

# Living well with dementia

A dementia strategy for Essex,  
Southend and Thurrock

Developed in partnership

DRAFT

Working in partnership:

**Essex County Council**

**Southend-on-Sea Borough Council**

**Thurrock Council**

**South Essex PCT Cluster**

**North Essex PCT Cluster**

**North Essex Partnership NHS Foundation Trust**

**South Essex Partnership University NHS Foundation Trust**

## Foreword

We are delighted to introduce the Essex, Southend and Thurrock Dementia Strategy which has been developed in partnership to improve the access to high quality diagnosis, treatment, support and advice for all people living with dementia and their carers in Essex Southend and Thurrock.

Since the publication of *“Living well with dementia: A National Dementia Strategy”*<sup>1</sup> in 2009, the Primary Care Trusts and Local Authorities in Essex, together with representatives from Voluntary, NHS and Independent Provider organisations have worked collectively to develop a strategy which encompasses Essex, Southend and Thurrock. The aim has been to provide an overarching statement of how we can work together to meet the objectives of the National Dementia Strategy in order to improve quality of life for people with dementia, whilst allowing the flexibility of responding to local needs. This is an accompanying document to the strategies and action plans which are being developed at a local level.

Within the geographical area of Essex, Southend and Thurrock there are estimated to be more than 22,000 people currently living with dementia. With a higher than average population of older people aged over both 65 and 85 it is likely that the number of people with dementia will increase to 35,000 by 2025.

Dementia is a complex condition where environmental, psychological, emotional and biological factors can all impact on an individual’s wellbeing. Although it is a devastating condition there is much which can be done to alleviate its impact. Improved public and professional awareness will reduce the stigma associated with dementia and will enable people at risk of developing the condition to be identified and to seek help at an earlier stage. Early diagnosis and intervention is imperative to enable access to appropriate treatment and support, and to avoid crises which may result in hospital admission or premature admission to long term care. Living well with dementia is dependent on a range of services that are commissioned from, and co-ordinated across, all relevant agencies encompassing the whole dementia care pathway.

At all stages people should receive health care and social support from staff that have the skills and training to provide the best quality care.

This Strategy is designed to meet this challenge and is inclusive of all citizens who may experience dementia, or are the carers of people with dementia, irrespective of age. It is in line with national, regional and local priorities to deliver quality outcomes for people living with dementia and their carers in Essex, Southend and Thurrock

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<sup>1</sup> *Living well With Dementia – A National Dementia Strategy* Department of Health 2009

Most importantly, the strategy is underpinned by our commitment to the values of dignity and respect, and the principles of personalisation and person centred support. In addition to developing a culture where health and social care organisations in Essex, Southend and Thurrock are committed to working together to realise the vision of delivering improved outcomes and enabling enhanced quality of life for people living with dementia and their carers.




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# Consultation Questions

**When you have finished reading this document we would welcome your views:**

- a) Is there anything that has been missed which would help us to deliver the Essex Southend and Thurrock Dementia Strategy?
  
  
  
  
  
  
  
  
  
  
- b) Does this Strategy fully address issues of equality and diversity and the needs of particular groups?
  
  
  
  
  
  
  
  
  
  
- c) What are your priorities for implementation? What can and should be done first?
  
  
  
  
  
  
  
  
  
  
- d) What can you or your organisation do in partnership to help deliver the outcomes?
  
  
  
  
  
  
  
  
  
  
- e) Please indicate where you live:
  - A District or Borough of Essex County Council
  - Southend on Sea Borough Council
  - Thurrock Council

Please send responses by 19<sup>th</sup> September 2011 to;  
[Dementia.strategy@essex.gov.uk](mailto:Dementia.strategy@essex.gov.uk) or by post to the address on the back cover of this document.

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## Acknowledgements

# 1. Introduction

This document forms the Essex, Southend and Thurrock Strategy for Dementia 2011-2014. It is based on national guidance, set out in “Living well with dementia: A National Dementia Strategy” (2009)<sup>1</sup>, a local needs assessment and review of current provision, encompassing the three local authorities, two mental health trusts and five primary care trusts in Essex and supports the strategies and action plans which are being developed at a local level across Essex Southend and Thurrock. The Strategy aims to provide an overarching statement of how we can collectively meet the objectives of the National Dementia Strategy whilst allowing the flexibility of responding to local needs and has been developed by the Older Adults Mental Health Programme Board in partnership with Adult Social Care, NHS Services, and third sector organisations.

This strategy should be viewed as a working document. It aims to refocus investment and current resources to improve access to high quality diagnosis, treatment, support, and advice for all people living with dementia in order to improve quality of life from diagnosis to end of life for people with dementia and their carers. This includes ensuring that people with dementia and their carers receive health care and social support from staff who have the skills and training to provide the best quality care and support. It also aims to support people in the comfort and familiarity of their own environment by moving care away from acute hospitals and reducing the number of people prematurely entering long term care.

The Strategy is designed to be inclusive of all citizens in Essex<sup>2</sup> who may experience dementia, or are the carers of people with dementia irrespective of age. It is inclusive of all user groups including, for example adults who may have a learning disability or other long term health conditions that impact on their cognitive abilities.

Underpinning the strategy and providing a framework for delivering high quality services is the rigour of world class commissioning and the philosophy of Putting People First which is a national initiative for the personalisation of Adult Social Care. Putting People First puts people who receive support at the heart of the process ensuring that their needs are clearly defined by them, they have clear understanding of the choices available to them and they make informed decisions about how those needs can and will be met. World class commissioning focuses on improvement in health outcomes, looking at technical competence, governance and the need to see real outcomes for individuals. The strategy has been developed against the background of a changing health care system following the publication of the Health and Social Care Bill 2011<sup>3</sup> with General Practitioners and

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<sup>1</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_094058](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058)

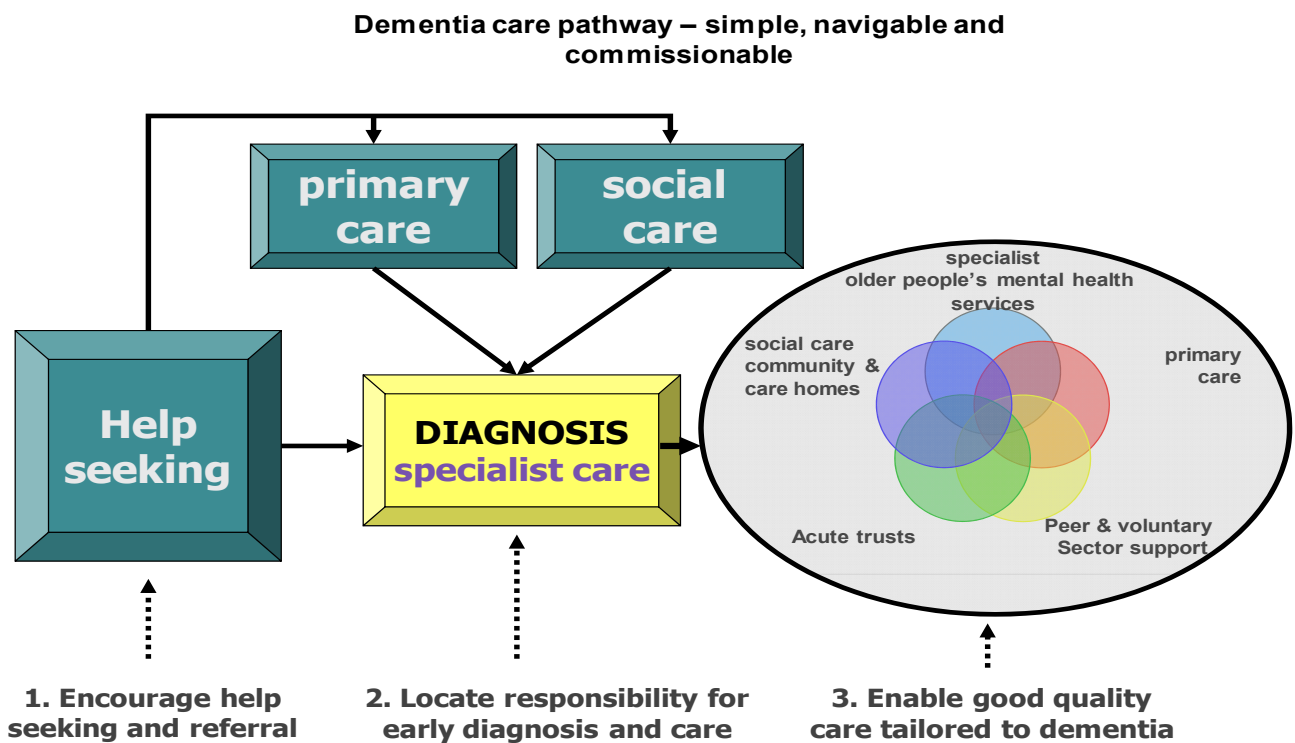
<sup>2</sup> **Throughout this document, where the term ‘Essex’ is used, this refers to the county of Essex, which includes the unitary authorities of Southend and Thurrock. Where information only applies to the county council locality, this is clearly identified.**

<sup>3</sup> <http://services.parliament.uk/bills/2010-11/healthandsocialcare.html>

local authorities taking over many of the commissioning responsibilities and accountabilities that primary care trusts currently have.<sup>4</sup>

This strategy is committed to the quality standard for dementia which requires that dementia services should be commissioned from and coordinated across all relevant agencies encompassing the whole dementia care pathway (see Fig 1). An integrated approach to the provision of services is fundamental to the delivery of high quality care to people with dementia.<sup>5</sup>

**Figure 1 Over arching pathway by Professor Sube Banerjee 1/12/2010**



The Strategy is based on UK and local evidence (where available), drawing together published data on cost-effective commissioning and care provision, and estimates on current and future costs (from the 2007 *Dementia UK* report). There is, however, no comprehensive local data on the current costs of dementia services in Essex. Psychiatric services for dementia often fall within block contracts with mental health trusts and there is no national “payment-by results” tariff for costing mental health activities. The Department of Health (DH) is in the process of commissioning a baseline audit of dementia which will include data on costs<sup>6</sup>.

<sup>4</sup> Wording from South East Essex Draft Local Dementia Strategy, March 2011

<sup>5</sup> NICE Quality Standard for Dementia 2010

<sup>6</sup> Report by the Comptroller and Auditor General Improving Dementia Services in England – an Interim Report HC 82 Session 2009-2010

## 2. Governance

The Essex Southend and Thurrock Dementia Strategy has been overseen by the Older Adults Mental Health Programme Board. The working group includes representatives from Southend and Thurrock Unitary Councils, Essex County Council, the five Essex Primary Care Trusts, the North Essex Partnership NHS Foundation Trust, the South Essex Partnership University NHS Foundation Trust, the Alzheimer's Society, Age UK and the Essex Independent Care Association.

- The Older Adult Mental Health Programme Board will be responsible for the production, publication, distribution and update of the document.
- The strategy will be reviewed in line with and replicate timescales identified for the National Dementia Strategy.



## 3. Background and Context

### 3.1 Information about dementia

Dementia is regarded as a severe and devastating disorder which impacts not only on the individuals with dementia but also on the family members who care for them. It is not a disease in itself but the term used for a collection of symptoms including changes in memory, reasoning and communication skills with a gradual loss of ability to carry out daily activities. These symptoms are caused by structural and chemical changes in the brain such as those which occur in Alzheimer's disease.<sup>7</sup> In addition individuals may experience behavioural and psychological symptoms at any stage in their illness. The wellbeing of people with dementia is affected by environmental, psychological and biological factors and people can easily become disoriented in strange surroundings such as hospital or when being cared for by different people.

