support people at the end of their life. These include:

### **End of Life Care Frameworks**

Gold Standards Framework	Liverpool Care Pathway	Preferred Place of Care
(GSF)	(LCP)	(PPC)
The GSF framework, aimed at both primary care and care home settings, seeks to improve the care provided to patients nearing the end of life by achieving the following goals:	The LCP framework is a clinical pathway that provides guidance to clinicians on how to improve care of the dying in the last hours/days of patient's life.	The PPC document is a patient record, designed to record and monitor patient and carers choices and services received by all terminally ill patients.
<ul> <li>1.Patients are as symptom controlled as possible</li> <li>2.Place of care – patients are enabled to live well and die well in their preferred place of care</li> <li>3.Security and support – better advanced care planning, information and</li> </ul>	It provides guidance on indications for comfort measures, prescribing and discontinuation of inappropriate interventions and meeting the personal wishes for the last days of life.	The aim of the document is to give patients and carers choices and aid communication with and between professionals.
less fear, hospital admissions , fewer crises 4.Carers are supported, enabled and empowered 5.Staff confidence, communication and co working are improved	Designed for hospital use for cancer patients, it can be used for people with any diagnosis, in nay setting, care home, hospice and community.	





A substantial number of Warwickshire residents die in care homes. Those with specific conditions such as dementia are more likely to die in a care home. Quality of end of life care in homes is reported as variable. Public health data highlights variation in care homes admitting to acute trusts for people at the very end of life.

A number of Warwickshire county council care homes have residents who have not had a formal diagnosis or may have mental health concerns, Warwickshire county councils own internal homes have produced a new End of life Policy and sensitively focussed practice guidance to cover the range of residents. Warwickshire County Council aim to be active participants in the Gold Standards Framework award by April 2011 and will begin to work more closely with our health colleagues to achieve the same aims within the same period of time.

Residents therefore can expect to be involved in the assessment and planning for their end of life care, based on best practice which when required will involve their relatives, staff, friends or advocates. The aim will be to ensure that any care planning processes are undertaken with a clear outcome focus which will provide what the resident wishes for, gives a clear indication of the quality of care that the home can offer in preparing for and dealing with this major life event.

## 7.4 Managing the Change

**Objective 13 - An informed and effective workforce across all services** 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.

The Joint Dementia Workforce Strategy supports the care pathway from initial diagnosis through to its conclusion or to such a point where the service user enters an alternative care pathway such as End of Life. The scope of the strategy includes all those people working with, supporting and caring for people with dementia. The overarching aim is to have a skilled, competent and confident workforce aligned to the care pathway.

This is achieved by introducing 3 levels of competencies with each level designed to meet the needs of the user and care / supporter at different points of their journey.

In order to improve the understanding of dementia overall and more importantly provide support, help and understanding across the Warwickshire health economies by using both qualitative and quantitative data we have been able to develop a workforce strategy that supports both service & clinical pathways whilst at the same time improving the service user and carers experience by improving the knowledge and skills





of those health and social care workers involved directly on indirectly with service users and their families.

### **Objective 14 - Joint commissioning strategy**

This joint commissioning strategy and delivery plan have been developed by NHS Warwickshire and Warwickshire County Council Adult Health and community Services Directorate working collaboratively over a number of months. Key contributors have been service users, carers and providers from across a wide range of partners. This collaborative approach will continue to drive this strategy forward.

## 7.5 Gap Analysis

In developing our commissioning intentions, the following gaps have been identified:

- There is a lack of awareness generally amongst the public of some of causes of dementia, its affect on individuals their families and the stigma it holds. This, in itself can reduce people's willingness to come forward for diagnosis. For example, people will wait up to 3 years before reporting symptoms of dementia to their doctor.<sup>11</sup>
- Community based provision is not geographically aligned to the demographic change predicted across the County.
- There is a disproportionate investment in specialist resources compared to investment in more generic support, such as domiciliary care.
- The referral route to memory assessment clinics is unclear causing a bottleneck and delay in people with dementia being diagnosed early
- There is limited use of assistive technology/telecare for people with dementia. This needs to begin early in their diagnosis.
- $\circ~$  Day services are variable in quality, access and focus. Plans are already underway to review these services.
- There is a high proportion of peer support and cafes in the North of the County. There needs to be a more equitable spread across the county of what people with dementia and carers confirm is a valuable resource.
- $\circ$   $\,$  There needs to be an information advice and signposting service across the whole County
- $\circ\;$  There needs to be scope within the reablement service for people with dementia.
- There needs to be an intermediate care service that supports people to avoid admission to residential care
- There is a need to develop extra care housing to reduce admissions to residential care



<sup>&</sup>lt;sup>11</sup> Alzheimers Society (2002). Feeling the Pulse. London.