### 3.2 Who is affected?

Dementia is usually a long term, progressive condition and whilst it is not a necessary part of ageing the incidence of dementia increases with age. Dementia is often associated with complex needs and, especially in the later stages, high levels of dependency and morbidity. These care needs often challenge the skills and capacity of carers and services. As the condition progresses people with dementia can present carers and social care staff with complex problems including behaviour that other people might find difficult or challenging, restlessness and seeking reassurance, eating problems, incontinence, delusions and hallucinations, and mobility difficulties that can lead to falls and fractures. The impact of dementia on an individual may be compounded by personal circumstances such as changes in financial status and accommodation, or bereavement.

The latest figures published by the Alzheimers Society suggest that 1 in 14 people over the age of 65 and 1 in 6 people over 80 years has some form of dementia.<sup>8</sup> Of those people over 65 who have dementia (late onset dementia) 55.4% have mild dementia 32.1% have moderate dementia and 12.5% have severe dementia.<sup>9</sup>

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<sup>7</sup> Healthcare for London Dementia services report

<sup>8</sup> Alzheimers Society Website, accessed 9/07/2010; *Alzheimers Society position statement on demography.*

<sup>9</sup> JSNA 2008 citing Alzheimers society Dementia UK (2007)

Alzheimer's disease is the most common form of dementia. The proportions of those with different forms of dementia are broken down as follows:<sup>10</sup>

- Alzheimers Disease 62%
- Vascular Dementia 17%
- Mixed Dementia (AD & VaD) 10%
- Dementia with Lewy Bodies 4%
- Frontal temporal dementia 2%
- Parkinson's Dementia 2%
- Other dementias 3%

Dementia can also occur alongside other long term conditions. As the Joint Strategic Needs Assessment (JSNA) states "dementia is a fast growing problem which is likely to put a huge strain on local authorities and the NHS as people are living longer and surviving common forms of cancer and heart disease." (JSNA 5.4. 5.2). It is, therefore, necessary to pay attention to the overall health and wellbeing of people with dementia.

Sight loss in people with dementia exacerbates problems of disorientation and confusion. People may not only experience age related changes in vision but the affects of some types of dementia cause additional difficulties. In Alzheimer's disease the proximity of the brain areas to the visual pathways may result in these becoming damaged through the spread of plaques and tangles and in PCA (posterior cortical atrophy) damage to the visual system is characteristic of the disease. Visuo-perceptual difficulties such as hallucinations are also experienced particularly in people with Lewy Body Dementia. Changes can occur to visual pathways following strokes thus affecting people with vascular dementia. An awareness of age related sight loss is important for those who support people with dementia as much can be done to lessen the impact of these conditions through adaptations to the environment, ensuring that appropriate eyewear is used, arranging regular sight checks and ensuring that communication adjustments are made<sup>11</sup>.

Falls have also been acknowledged as a cause of substantial morbidity and mortality in people living with dementia. Impairments of gait and balance, medication, cardiovascular problems and the environment can all be contributing factors to falls for people with dementia<sup>12</sup>.

Other risk factors which have been identified through various reports and studies that contribute to the development of dementia are smoking, alcohol, diabetes and high blood pressure<sup>13</sup>.

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<sup>10</sup> Alzheimers Society Website, accessed 9/07/2010; *Alzheimers Society position statement on demography*.

<sup>11</sup> *Visuoperceptual difficulties in dementia* Alzheimers Society Fact sheet 527

<sup>12</sup> [http://findarticles.com/p/articles/mi\\_m2459/is\\_1998\\_Jan/ai\\_53233904/?tag=content;col1](http://findarticles.com/p/articles/mi_m2459/is_1998_Jan/ai_53233904/?tag=content;col1)

<sup>13</sup> <http://www.biomedcentral.com/1471-2318/8/36>

### 3.3 Younger people with dementia

Dementia can affect people as young as 30 although this is extremely rare. Most younger people with dementia are middle aged; in their 40s 50s and early 60s. The term ‘young onset dementia’ refers to people diagnosed with dementia under the age of 65.

The figures regarding the numbers of people under 65 who have dementia vary widely. The Alzheimer’s Society figures suggest that there are approximately 16,000 people diagnosed with young onset dementia in the UK but it is estimated that because of low referral rates the actual figure could be up to 3 times higher.<sup>14</sup> In 2010 the Alzheimer’s Research Trust (now Alzheimer’s Research UK) suggested that there could be an even higher figure of 64,037 people under 65 with diagnosed or undiagnosed dementia in the UK. This is compared with just 16,737 in 1998. The majority of those affected in this younger age group – 70 per cent – are men. Younger people with dementia were estimated to make up 8 per cent of the total number of people with dementia.<sup>15</sup>

The main causes for of young onset dementia differ from the overall figures and are identified as:<sup>16</sup>

- Alzheimers Disease 34%
- Vascular Dementia 18%
- Frontal temporal dementia 12%
- Alcohol related 10%
- Lewy Body dementia 7%

This group of people have specific needs as they and their carers may still be working when they receive a diagnosis and may also have dependent children living with them. Therefore, in addition to the difficulties associated with late onset dementia, the condition in younger people may also impact upon the family, work and income. The presentation of young onset dementia may also be complex leading to difficulties in diagnosis. This can lead to delays in intervention, treatment, and arrangements for appropriate support. Frontal temporal dementias and alcohol related dementias are frequently associated with behaviour changes which can be very distressing for individuals and their families. Therefore the high prevalence of these forms of dementia for younger people is a significant issue for this group.

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<sup>14</sup> *Younger People with Dementia* Fact Sheet 440, Alzheimer’s Society [www.alzheimers.org.uk](http://www.alzheimers.org.uk)

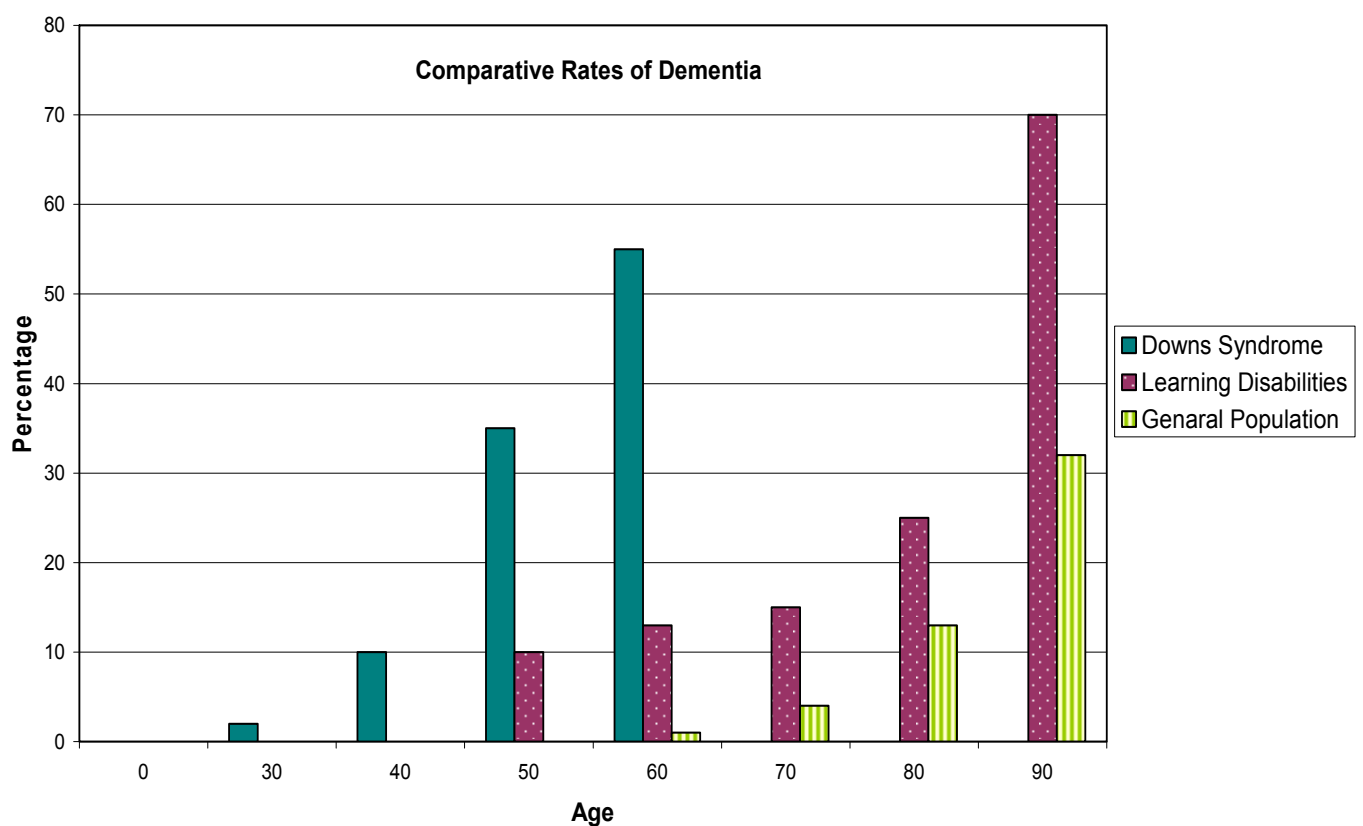
<sup>15</sup> Alzheimer’s Research Trust *Dementia 2010 - The prevalence, economic cost and research funding of dementia compared with other major diseases.*

<sup>16</sup> Harvey et al 2003 *The prevalence and causes of dementia in people under the age of 65.*

### 3.4 People with learning disabilities

People with learning disabilities are at higher risk than the general population of developing dementia before the age of 65 and people with Down’s syndrome are particularly affected. About 20% of people with a learning disability have Down’s syndrome. This group of people often have complex needs as dementia impacts upon their pre-existing psychological and physical health conditions.

Figure 2 Comparative Rates of Dementia – Down’s syndrome, Learning Disabilities



Source: Cooper S.A. (1997) and BPS and RCP 2009

Figure 2 above summarises the age-related prevalence rates of dementia in people with Down’s Syndrome, those with learning disabilities without Down’s syndrome, and in the general population. The figures are not exact but it is suggested that the trend represented in the chart above is increasingly accepted. However, the rates for people with Down’s syndrome are now well established and they appear to have a unique risk for developing dementia – usually Alzheimer’s type - at an early age. For those with learning disabilities but without Down’s syndrome the rates for developing dementia before the age of 65 are brought forward to a small degree compared to the general population but not to

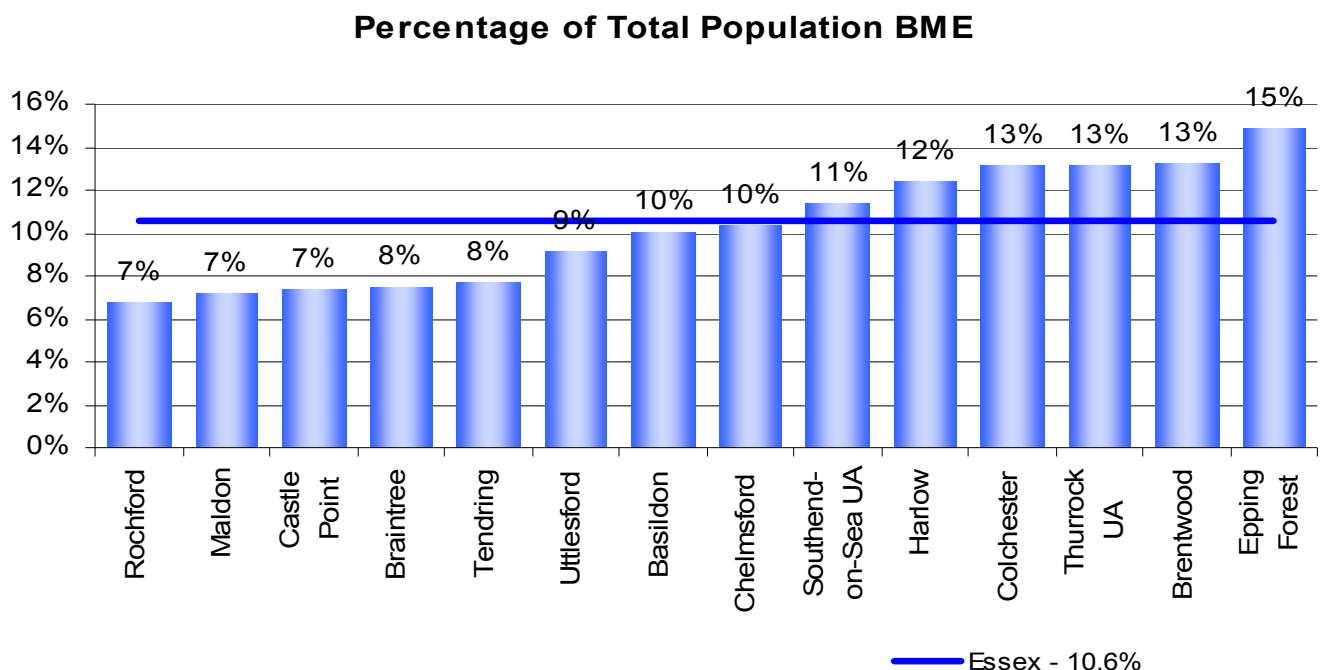
the same extent as for people with Down’s Syndrome. For this group the full range of causes of dementia is observed.<sup>17</sup>

### 3.5 Black and minority ethnic groups

The Alzheimer’s Society estimates that there are approximately 11,000 people from black and minority ethnic groups living with dementia in the UK. This relatively low number probably relates to the small numbers of older people from these groups living in the UK. Therefore, as the current population ages it is likely that the number of people from these communities will also rise. Thus it is important that services are able to be flexible to meet the needs of this group.

Essex has become more diverse with the areas closest to London and those containing the largest towns tending to have the highest concentrations of people from BME groups. The highest proportions of people from all BME groups are residing in Epping Forest, Brentwood, Thurrock and Colchester as Figure 3 illustrates.

**Figure 3 Essex BME groups, 2007**



Source: ONS, MYE 2007

<sup>17</sup> Cooper, S.A. (1997). Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry*, 170, 375–380 and The British Psychological Society and The Royal College of Psychiatrists *Dementia and People with Learning Disabilities* 2009

## 3.6 Carers

It is recognised that Carers play a significant role in providing support to people with dementia. Often this support is unpaid with people frequently providing in excess of 50 hours per week, with almost half of those providing such high levels of care being over 60 years of age.<sup>18</sup> It is identified in the NDS that “family carers are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life”<sup>19</sup>.

Family carers need specific emotional and practical support. Many family carers find the diagnosis of dementia traumatic. Where the family are the main carers, they must be offered a comprehensive Carer’s Assessment. Many carers, particularly the parents of people with Down’s syndrome, may themselves be at risk of developing dementia or other age-related conditions.

Services need to be sensitive to the needs and beliefs of carers and to see things from their perspective. Some carers believe that it is their duty to care and may find it very difficult to accept support and help into their own home. Carers need to have prompt access to appropriate information about supports and resources available including short breaks (both within and away from the home), individualised budgets and direct payments, and aids and adaptations.

Staff need to be very sensitive to the small number of carers who cannot cope with seeing their family member deteriorating and may opt out of being involved. Life Story work is one positive way of engaging family carers in the care.

Carers often need a great deal of support to prepare for the eventual death of the person they are supporting.

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<sup>18</sup> Institute of Public Care: Pan Essex Strategy Reviewing and Repositioning Older Adults Mental Health Services 2008

<sup>19</sup> Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy* p.10

## 4 Living Well with Dementia: A National Strategy

### 4.1 National Context

In 2007 the Department of Health (DH) announced that dementia would now be a national priority. It also announced that it would develop a National Dementia Strategy. A period of extensive consultation followed and Professor Sube Banerjee, Senior Professional Advisor in Older Peoples Mental Health and Jenny Owen, Executive Director of Social Care in Essex jointly led on the development of a National Dementia Strategy. This five-year Strategy 'Living Well with Dementia – A National Dementia Strategy' (NDS) was published by the Department of Health in February 2009. The DH acknowledged that dementia was the biggest challenge it had ever faced, largely due to the complexities of joining up health and social care departments and resources.

It was estimated that the Strategy would cost £1.9 billion to implement over 10 years and that this would be funded largely through efficiency savings. National and regional leadership was put in place and initial seed funding of £150 million was allocated to Primary Care Trusts to assist implementation over the first two years.

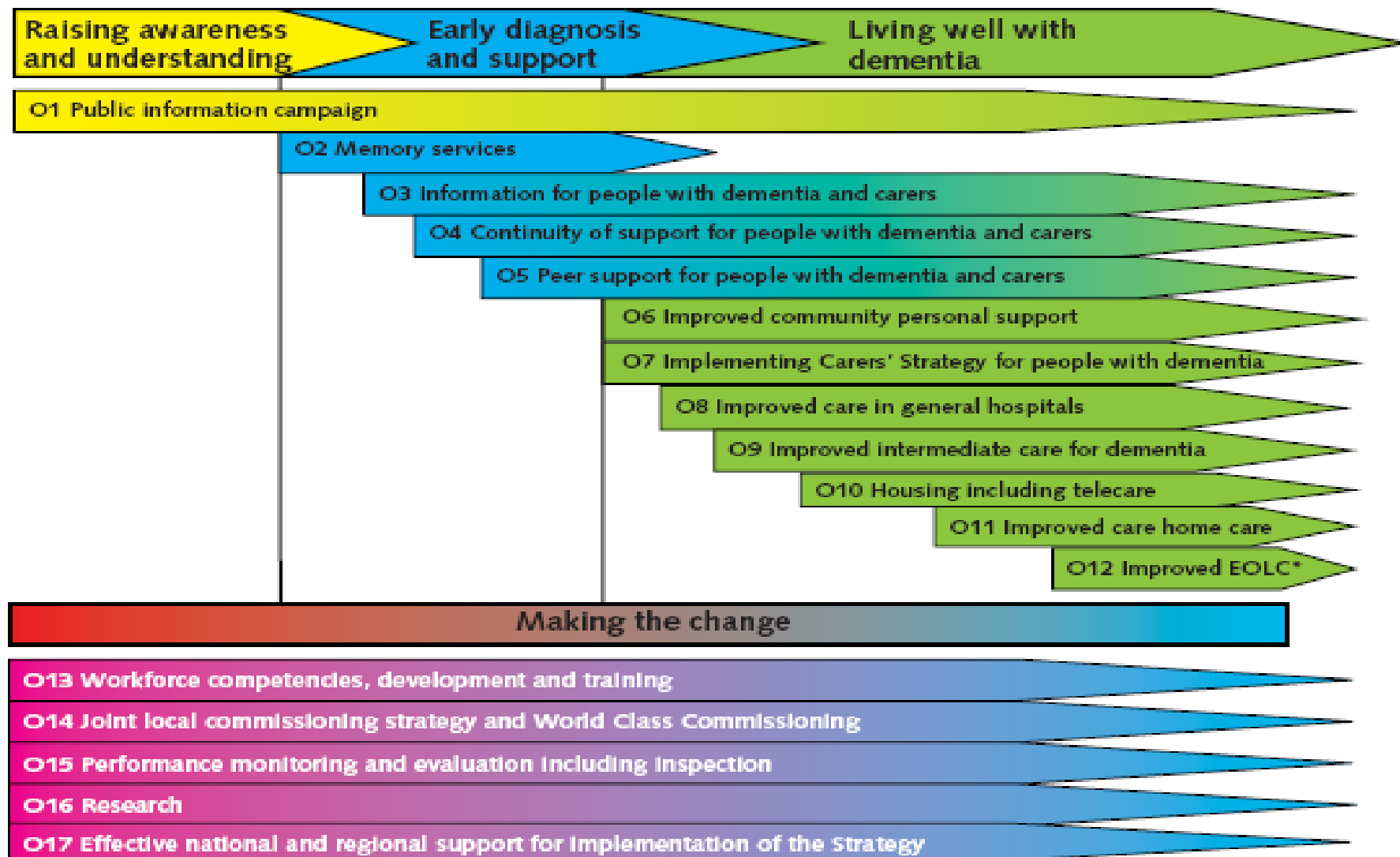
The vision in the national strategy is that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia, no matter what the stage of their condition or where they are in the health and social care system. This is in contrast to the current situation where in many services people with dementia are simply 'managed'.

In order to achieve this vision 17 objectives were identified specifying improvements in 3 key areas. Objectives 1 to 12 are grouped under 3 main headings to support a defined pathway for commissioning services;

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

The remaining 5 objectives are cross cutting objectives which enable change to be implemented which include workforce development, commissioning, performance monitoring and evaluation, and research. In addition there is a commitment to ensuring both national and regional support for the implementation of the strategy. (See fig 4).

Figure 4 Delivering the National Dementia Strategy - joint commissioning of services along a defined care pathway to enable people to live well with dementia<sup>20</sup>



\*End of life care

<sup>20</sup> Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy*



Professor Banerjee later conducted a review into the use of antipsychotic drugs for people with dementia which reported in November 2009. An action plan has been published with the aim of reducing the use of anti-psychotic medication and making this a key priority across the NHS.

The current government re-iterated its commitment to the needs of people living with dementia and their carers and in 2010 identified the implementation of the National Dementia Strategy as one of its priorities. This was reflected in a number of announcements and initiatives with the four priorities for dementia in being:

- 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 180000 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.

More generally the improvement of community personal support services is integral to and underpins each of the four priorities as it supports early intervention, prevents premature admission to care homes and impacts on inappropriate admission to hospital and length of stay.<sup>21</sup>

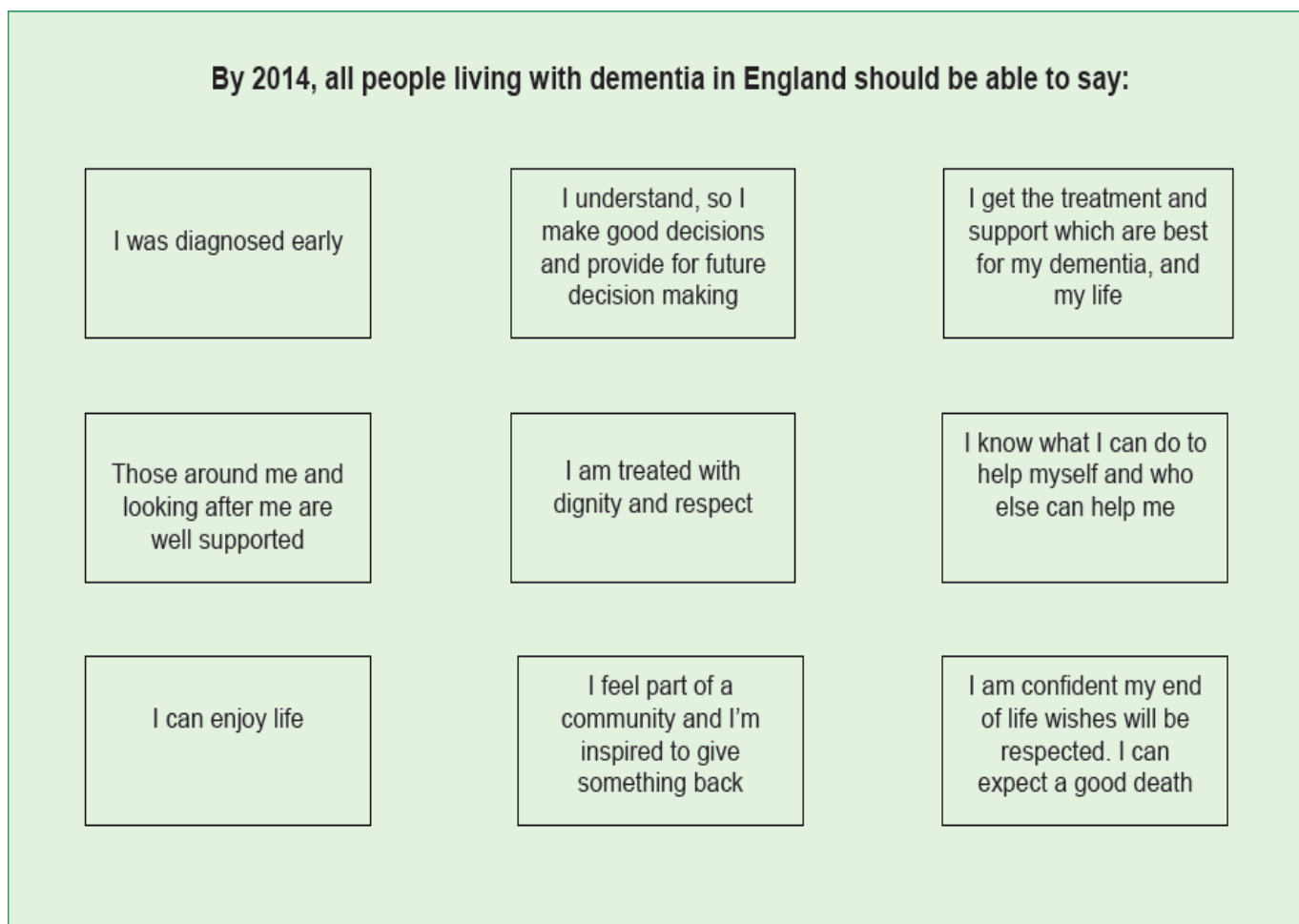
The government has also stated its commitment to ensuring there is a greater focus on accelerating the pace of improvement in dementia care through local delivery of quality outcomes and local accountability for achieving them<sup>22</sup>. A key element of the outcomes-focused approach is ensuring greater transparency and provision of information to individuals. The following nine statements have been proposed which capture what people with dementia have said they aspire to in terms of their health and social care systems.