- $\circ$   $\,$  There is a lack of capability to meet the needs of those with early onset dementia
- There is limited access to these services for people with learning disability or from minority communities.
- $\circ\;$  Respite care, breaks from caring and emotional counselling support is limited
- $\circ~$  A more co-ordinated approach to workforce planning needs to be adopted





### 8 Market Management

Positive and effective partnerships between commissioners and providers are the cornerstone of any strategy and are essential to build a strong health and social care economy that can meet and compete in the current market. In taking this strategy forward it will be important to establish the relationship on which future partnerships will be built. These include:

- Engaging early with the market
- Providing clarity around commissioning intentions
- Take the markets own needs into account and support them through training and development where necessary
- Stimulate a competitive supply market, where none exists
- o Facilitate consortium/co-operative arrangements
- $\circ\,$  Monitor effectively and take action to develop or manage supply as needed

Relationships with the market need to be built on trust. To do this, regular provider forums will be established, where none exist so that these relationships can be formed.

Importantly for this client group and the particular specialist knowledge that will be required when working with some clients, such as those displaying complex and challenging behaviours, consideration will be given to a framework of enhanced fees.

Through a redesign of services, for example by improving community based services, both the rates of inappropriate admissions and delayed transfer of care will reduce. This is our ultimate aim because this will enable a reduced reliance on a bed based model and re-investment to ensure more effective community based services reach more people, equipping Warwickshire with the necessary scarce resources to meet demand in the future.





## **9** Commissioning Intentions

Based on the information above and by shifting resources from the point of crisis to prevention and early intervention and within available resources Warwickshire County Council and NHS Warwickshire have together agreed the following commissioning intentions:

### **Key Theme 1: Awareness and Understanding**

- Address the understanding of some of the causal affects of dementia and promote healthier lifestyles through the prevention strategy.
- Provide universal information and advice for everyone about dementia.
- Have available advocacy services, including Independent Mental Capacity Advocate and access to support to develop living wills.
- Include dementia awareness in induction training for employees within the NHS, Council and partner organisations.
- Awareness campaigns will be developed in line with other services to ensure that any additional demands can be responded to

### **Key Theme 2: Early Diagnosis and Support**

- Improve referrals to the Memory Assessment Services to increase the number of people diagnosed early with dementia.
- Implement the agreed Dementia Care Pathway for Warwickshire.
- Work with GPs to review/remove/decrease the inappropriate use of medication which is a particular issue in care homes and which poses medical risk in older people
- Review the Dementia Advisor service in the North of the county and review the role of the Admiral Nurses, who provide specific support to carers of people with dementia, including cost effectiveness and use this to agree a model for future provision.
- Commission specialist carer education and support programmes to ensure Carers are equipped with the skills and confidence to manage at home and ensure that carers are supported to lead a life of their own and to have a break where needed.
- Have access to effective peer support including Alz's/Joe's cafes to become countywide.
- Support to younger people who are employed eg; either those with dementia who are younger and employed and/or their carers.
- Re-commission the IAPT service to include services for people with newly diagnosed dementia and their carers.
- Improve the awareness and use of advance directives and advance care planning for people with a diagnosis of dementia.