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<sup>21</sup> Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy*, Department of Health , September 2010

<sup>22</sup> Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy*, Department of Health , September 2010

**Figure 5 Draft synthesis of outcomes desired by people with dementia and their carers<sup>23</sup>**



There is further information in the form of a chart to show how these outcomes link with the objectives of the NDS and NICE quality standards in *Appendix 1*.

Public and political commitment to dementia has grown significantly in recent years to a position where dementia is now a major strand of public policy discussion. To continue and progress the momentum the Dementia Action Alliance<sup>24</sup> was launched on 26 October 2010. The Alliance is a coalition of 45 organisations committed to improving quality of life for people with dementia and their carers in England by 2014 (the date when the National Dementia Strategy comes to an end). On the launch date the Alliance published a National Dementia Declaration explaining the outcomes they seek to deliver for people with dementia and their carers. In addition each signatory organisation has published an action plan setting out what their role is in delivering better quality of life for people with dementia and their carers, and the actions they intend to take in order to help deliver those outcomes.

<sup>23</sup> <sup>23</sup> Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy*, Department of Health, September 2010

<sup>24</sup> <http://www.dementiaaction.org.uk/>

The seven agreed outcomes come under the following headings:

- I have personal choice and control or influence over decisions about me
- I know that services are designed around me and my needs
- I have support that helps me live my life
- I have the knowledge and know-how to get what I need
- I live in an enabling and supportive environment where I feel valued and understood
- I have a sense of belonging and of being a valued part of family, community, and civic life
- I know there is research going on which delivers a better life for me now and hope for the future

There is a noticeable similarity with the outcomes identified in the revised NDS implementation document.

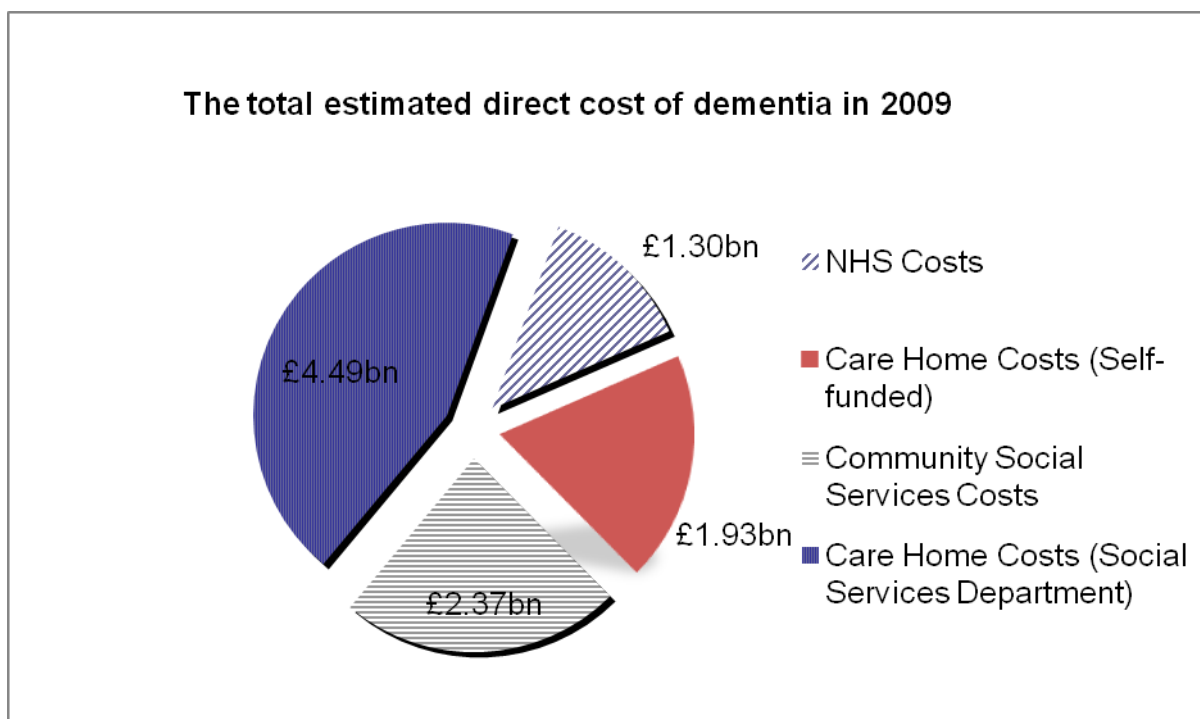
## 5 Organisational Challenge and Policy

### 5.1 The Challenge

In 2007 it was estimated that there are over 700,000 people living with dementia in the UK (570,000 in England) and this figure is likely to double over the next 30 years. Two thirds of these people live in their own homes<sup>25</sup>. Therefore it is important to ensure that we are providing the type of timely personalised support that we know can make a real difference to people living with dementia and those who care for them, which in turn can prevent premature admission to residential care homes as well as reduce crisis admissions to acute care settings.

Figures 6 and 6a show the total estimated direct cost of dementia in 2009 to be approximately £10.1 billion. Two-thirds of this (£6.42 billion) relates to the cost of care home provision<sup>26</sup>. These costs are split between families the NHS and social services. The remaining one third (£3.68 billion) were for NHS and social services community provision.

**Figure 6 Estimated Direct Cost of Dementia**



Source: Adapted from Knapp et al (2007) *Dementia UK* and the King's Fund (2008) *Paying the Price*

<sup>25</sup> Knapp M, Prince M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.

<sup>26</sup> Knapp et al (2007) *Dementia UK* and The King's Fund (2008) *Paying the Price*

**Figure 6a Estimated % of Direct Cost of Dementia**

Provision	Costs	% of spend
Care Home Costs (Social Services Department)	£4.49bn	44%
Community Social Services Costs	£2.37bn	23%
Care Home Costs (Self - funded)	£1.93bn	19%
NHS Costs	£1.30bn	13%
<b>Total</b>	<b>£10.1bn</b>	<b>100%</b>

Source: Adapted from Knapp et al (2007) *Dementia UK* and the King's Fund (2008) *Paying the Price* (Note: Figures may not add due to rounding)

If we include the costs of care provided by informal carers which do not appear within the direct costs identified above, the estimated average cost of caring for a person with dementia is £25,500 per year. 36% of those costs fall on informal carers, 41% on accommodation, 19% on social care and 8% on NHS.<sup>27</sup>

According to the Department of Health's *Impact Assessment of the National Dementia Strategy* around 208,000 people with dementia live in care homes,<sup>28</sup> 91,000 of whom are in dedicated dementia care beds, but the quality of care varies and as reported in 2007, services do not currently provide value for money.<sup>29</sup>

In 2008 the Commission for Social Care Inspection (now part of the Care Quality Commission) rated as 'poor' to 'adequate' over a quarter of care homes in Eastern and West Midlands regions and 15% in the North East and London.<sup>30</sup> Around 59,000 people with dementia receive domiciliary care – quality inspectors rated between 10% (North West region) and 18% (West Midlands) of providers as 'poor' to 'adequate'. The impact assessment identifies savings of £130 million a year from 2013-14, based on delaying entry into care homes through early diagnosis and intervention.

In a report released earlier this year the National Audit Office concluded that improving services and support for people with dementia lacks the urgency and priority that the Committee had been led to expect and there is a strong risk that value for money will not be significantly improved within the Strategy's five-year implementation timetable.<sup>31</sup>

<sup>27</sup> Mitchell-Baker, A., Greene, R. *Health and Social care best practice Catalogue. Older Peoples Services Essex. Version 6* (July 2010)

<sup>28</sup> Department of Health (2009) *Impact Assessment of National Dementia Strategy*.

<sup>29</sup> Report by the Comptroller and Auditor General (2007) *Improving Services and 3 Support for People with Dementia HC 604 Session 2006-2007*.

<sup>30</sup> Care Quality Commission [www.cqc.org.uk/registered-services-directory/13-rsquicksearch.asp](http://www.cqc.org.uk/registered-services-directory/13-rsquicksearch.asp) (September 2009 data)

<sup>31</sup> National Audit Office *Improving Dementia Services in England – an Interim Report*

## 5.2 Cross cutting policies

There are a number of key cross cutting policies, strategies and drivers that need to be imbedded in the Essex Southend and Thurrock Strategy to ensure our approach is joined up and fit for the future. These include the following:

**NICE Dementia Quality Standard** which provides clinicians, managers, and service users with a description of what a high-quality dementia service should look like, identifying the following key quality statements.<sup>32</sup>

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

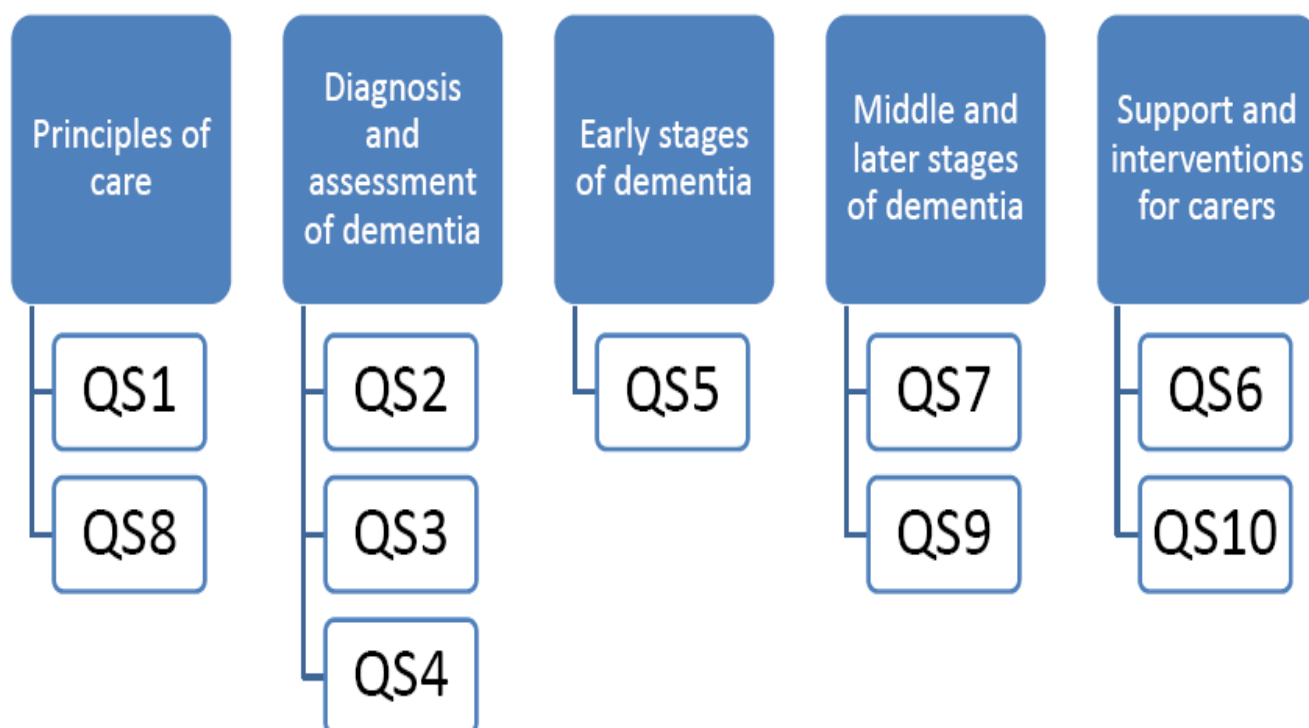
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<sup>32</sup> <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/>

10. Carers of people with dementia have access to a comprehensive range of respite/short-break services that meet the needs of both the carer and the person with dementia.

The quality standard for dementia is based on the understanding that dementia services are commissioned from and co-ordinated across all relevant agencies encompassing the whole dementia care pathway. An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.<sup>33</sup> This can be viewed clearly in the diagram below.

**Figure 7 Dementia, areas of care map**



**Age Equality and the Equality Act.** The Equality Act became law in October 2010<sup>34</sup> and will eventually impact on the way public services are delivered by creating a single new Equality Duty on public bodies to tackle discrimination, promote equality of opportunity and encourage good community relations

The new duty will cover race, disability, and gender, as now, but also include age, sexual orientation, gender reassignment and religion or belief, replacing the three existing, separate duties with a single more effective framework. It will ban age discrimination in

<sup>33</sup> <http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp>

<sup>34</sup> <http://www.legislation.gov.uk/ukpga/2010/15/contents>

the provision of goods, facilities, or services and tackle unjustifiable age discrimination where it has negative consequences. There will be further consultation on this and a transition period before it is implemented but we need to ensure that services for people with dementia in Essex are age inclusive, providing equity of available resources to achieve identified outcomes. The aim of the age equality agenda is for services to be of equivalent good quality for people of all ages.

A national study of older people's mental health services highlighted likely age discrimination within services. It found: older people's services were falling behind those for working age adults; clear evidence of age discrimination in access to services; and a lack of age appropriateness.<sup>35</sup>

**The NHS Operating Frameworks for 2010-11 and 2011-12** identified dementia as an area for local prioritisation. Getting dementia care right should be a priority for local services from an efficiency as well as quality perspective<sup>36</sup>. For example, there is already a requirement for PCTs to publish locally how they are delivering services in line with the most recent implementation plans, *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*<sup>37</sup> (see section 4.1 above). This requirement holds that wherever possible commissioners must be accountable to the people they serve, not the centre.

The 2011-2012 NHS Operating Frameworks also emphasise that people with dementia and their carers need information to help them understand the range and quality of local services. NHS organisations are expected to make progress on the National Dementia Strategy including the four priority areas as set out in the implementation plan published in September 2010 (see Section 4.1). While also stating that NHS organisations should agree with their social care commissioning partners the aspects of the strategy that could be delivered by using section 75 flexibilities<sup>38</sup>.

- There are over 570,000 people in England and over 700,000 people in the UK with dementia and numbers are expected to double in the next thirty years
- Direct costs of dementia to the NHS and social care are in the region of £8.2bn annually
- 40% of people admitted to hospital have dementia
- 40% of the work of community matrons is focused on people with dementia as a co-morbid condition
- At least 50% of long term care residents have dementia

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<sup>35</sup> Healthcare Commission (2009) *Equality in Later Life: A National Study of Older People's Mental Health Services*

<sup>36</sup> Revision to the Operating Framework for the NHS in England 2010/11 Department of Health 2010

<sup>37</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_119827](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827)

<sup>38</sup> [http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_122738](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122738)



While the numbers and the costs are daunting, the impact on those with the illness and on their families is also profound.

**End of Life Care Strategy: quality markers and measures for end of life care** (DH, 2009)<sup>39</sup> The end of life (EoL) care quality markers provide detailed structure and process markers and measures which will be relevant for end of life care for people with dementia. Within these there are particular points of consideration for end of life care for people affected by dementia which directly link in with many of the NDS objectives and particularly objective 12, – *Improved end of life care for people with dementia*.

The following are the seven EOL markers:

- Public awareness
- Strategic Planning
- Identification, communication and care planning
- Co-ordination of care across organisational boundaries
- Availability of services
- Care in the last days of life
- Care in the days after death
- Workforce planning
- Monitoring.

### **Quality, Innovation, Productivity and Prevention**

The same key messages keep coming through; training, integration, clear pathways, information, and equality. Now we need to make sure that we know how we are going to implement them. The tool to drive through this transformation change is the QIPP - Quality, Innovation, Productivity and Prevention - programme<sup>40</sup>. The key objectives of the QIPP programme which are set out in 'Inspiring Change in the NHS'<sup>41</sup> are:

- To improve quality and productivity
- To engage, inspire and empower staff
- To create a legacy of change leaders and a quality culture.

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<sup>39</sup> End of Life Care Strategy *Quality Markers and measures for end of life care* Department of Health June 2009

<sup>40</sup> <http://www.improvement.nhs.uk/QIPP/tabid/61/Default.aspx>

<sup>41</sup> <http://www.nhsbreakingthrough.co.uk/Pdfs/Inspiring%20Change%20in%20the%20NHS.pdf>

**Figure 8 QIPP key objectives**



Led by the NHS Management Board the implementation of QIPP has become a priority for Strategic Health Authorities and Primary Care Trusts and establishes the context for the future development and planning of service provision. Therefore, when we look at transforming support for people with dementia in Essex we need to ensure the QIPP objectives are central to implementing the strategy.

## 5.3 Essex Position

Essex has been developing its understanding of the impact of dementia and the wider mental health agenda for older adults for a number of years. In 2006 Essex County Council and the five PCT's jointly commissioned the Institute of Public Care to review its Older Adult Mental Health Strategy and following a consultation exercise the final report *Essex County Council and Primary Care Trusts - Reviewing and Repositioning the Older Peoples Mental Health Services* was produced in August 2008<sup>42</sup>.

Whilst this report focused on the wider mental health agenda for older adults, it also identified a number of recommendations in relation to dementia services and future challenges for health and social care, as well as housing and the third sector. Recommendations included developing a joint and multi-disciplinary strategic approach to commissioning services; ensuring equality of access to services; providing training to staff who are not in specialist older adult mental health teams; and ensuring that there is a range of services to support people at home including assistive technology. In response to this report there is an ongoing programme to develop the OAMH strategy across Essex which includes addressing the challenges of dementia.

Other policies and strategies which impact on the Essex, Southend and Thurrock Dementia Strategy include the County Council's and Unitary Authorities' local Carers Strategies, the PCT End of Life Strategies, NICE Quality Standards for Dementia, My Home Life, Dignity in Care and Putting People First: *A shared vision and commitment to the transformation of adult social care*<sup>43</sup>.

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[http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/Older Peoples Mental Health Strategy.pdf](http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/Older_Peoples_Mental_Health_Strategy.pdf)

43 Department of Health. Putting People First: A shared vision and commitment to the transformation of adult social care, 2007

## 6 The Current Position

### 6.1 Current Needs and Services

#### Demographic Information

Essex<sup>44</sup> is the sixth largest county in England and borders East London, Hertfordshire, Cambridgeshire, and Suffolk. The county has urban, rural and coastal communities, ranging from densely populated areas such as Chelmsford, Basildon, Colchester and Harlow, to countryside and coastal villages. It is estimated to have a total population of 1.7 million which is expected to rise to 1.9 million by 2029.

Southend is the largest urban conurbation in the east of England with a population of 160,000 and the closest seaside resort to London. It is located on the north side of the Thames Estuary approximately 40 miles east of central London and is bordered to the north by Rochford, and the west by Castle Point.

Thurrock is situated 25 miles east of London on the River Thames, with over 18 miles of riverfront. It covers an area of 64 square miles, over half of which is green belt. Thurrock has a population of 148,900 (2008 figures). The Borough has a number of main settlements including Grays, Stanford, Corringham, South Ockendon and Tilbury, together with a number of villages.

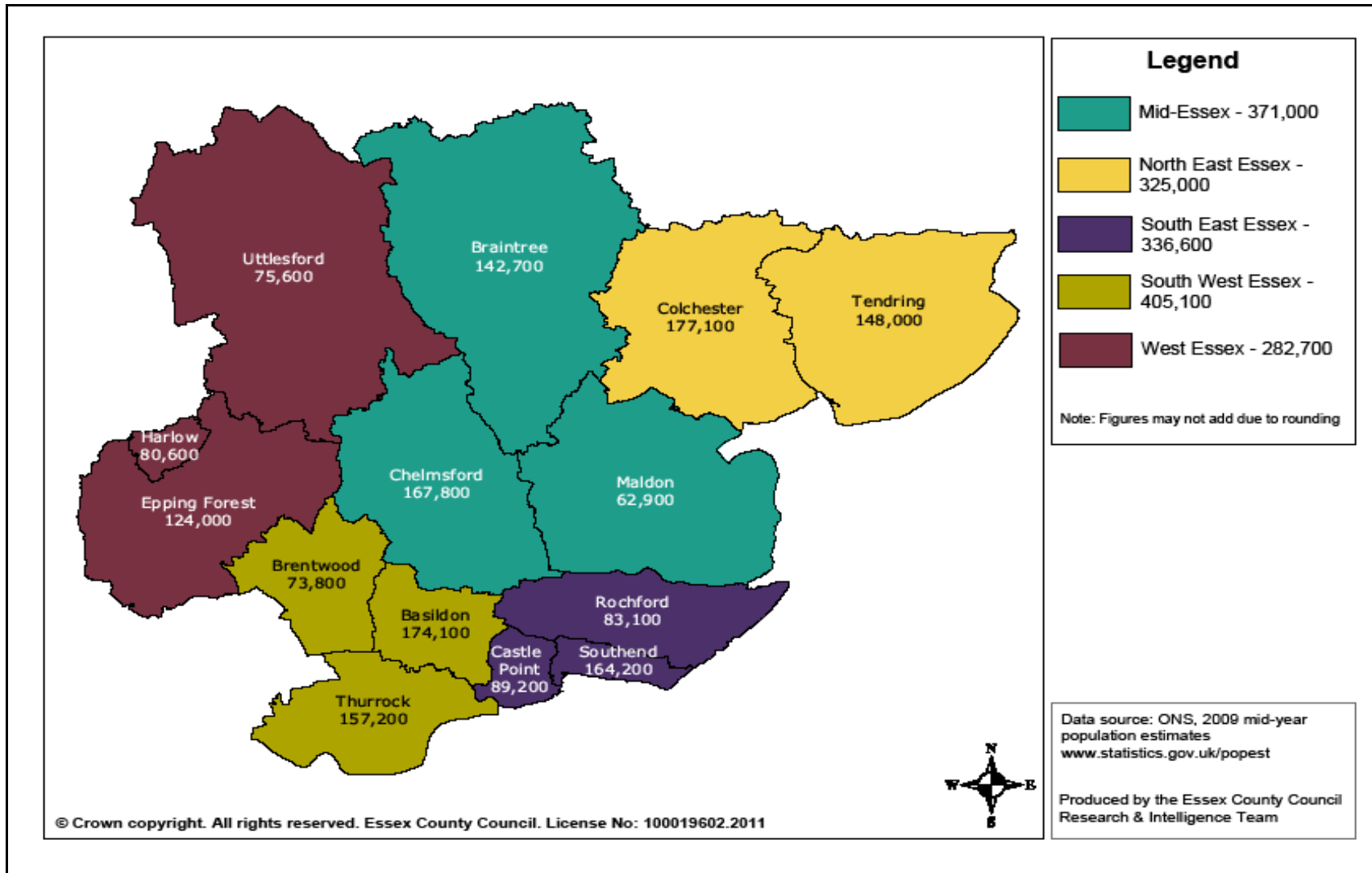
A number of health and social care organisations work together to deliver a range of services to the people of Essex which includes; 12 District and Borough Councils 2 Unitary Authorities 1 County Council and 5 Primary care Trusts in two clusters North and South (see figure 9); 5 Acute Hospital Trusts and 2 Mental Health Partnership Trusts.