### **Key Theme 3: Living Well with Dementia**

• Increase choice and control for people with dementia and carers by rolling out the use of personal budgets (and personal health budgets), to these groups





- Develop innovative and flexible services to support individual needs.
- Increase the take up of Direct Payments by 25% by 2014.
- Change the scope of re-ablement to include people with dementia and this will equate to 15% of re ablement users.
- Increase the use of intermediate care at point of discharge by 20% by 2014 for people with dementia.
- Promote referral route to aids and adaptations.
- Jointly review the use of building based day provision and reduce by 30% by 2014.
- Move to a model of flexible day care support for people with dementia, this will include day and night (24hr) options for support.
- Review respite provision to increase the range and type available
- Commission a range of community based general services that have appropriately trained staff able to respond to people with dementia and promote recovery and continue to enable independence.
- Commission residential and nursing care contracts that reflect the commissioning intentions laid down in the National Dementia Strategy;
  - An identified Dementia Champion in the home
  - Jointly commissioned in reach services to care homes through Community Mental Health Team Older Peoples services
  - Reduction and adherence to protocols for use of anti-psychotic drugs use.
- Dementia appropriate End of Life services that support individuals to have a 'Good Death'.

In commissioning housing related support we will work with housing partners, supporting people, housing associations, extra care providers and independent care homes to;

- Through service re-design and within existing resources commission specialist dementia residential care units within key areas of the County each incorporating the provision of respite.
- Decrease the use of residential care by 20% over the next three years at the point of discharge.
- Make available at least 25% of extra care units to people with dementia within the Care & Choice Accommodation Programme.
- Commission a range of housing options that better meet the specialist needs of people with dementia. Include offering people the option (early) of living in Extra care ensuring that families see Extra Care housing as a viable option for people with Dementia.
- Ensure that the supporting people programme offers appropriate housing related support to people with dementia.
- Increase the use of assistive technology to support people to live at home by 10%

### Key Theme 4: Managing the Change

• Developing a joint health and social care Workforce Development Strategy train 30% of staff to ensure a competent and confident workforce underpinned by the findings from the recent Dementia





Education Projects research and outcomes of other regional projects e.g. Strategic Health Authority initiatives

- Including people and their carers in the delivery and evaluation of learning programmes where *appropriate/possible*.
- Ensuring all relevant workers complete a level one development programme
- Commission and deliver the second or intermediate level development programme by *Sept 2011*. This programme is for workers who are most likely to come into contact with patients who may undergoing treatments or interventions that may not be related to dementia, for example within A&E or a planned elective intervention. A significant part of this programme will be focused upon communication, managing difficult behaviour and support
- Commission and deliver an advanced / specialist programme for those workers whose involvement is likely to be at the original diagnosis of the disease and then later on as they move towards the end of life pathway.





# **10** Financial Envelope

## **10.1. Current Financial Climate**

Because of the significant financial savings that Warwickshire County Council have to make during a time of transformation, it is important to state that currently, dementia services have not been set a savings target unlike other client groups. However, with the significant financial pressures faced by NHS Warwickshire, Warwickshire County Council combined, coupled with demographic pressures that are well known and documented any changes in services must ensure the best use of resources to place the health and social care economy in a good position to meet growing demand.

Given the complex nature of funding arrangements within the council, it is difficult to determine the precise amount of funding available and used for people with dementia. This is primarily because of the difficulties in diagnosing someone with dementia and the fact that the expertise to meet individual needs are based within older people mental health teams. Whilst the prevalence of dementia continues to grow and will become a significant factor in future years, it is not economically viable to separate out the needs of people with dementia from other older people with mental health issues, such as depression. The financial envelope below must therefore be taken with some degree of caution. It is fair to estimate that the spend on people with dementia and their carers, within adult social care, is likely to be in the region of between £8 million to £11 million as shown below.

2010/11 Forecast	External Services - Older People Mental Health Client Group	Internal Services	LD Services - Customers Over 55	Total
Transport	26,771			26
Homecare	938,045			938
Daycare	670,630			670
Residential E.M.I	9,829,465			9,829
Respite E.M.I	137,364			137
Direct Payments Ongoing	416,058			416
Direct Payments One Off	11,520			11
Service Level Agreements				
Internal Dementia Residential Care		711,750		711
Internal Dementia Residential Respite Care		162,655		162
Internal Care Home Dementia Day Care				
Internal Dementia Homecare		743,308		743
Sub Total - Gross Expenditure	12,029,852	1,617,713	0	13,647
Reimbursements	(118,662)			(118,
Residential Charges	(3,820,415)			(3,820,
Respite Charges	(15,123)			(15,
Estimated Charges for Community Care Services	(309,453)			(309,
Estimated Charges for Internal Services		(183,047)		(183,
Sub Total - Gross Income	(4,263,654)	(183,047)	0	(4,446,
Total Net Expenditure	7,766,198	1,434,666	0	9,200

#### Estimated Total Dementia Expenditure





## **10.2 Financial Projections for 2011-2014**

Given the financial and demographic pressures considerable work has been completed to identify the 'push / pull' factors that will impact on the financial viability of this strategy over the next three years.