The acute trusts which provide general hospital care are; Mid Essex Hospital Services NHS Trust, Princess Alexandra Hospital NHS Trust (West Essex), Basildon and Thurrock University Hospitals NHS Foundation Trust, Southend University Hospital NHS Foundation Trust and Colchester University Hospital NHS Foundation Trust. The North Essex Partnership NHS Foundation Trust (NEPFT) and the South Essex Partnership University NHS Foundation Trust (SEPT) provide mental health services across Essex.

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<sup>44</sup> The term 'Essex' refers to the County of Essex which includes the unitary authorities of Southend and Thurrock.

Figure 9 Population by District council and PCT area



Despite its population Essex remains largely rural but has a higher than average population of people aged over 65 and over 85. The Essex Joint Strategic Needs Assessment reports that across Essex the population aged over 65 is expected to increase by 45% by 2021, with the numbers of people aged 85 expected to rise by 75%. This is recognised as presenting one of Essex's most significant challenges with an associated risk of an increasing number of people developing long term conditions including dementia.<sup>45</sup>

The proportion of people from groups other than White British is approximately 9.7%, which is lower than the national average which is 15.8%. The largest communities other than White British in Essex are Asian, Asian British, Black, Black British, and Chinese. Essex also has an established gypsy and travelling community. (For further information see Section 3.5 figure 3).

Life expectancy can vary greatly as Essex has both socio-economically deprived areas and relative affluence within its borders. This can result in as much as 18.6 years between the poorest ward in Tendring and the most affluent in Uttlesford.<sup>46</sup>

## 6.2 Impact of Dementia in Essex Southend and Thurrock

When it was published in February 2009 the National Dementia Strategy<sup>47</sup> stated that there were 570,000 people in England living with dementia and over the next 30 years that figure would double. However, in February 2010 the Alzheimer's Research Trust (now Alzheimers Research UK) suggested that the original figures of people living with dementia were under represented and that the figure in the UK is closer to 820,000 people.<sup>48</sup> This figure is about 15% higher than originally estimated.

With an increasing ageing population, the numbers of people in Essex Southend and Thurrock living with dementia is set to rise by a higher rate than across England. By 2025 it is estimated that the number of people with dementia in Essex will increase from 22,300 to 35,500<sup>49</sup>. If the Alzheimer's Research Trust figures are considered, this figure could increase to 40,750 by 2025. The incidence of dementia in older age groups is marginally more prevalent in women than for men with 25.2% of women over 85 being affected, and 19.7% of men.

There are high numbers of people over 65 living with dementia in residential and nursing settings. 79.9% of the people in homes specialising in dementia care, 66.9% in nursing

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<sup>45</sup> Essex Southend and Thurrock *Joint Strategic Needs Assessment 2008* para 5.7.

<sup>46</sup> IPC report *Reviewing and Repositioning the Older Peoples Mental Health Services*

<sup>47</sup> Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy*

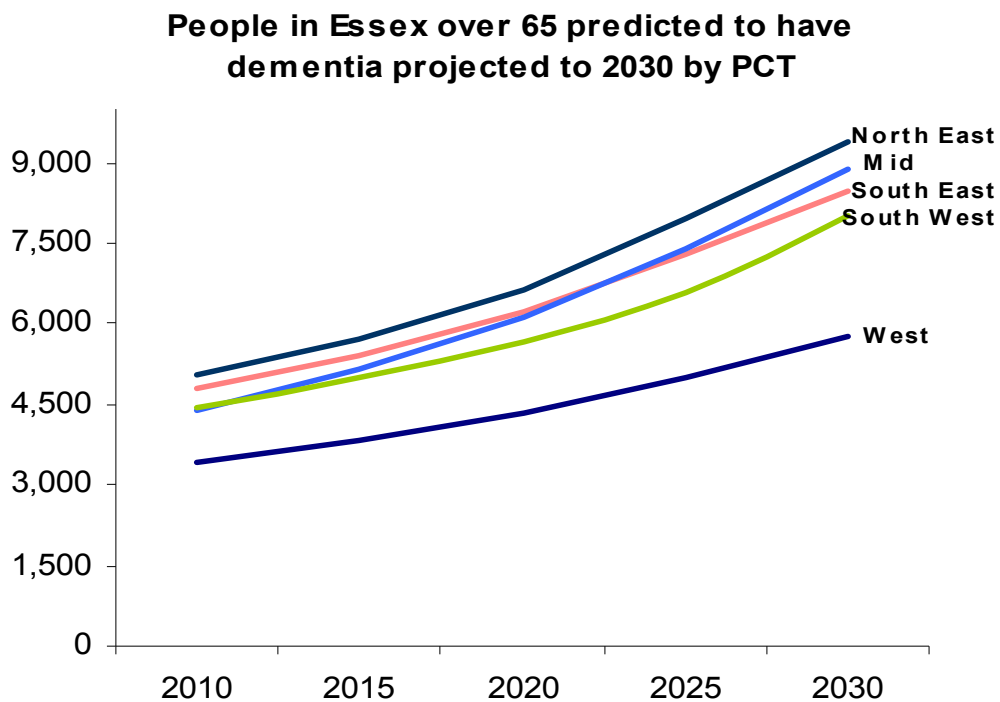
<sup>48</sup> Alzheimer's Research Trust 2010 *Dementia 2010 – The economic burden of dementia and associated research funding in the UK.*

<sup>49</sup> JSNA 2008 quoting POPPI figures

homes and 52.2% in care homes have dementia<sup>50</sup>. With 296 residential and nursing homes across Essex which cater for older people and people with dementia with approximately 11,582 places, this is a significant number of people in Essex living with dementia in residential care.

The following tables show the projected growth in dementia among people in Essex Southend and Thurrock from 2010 to 2030. Figures 10 and 11 represent the numbers of people whilst the table in figure 12 shows the percentage increase. The data is adapted from the Care Services Efficiency Delivery (CSED) Programme’s *Projecting Older Peoples Population Information (POPPI)* figures for the projected increase in numbers of people with dementia. These are based on the Alzheimer’s Society prevalence rates applied to the estimated population growth from the Office of National Statistics. The estimates for the PCT areas have been drawn from the POPPI figures for Districts and Borough Councils in Essex and the Unitary Councils of Southend and Thurrock. However, it is important to acknowledge that data on figures relating to prevalence of dementia locally and nationally are based on best estimates and can vary significantly.

**Figure 10 People in Essex Southend and Thurrock over 65 predicted to have dementia**



Source: POPPI 2010. Based on ONS figures for 2008 published May 2010<sup>51</sup>

<sup>50</sup> JSNA 2008 Citing Dementia UK Report 2007

<sup>51</sup> CSED Projecting Older Peoples Population Information 2010. [www.poppi.org.uk](http://www.poppi.org.uk)

**Figure 11 Table showing numbers of people over 65 predicted to have dementia by PCT area**

	2010	2015	2020	2025	2030
North East	5,029	5,727	6,629	7,937	9,386
South East	4,816	5,412	6,243	7,277	8,484
South West	4,430	5,024	5,682	6,579	7,986
Mid	4,401	5,137	6,145	7,380	8,872
West	3,405	3,810	4,327	4,978	5,768
<b>EST Total</b>	<b>22,081</b>	<b>25,110</b>	<b>29,026</b>	<b>34,151</b>	<b>40,496</b>

Source: POPPI 2010

**Figure 12 Projected percentage increase in the numbers of people over 65 with dementia from 2010 to 2030**

	to 2015	to 2020	to 2025	to 2030
North East	14%	32%	58%	87%
South East	12%	30%	51%	76%
South West	13%	28%	49%	80%
Mid	17%	40%	68%	102%
West	12%	27%	46%	69%
<b>EST Total</b>	<b>14%</b>	<b>31%</b>	<b>55%</b>	<b>83%</b>

Source: POPPI 2010

The tables indicate that North East Essex has the largest population of people over 65 with dementia and this is projected to still be the case in 2030. However, the greatest increase will be in Mid Essex where the population affected is projected to increase by 102% (ie the figures are set to double) within the next twenty years. The lowest numbers are projected to be in West Essex which is likely to have the lowest percentage growth although this will still be an increase of over two thirds by 2030.

The prevalence of younger adults who may develop dementia in Essex has been estimated to be in the region of 800 by the year 2015.<sup>52</sup> The numbers of men who develop young onset dementia is higher than the numbers of women. This may be significant in terms of preventative strategies that may be developed in relation to some types of dementia. The number of people with learning disabilities in Essex who may develop dementia is estimated to be in the region of 500 by 2019<sup>53</sup>.

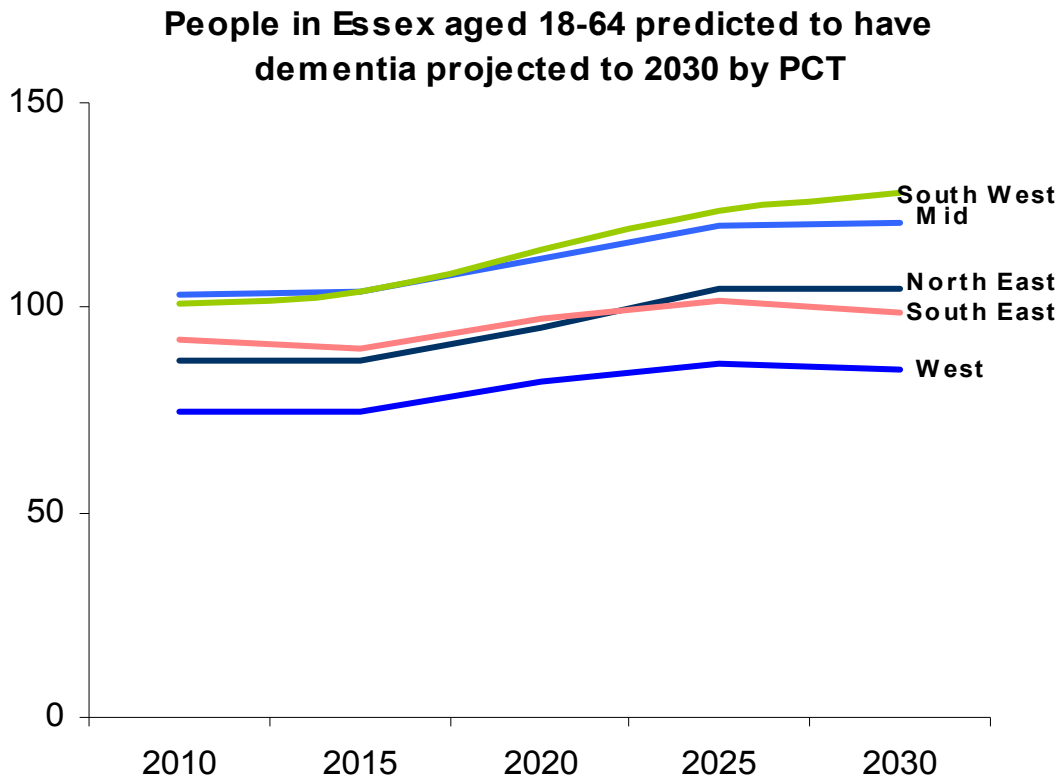
<sup>52</sup> IPC report *Reviewing an Re-positioning the older peoples Mental Health Services*

<sup>53</sup> Estimates quoted in IPC report *ch 3*



The figures below have been drawn from the CSED *Projecting Adults Needs and Service Information (PANSI)* projections for the prevalence of dementia among people in Essex aged under 65 years.

**Figure 13 People in Essex Southend and Thurrock under 65 predicted to have dementia**



Source: PANSI 2010. Based on ONS figures for 2008 published May 2010<sup>54</sup>

**Figure 14 Table showing numbers of people under 65 predicted to have dementia by PCT area**

	2010	2015	2020	2025	2030
Mid	103	104	112	120	121
South West	101	104	114	124	128
South East	92	90	97	102	99
North East	87	87	95	105	105
West	75	75	82	86	85
<b>EST Total</b>	<b>458</b>	<b>460</b>	<b>500</b>	<b>537</b>	<b>538</b>

Source: PANSI 2010

<sup>54</sup> CSED Projecting Adults Needs and Service Information [www.pansi.org.uk](http://www.pansi.org.uk)

**Figure 15 Projected percentage increase in the numbers of people under 65 with dementia from 2010 to 2030**

	to 2015	to 2020	to 2025	to 2030
Mid	1%	9%	17%	17%
South West	3%	13%	23%	27%
South East	-2%	5%	11%	8%
North East	0%	9%	21%	21%
West	0%	9%	15%	13%
<b>EST Total</b>	<b>0%</b>	<b>9%</b>	<b>17%</b>	<b>17%</b>

Source: PANSI 2010

The greatest increase in the numbers of people with young onset dementia is projected to be in South West and North East Essex with a steep rise occurring between 2020 and 2025.

The JSNA identifies that there are high numbers of people who are unpaid carers in Essex with the 2001 census recording approximately 159,000 – almost 10% of the Essex population. Some 30,000 of these spend 50 hours or more on caring tasks every week and almost half of this group are themselves aged over 60. As we have already stated in 5.1 above, approximately two thirds of people with dementia live in their own homes and many of these will be dependent on the informal carers who bear 36% of the annual £25,500 costs of caring for a person with dementia.

It is identified in the NDS that “family carers are often old and frail themselves and have high levels of carer burden, depression and physical illness, and decreased quality of life”<sup>55</sup> Therefore access to carers assessments, good quality respite breaks and signposting to appropriate support to enable people to continue in their caring role is paramount to ensuring carers needs are met. Early diagnosis and access to treatment should be seen as fundamental to supporting people living with dementia and their carers in order that they are able to maintain independence and choice for as long as they have the ability to do so.

<sup>55</sup> Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy* p.10

## 6.3 Bench Marking and Mapping Current Performance

Southend, Essex and Thurrock and the localities of Luton formed an early adopter site for the NDS. Mental Health Strategies was commissioned to undertake a benchmarking and mapping exercise of the services available for people with dementia and their carers related to the objectives of the strategy.<sup>56</sup> This report highlighted the difficulties of obtaining data across the complex health and social care systems in Essex. However, it did identify the need for organisations to make links with other stakeholders (eg libraries) and strategies (carers, end of life) and the need for training within general services to have the skills and knowledge to deliver a person centred care.

In producing this strategy, a mapping exercise has been undertaken to identify what is available for people with dementia and their carers in Essex, Southend and Thurrock, how these services meet the objectives of the NDS, where the gaps are and what the actions should be to fully implement the NDS. See [Appendix 3](#) for a summary of our findings under each objective.

From the mapping exercise, we have learnt that considerable progress is being made to implement key objectives in the strategy and that we have a lot to be proud of. There is evidence of innovative practice and a real commitment to improving the outcomes of people living with dementia and their carers in Essex, Southend and Thurrock. We have also been able to identify some of the gaps and areas where further work is needed.

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<sup>56</sup> Mental Health Strategies: Mapping of Dementia Services – report prepared for Essex and Luton Council and Health Services October 2009

## 7. Overall conclusions

The numbers of people living with dementia in Essex, Southend and Thurrock is already predicted to be in the region of 22,300. With the projected increase in the ageing population this is set to rise to 35,000 by 2025 and is a significant challenge for the whole health and social care economy. Preliminary analysis reveals that services for people with dementia often lack a whole system approach, resulting in fragmentation and inconsistencies in pathways, which leads to difficulties in providing accurate signposting, information, and navigation to the person who is on their journey into dementia. Care Management/care coordination is provided in a variety of teams and settings including, Older Adult Mental Health Teams, Adults of Working Age Mental Health Teams, Community Assessment Teams, Review Teams, Long Term Management Teams, Learning Disability Teams, Memory Assessment Services. There are areas of innovative practice and progress in supporting people with dementia and their carers across Essex Southend and Thurrock, but this can result in an inequity of service if it is not built upon.

There is an established clinical and health economic case for early diagnosis and intervention services in dementia<sup>57</sup> whereby investment in early diagnosis and support will reduce the need for costly crisis intervention and premature residential, nursing or inpatient care. To date there has been progress in Essex with memory assessment services providing early diagnosis, treatment and support in all locations. However, there remain challenges in respect of ensuring a single point of access for all referrals, and ensuring that services are available to all those who need them including people with young onset dementia and learning disabilities.

The increasing numbers of referrals will have an impact on the services required to support people who are diagnosed with dementia. The Alzheimer's Services are providing support but this needs to be co-ordinated across Essex to ensure that there will be ongoing support in the future. Currently many of these services are being funded on a yearly basis. Further investment will also be required in preventive services such as intermediate care, hospital admission avoidance, and reablement. The effective use of these services will reduce the need for costly and premature residential and inpatient care.

Although considerable investment was made on a regional basis through the Joint Improvement Partnership project (see appendix 3 objective 6), the uptake of cash payments of personal budgets is still lower for people with dementia and their carers so that more people with dementia are likely to receive managed services. Therefore, it is

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<sup>57</sup> Banerjee, S. Wittenberg, R. *The clinical and health economic case for early diagnosis and intervention services in dementia* Living with Dementia – a National Dementia Strategy app.4 2009

imperative that the services which are provided to people with dementia and their carers are person centred and appropriate to support the individual's needs. This applies to all services whether they are from the voluntary independent or statutory sector, and whether they are delivered in the person's home, the community, a day centre, or residential care. This also includes intermediate care and reablement which are not readily available for people with dementia in all areas. Currently we do not have a full picture of the quantity and quality of the services available across Essex.

It is identified that a high level of care is provided by informal carers who bear 36% of the costs of caring for people with dementia.<sup>58</sup> There is a need to ensure that the carers of people with dementia have access to a range of personalised breaks which meet the needs of carers and the people with dementia who they are caring for. Carers of people with dementia should expect the same outcomes as any other carers within the context of the priorities for carers outlined in the Department of Health's "Next Steps" document for the Carers Strategy<sup>59</sup>. Whilst carers' assessments are routinely offered and undertaken further work is required to ensure that carers' emotional, psychological and social needs are met and to increase the availability of appropriate breaks, (Nice Quality standards 6 & 10, NDS Objective 7).

Improving the quality of care within residential and nursing homes and in general hospitals are current national priorities. Further work is required to identify the current position regarding skills and staff development within these areas and these should be addressed through the Essex Southend and Thurrock workforce development strategy which will complete its work in March 2011, (Nice Quality standard 1, NDS Objective 13). However, enhanced liaison services (NICE Quality Standard 8, NDS Objectives 8 and 11) and in reach from specialist teams have been identified as a necessary form of support but at present they are not available in all areas of Essex.

Audits have been undertaken in respect of the use of anti-psychotic medication in several areas and this is a priority for all PCT localities. However, this also requires training for staff who work with people with dementia to improve their skills in managing the distressing behavioural symptoms which have previously been treated with anti-psychotic medication.

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<sup>58</sup> Mitchell-Baker, A., Greene, R. *Health and Social care best practice Catalogue. Older Peoples Services Essex. Version 6* (July 2010)

<sup>59</sup> Department of Health: *Recognised, valued and supported: Next Steps for the Carers' Strategy* November 2010

The priorities for action fall broadly under the two headings of early diagnosis and support and living well with dementia. These are:

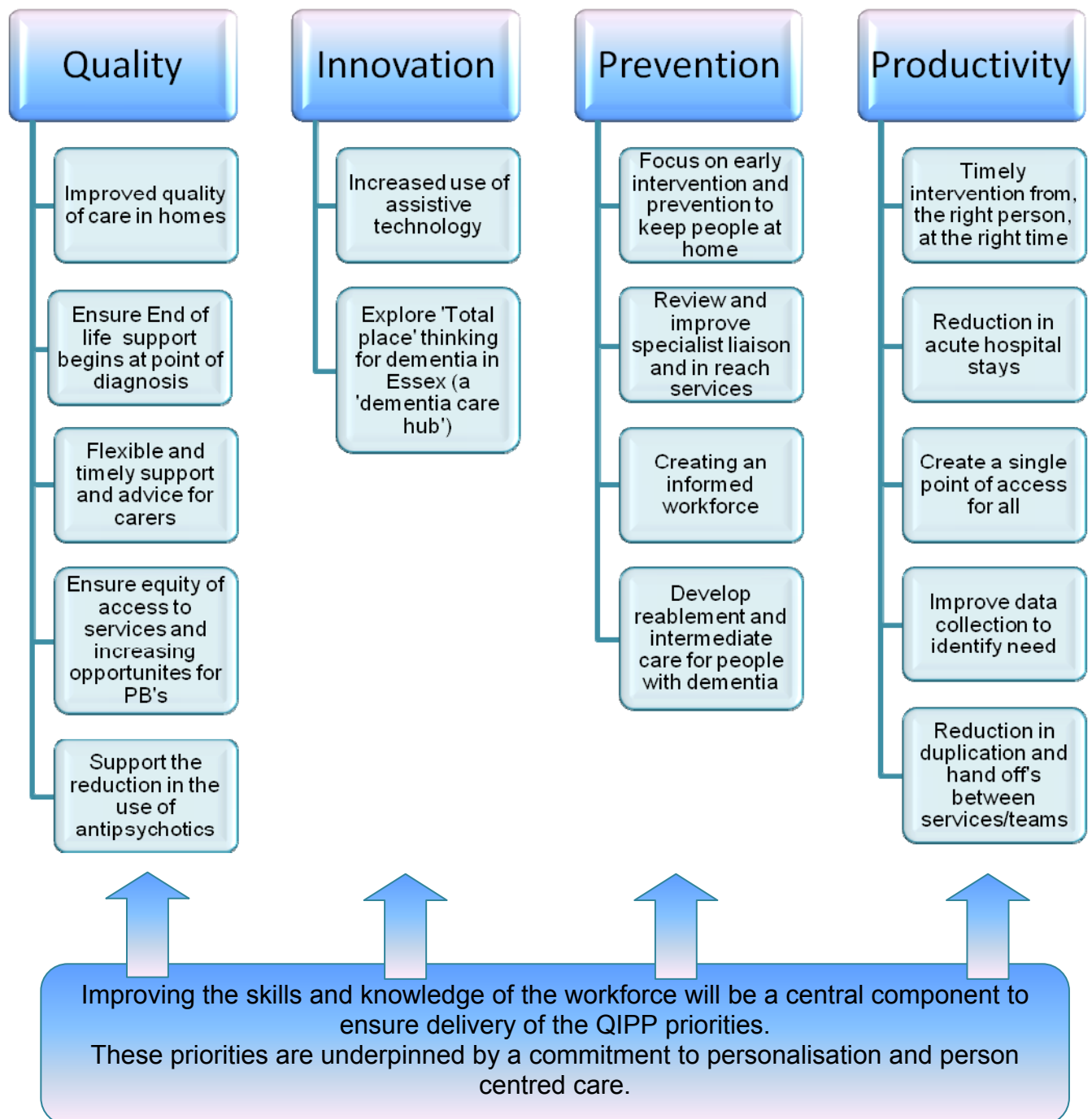
- ensuring clear pathways are available for all people including those with young onset dementia or learning disabilities to access timely assessment, diagnosis, treatment and support;
- access to admission avoidance schemes, reablement and intermediate care;
- enhanced liaison and in reach services to acute hospitals and nursing homes which includes strategies to reduce the use of anti-psychotic medication;
- an effective, trained and skilled workforce;
- appropriate support to carers and recognition of carers as partners in the care of people with dementia;
- access to palliative care and support to people with dementia at the end of life.