### **'Push / Pull Factors**

There are a variety of different factors that will 'push and/or pull' the funding for services, for example; residential care – price inflation and demographics will push the price but at the same time improvements in Public Health, Telecare and Prevention, will all pull expenditure on residential care down. For each type of expenditure there are all these factors pushing and pulling.

As discussed earlier we will shift resources from the point of crisis to prevention and early intervention. The graph below illustrates, over the next three years the impact of making these changes will have on spending on dementia services. This will be achieved through service reengineering which will result in Warwickshire County Council and NHS Warwickshire being in a good position to meet demand. All of the proposed commissioning intentions and the impact of service reengineering, together with the anticipated 'push / pull factors' result in a shift in how the financial envelope will be used. The graph and financial table below illustrates the impact of these forces and the net result for 2014. Importantly several assumptions have been made including:

Assumptions:

- Inflation of approximately 2.5% per year
- Demography increasing costs by approximately 9% per year
- Significant switching from traditional services to direct payments under self directed support, with new services costing less than traditional services (the illustration shows day services 50% saving, homecare 10% saving, residential care 5% saving)
- Re-ablement and telecare investment generating net savings on homecare and residential care (illustration shows 2% saving on homecare and SDS, and 1% on residential care)
- Carers (illustration shows a 20% increase in Carers spending offset by savings on package costs)
- Early intervention and diagnosis this would significantly mitigate demographic pressure.
- Extra care will provide a cheaper alternative to residential care.

Overall, service re-engineering has the potential to significantly mitigate increases in spending







Future Size and Shape of Dementia Spending









				2014 'Do					Early Intervention		
	2010			Nothing'				Carers	and		2014 New
	Basleine	Inflation	Demography	Projection	SDS	Reablement	Telecare	Services	Diagnosis	Extra Care	Model
Reablement/Intermediate Care						500,000					500,000
Telecare	20,000	2,076	8,232	30,308			40,000				
Self Directed Support	366,568	38,054	150,873	555,495	1,081,595	(163,709)		(29,468)	(72,196)		1,371,717
Home Care	1,441,444	149,640	593,272	2,184,356	(436,871)	(674,749)	(61,455)	(21,455)	(49,491)		940,336
Day Services	574,939	59,686	236,634	871,259	(435,630)				(21,781)		413,848
Extra Care										780,000	780,000
Carers Sevices	280,161	29,084	115,309	424,554				84,911	(25,473)		483,992
Residential Care	6,537,753	678,703	2,690,819	9,907,275	(495,364)	(188,238)	(92,237)	(184,473)	(447,348)	(1,310,400)	7,189,215
Total	9,220,865	957,245	3,795,138	13,973,248	(286,270)	(526,696)	(113,691)	(150,485)	(616,290)	(530,400)	11,679,108

Impact of the Push / Pull Effect and the projected re-engineering to meet commissioning intentions.









# **11. Priority Actions and Implementation**

# **11.1** Our actions in taking forward the Strategy will be:

- Explore with Warwickshire Observatory the development of a systematic approach to capture and report intelligence including accurate local prevalence and demographic information. For example, it would be beneficial to have better commissioning information around; people or groups at risk, geographical locations, and specific groups such as learning disabilities, minority community groups and people with mild cognitive impairment.
- AH&CS to develop with Warwickshire PCT a robust performance dashboard to include primary care QOF data, secondary, acute and community based services to improve commissioning intelligence.
- To utilise and develop national and local research and benchmarking information to enhance performance of services locally.

## **11.2 Measuring for Success**

The Department of Health Quality outcomes for people with dementia, in consultation with people with dementia and their carers have developed a series of outcome measures:

# By 2014, all people with dementia living in England should be able to say:

### Living Well with Dementia in Warwickshire



We will also identify a number of the following outcome measures for adult social care and use these to measure progress over the lifetime of this strategy.

### Enhancing independence and control over own support

• The proportion of those using social care who have control over their daily life

### **Enhancing quality of life for carers**

• Carer-reported quality of life

### Ensuring people feel supported to manage their condition

• Proportion of people with long-term conditions feeling supported to be independent and manage their condition

#### Helping older people to recover their independence

• Proportion of older people (65 and over) who were still at home after 91 days following discharge from hospital into re-ablement/rehabilitation services

#### Preventing deterioration and emergency admissions

• Emergency bed days associated with multiple (two or more in a year) acute hospital admissions for over 75s

### **Improving recovery from falls and falls injuries**

• The proportion of people suffering fragility fractures who recover to their previous levels of mobility / walking ability at 120 days

### Supporting recovery in the most appropriate place

Delayed transfers of care

Dementia Strategy V1.00.doc







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### **Delivering efficient services which prevent dependency**

### Improving access to information about care and support

• The proportion of people using social care and carers who express difficulty in finding information and advice about local services

#### **Treating carers as equal partners**

• The proportion of carers who report that they have been included or consulted in discussions about the person they care for

### **Providing effective safeguarding services**

• The proportion of referrals to adult safeguarding services which are repeat referrals





# **12 Appendices**

### Appendix 1

Below are the outcomes that people with dementia and their family carers have told us are important to them in order to live well with dementia. This information has been gathered through a variety of workshops, conferences, visits to services and clubs and events held locally.

# What people with dementia and their carers have told us

### Key Theme; Raising Awareness and Understanding

People in Warwickshire want to be well informed and to know where to go to, to get good quality information, advice and a timely diagnosis when they are ill. The same applies for those with Dementia. To support individuals to keep well or seek timely advice and referral on for diagnosis you have told us that you want to see:

- Joined up local campaigns providing evidence based information and advice about how to keep well and reduce the likelihood of acquiring early onset of dementia.
- Advice and information about who to see and what to do if you suspect you have dementia and where to go to get help.
- Local media campaigns including advertising and specific web links to be made available to the general public and to specific agencies who deal with advice and information for the public. This should include local education facilities, i.e. both schools and colleges to ensure young people hear the message and act wisely.
- That campaigns include and link with other campaigns and information, i.e. stroke, alcohol, healthy eating.
- That information published should be clear and easy to understand, readily available on request and distributed through a range of resources i.e. supermarkets, libraries and is suitable for all abilities and cultures.
- That relevant tests and treatments to confirm diagnosis early are made available, enabling you to plan your life and adjust where appropriate to life changes produced by the condition.
- If you do not have a clear diagnosis you want to be advised as to what to do to improve your memory and be supported in this through Primary care or memory services.
- Not to have to wait a long time to be seen because more people are being referred to services earlier. This may mean services opening more frequently or being better staffed and more flexible.

### Key Theme 2; Early Diagnosis and Support

Users and Carers tell us that services are different across the county, access to these services is not always timely and support, information and





advice limited. You want confidence to know that any services provided to you or the person you care for are of the highest quality.

You have particularly stated that you would want to see;

- Model the impact of increasing early diagnosis on other services. People diagnosed early are more likely to receive pharmaceutical and therapeutic interventions that will help them live active lives for longer therefore reducing hospital admissions and delaying the need for long term care. Establish formal processes to ensure that people who are admitted to hospital with a diagnosis of dementia are notified to the appropriate GP practice to ensure that the patient is placed on the dementia register.
- A single dementia pathway for Warwickshire that is publicised and accessible is measured for quality and is staffed with competent, capable practitioners throughout.
- Eligibility throughout the pathway that is published and accessible to all.
- A 'navigator' to assist you, and stay with you throughout your journey (Dementia Advisor).
- Key health and social care support staff at specific intervals across the pathway, i.e. in Primary Care, Memory Assessment services and End of Life care that offer specialist support, reviews if your conditions changes and advice in change of circumstances.
- Support to remain at home and a care plan that reflects this that you have control of and contribute to.
- Support for carers to include information (including on line information and forums), education, and peer support. Carers have said that if they do not know how to deal with issues they become crisis. To avoid this carers would like to be better able to meet the presenting symptoms and issues.
- A care pathway between Acute services, Learning Disability and dementia services need to be part of the services developed, they also need to be robust and be performance managed.

### Key Theme 3; Living Well with Dementia.

You have told us that once diagnosed with dementia we needed to develop a range of services that fully meet your changing needs as both an individual and those of your carer/supporter. Things you told us included:

- The need for a person GP to work with mental health services and Learning Disability services to support the whole person's health throughout.
- The need to have a dedicated person in acute care settings responsible for dementia, this should include a lead clinician and a liaison service.
- Help to stay at home for as long as possible.
- Avoidance of repeat admissions to hospital and once there frequent moves that continue to confuse and disorientate people
- To learn from best practice in other authorities and PCT's.





- Equal access to MH services, this includes Crisis Resolution and Home Treatment teams and Assertive Outreach support for people with challenging behaviour or hard to engage/support.
- Not being transferred from Hospital straight to residential care
- More appropriate age related services for Early Onset dementia.
- Access for both users and carers to IAPT services.
- Short breaks for carers which include:
  - Domiciliary care
  - Day services
  - Peer support groups
  - Voluntary sector support services
  - Expanding direct payments to carers
  - Expanding individual budgets for people with dementia
- The need for people to be treated with Dignity and Respect
- A diagnosis no matter where you are. Ie in a care home and an appropriately adjusted care plan to reflect your needs

Extra care housing, telecare and assistive technology are an integral part of services for people with dementia, if improving quality of care and maximising choice, independence and control are to be achieved. Housing should be based on need not the environment in which it is provided. To do this you tell us we must:

- Promote and commission extra care housing options that are able to support long term users with a diagnosis of dementia or who are diagnosed with dementia whilst in an extra care housing setting.
- Make available assistive technology, enabling users and carers to experience the technology within a specialist support package which will assist them to live at home.
- Offer flexible day care support options that are available at home (to include short breaks), or in the community.
- Ensure housing staff are trained in dementia
- Flexible use of individual budgets.
- Establish a research and evidence base for services offered and technology made available to ensure it is fit for purpose.

### Key Theme 4; Making the Change

Users and Carers applauded the National Dementia Strategy recommendation for an informed and effective workforce. Locally their views included the need for:

- Awareness raising/training for staff working within the general health, housing, social care and community sectors, including GP's, Police and Fire, Probation and Education to both ensure early recognition of dementia onset and progression/deterioration in those with a diagnosis necessitating referral to specialist services.
- Mandatory training for staff in primary and secondary care from GP to receptionist, from consultant to porter / cook; from management to students.





- Accredited dementia training for the whole workforce, in particular contractual requirements necessitating accredited training for staff at all levels.
- Specific training for risk and risk management that supports service users to stay at home and that takes account of carers concern within the framework of the personalisation agenda.
- Ensure that all commissioned services include service specifications that specify dementia training and core competencies that include, but are not limited to, the national minimum standards.
- All community based health and social care staff will receive core training in dementia.
- Home care services specify core competencies and training in dementia care for all staff and that home care staff have access to specialist dementia training.
- Profile the capacity and skills of the workforce so that training and support can be targeted. Work with a number of joint projects for example, with Universities and GP training through online programmes.









Appendix 2

Dementia Respite services - Financial year 2010/11

### Specialist Dementia respite services

	External				Internal		Total			
District	Externally Provided Respite Nights	External Costs £	External Unit Cost Per Night	Internally Provided Respite Nights	Estimated Internal Costs £	Internal Unit Cost Per Night	Total Respite Nights	Total Costs £	Overall Unit Cost Per Night	
Stratford	37	2,829	76.46	258	23,957	92.86	295	26,786	90.80	
North Warks	367	24,126	65.74	59	5,479	92.86	426	29,605	69.49	
N and B	708	52,783	74.55	7	650	92.86	715	53,433	74.73	
Rugby	473	33,577	70.99	65	6,036	92.86	538	39,613	73.63	
Warwick/ L	44	3,293	74.84	107	9,936	92.86	151	13,229	87.61	
Total	1,629	116,608	71.58	496	46,057	92.86	2,125	162,665	76.55	