## 8. The Way Forward

### Priorities for 2011 – 2014

This strategy will help drive up quality and improve dementia care services. It reflects a shift in emphasis from structures and processes towards our agreed priorities, centred on improving outcomes for people with dementia and their carers.

Figure 16 QIPP and strategy priorities



With a focus on the Care Quality Commission's three outcome areas for 2010/11, which are:

- Improved health and wellbeing
- Increased choice and control
- Maintaining personal dignity and respect

We will also pay particular attention to the way in which safeguarding, Putting People First and value for money have been the key drivers for effective delivery of these outcomes. This will provide a clear focus to the assessment and has been developed with key stakeholders, including people who use services.

Our approach will be targeted, proportionate risk based and make the most efficient use of publicly available data.

We have used the information gathered in the Mapping and Progress Report and the summary of our findings in Appendix 3 to identify the above priorities. We will also use this information to develop local service plans, building on the work that has already been undertaken by the Primary Care Trusts, Mental Health Trusts, the County Council and Unitary Authorities.



# Appendices

## Quality Outcomes for People with Dementia

Outcome	Descriptor	NICE Quality Standard	National Dementia Strategy Objective
I was diagnosed early	People will have the information they need to understand the signs and symptoms of dementia. Those concerned about dementia will know where to go for help. The time between people presenting symptoms to a doctor and being diagnosed will be as short as possible for everyone.	2, 3	1, 2
I understand, so I make good decisions and provide for future decision making	Everyone affected by dementia will get information and support in the format and at the time that best suits them. They will be supported to interpret and act on the information so that they understand their illness and how it will impact on their lives, including any other illnesses they may already have. They will know what treatments are best for them and what the implications are and they will be supported to make good decisions.	3, 5	3, 4, 5
I get the treatment and support which are best for my dementia, and my life	Everyone living with dementia will receive the best dementia treatment and support, no matter who they are or where they live. They will feel that their personal needs have been appropriately assessed and that their treatment and potential consequences of treatment have been well planned and delivered in a coordinated way that is appropriate to their individual needs and preferences. They will be able to exercise personal choice in social care and ongoing support will be of a high quality.	1, 4, 5, 7, 8	2, 6, 8, 9, 10, 11, 13, 18
I am treated with dignity and respect	People living with dementia will report that they are treated with dignity and respect by all those involved throughout their dementia journey. They will also be open about living with dementia without fear of stigma or discrimination. It will be well recognised and understood by the public and professionals that dementia is a condition that increasing numbers of people will live with.	1	1, 13

<b>Outcome</b>	<b>Descriptor</b>	<b>NICE Quality Standard</b>	<b>National Dementia Strategy Objective</b>
I know what I can do to help myself and who else can help me	People living with dementia will be supported to self-manage the consequences of dementia and its treatment, to the degree they are able/wish to. They will know where to turn to get the clinical, practical, emotional and financial support they need when and where they need it. They will feel confident that they can practice their faith and spirituality and that others will help them when they need support.	1, 3, 4, 5	3, 4, 5, 6, 13
Those around me and looking after me are well supported	People living with dementia will feel confident that their family, friends and carers have the practical, emotional and financial support they need to lead as normal a life as possible throughout the dementia journey. They will know where to get help when they need it.	3, 4, 6, 10	3, 4, 5, 7
I can enjoy life	People living with dementia will be well supported in all aspects of living with dementia, leaving them confident to lead as full and active life as possible. They will be able to pursue the activities (including work) that allow them to be happy and feel fulfilled while living with dementia.	3, 4	1, 4, 5, 6
I feel part of a community and I'm inspired to give something back	People who have been affected by dementia and others will feel inspired to contribute to the life of their community, including action to improve the lives of others living with dementia. This includes having the opportunity to participate in high quality research		1, 5, 16
I am confident my end of life wishes will be respected. I can expect a good death	People who are nearing the end of their life will be supported to make decisions that allow them and their families/carers to be prepared for their death. Their care will be well co-ordinated and planned so that they die in the place and in the way that they have chosen.	5, 9	12, 13

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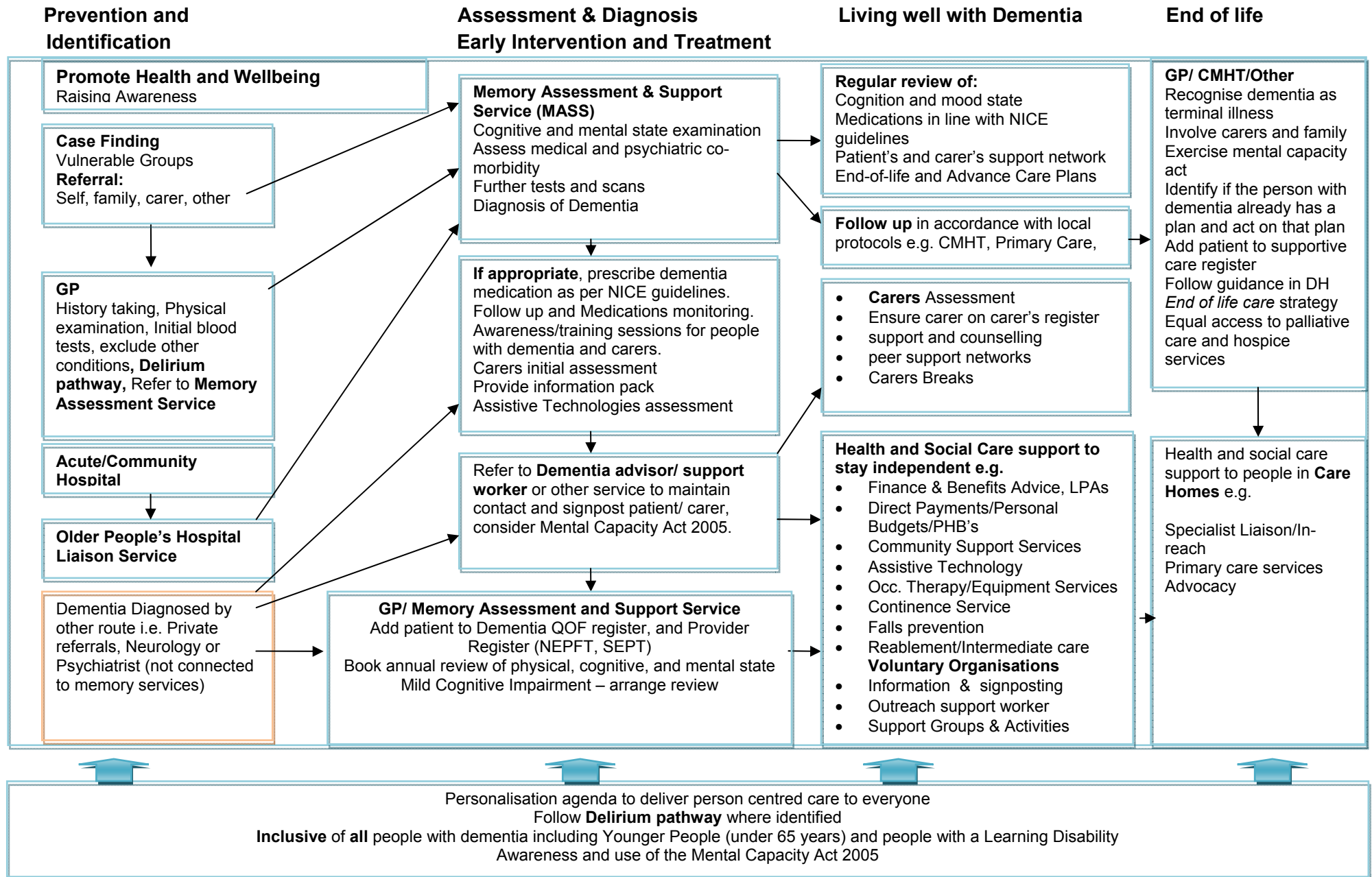
<sup>60</sup> Reproduced from DH [http://www.dh.gov.uk/prod\\_consum\\_dh/groups/dh\\_digitalassets/@dh/@en/@ps/documents/digitalasset/dh\\_119828.pdf](http://www.dh.gov.uk/prod_consum_dh/groups/dh_digitalassets/@dh/@en/@ps/documents/digitalasset/dh_119828.pdf) pp21-22

**Essex, Southend and Thurrock Dementia Care Pathway – Agreed Principles**

This is an integrated pathway agreed by all stakeholders across the geographical areas of Southend, Essex and Thurrock

- The integrated pathway includes access to primary care, social care and voluntary agency support, secondary mental health support and prevention.
- All parties acknowledge the importance of delivering all parts of the pathway, but that local arrangements to achieve the stated goals may vary.
- The pathway aims to be clear, understandable and useable to all people who read it. This includes individuals and their carers as well as those working with people with dementia in health, social care and allied professions.
- The pathway relates to consistent standards which support quality outcomes for people with dementia and are in line with the NICE Dementia Quality Standard and the values of dignity and respect.
- The principles of Personalisation and person centred support are integral to all stages of the pathway to maximise opportunities for independence and improved quality of life.
- Individual needs and identified outcomes should dictate the level of support required across the pathway.
- Carers' needs are integral to the care pathway.
- There will be a single point of access identified for access to Memory Assessment Services
- The pathway identifies key points for identification and review in order to prevent people being lost in the system eg people with mild cognitive impairment and less complex presentations, or those people who may have been diagnosed outside of the pathway, to ensure that they are regularly reviewed and receive appropriate support.
- The principles and provisions of the Mental Capacity Act will be followed at all stages, including specific reference to enabling the person with dementia to be fully involved with decisions relating to their health and welfare, Advance Statements and Decisions, and provisions for Lasting Powers of Attorney.

## Essex, Southend and Thurrock Dementia Care Pathway



### Summary of progress in respect of the objectives of the National Dementia Strategy across Essex, Southend and Thurrock - February 2011

**Raising awareness and understanding** (Objective 1) Public and professional awareness and understanding of dementia to be improved and the stigma associated with it addressed. This should inform individuals of the benefits of timely diagnosis and care, promote the prevention of dementia, and reduce social exclusion and discrimination. It should encourage behaviour change in terms of appropriate help-seeking and help provision.

In addition to the national public information campaign the Alzheimer's Society has been funded by Local Authorities and PCT's in Essex to provide information via its network of services throughout Essex and through its Countywide Information Service.

Other initiatives have taken place in most areas.

- The Alzheimer's Society are commissioned by Southend on Sea Borough Council to provide dementia cafés and peers support groups as well as having a responsibility to increase awareness of dementia in the general population.
- South West PCT held a series of Dementia Roadshows which aimed to provide information for people with dementia, their carers and all those who work in this area.
- South Essex Partnership Trust has produced DVDs which raise awareness about memory services and the experience of people affected by dementia.
- North Essex partnership Trust in Mid Essex is currently developing a DVD about working with people with dementia.
- Dementia cafes are being developed in many areas which are a source of information and advice.
- Plans are being made to increase training and awareness for GPs across Essex. Liaison and in-reach services to residential homes also improve awareness among residential and nursing home staff.

**Good quality early diagnosis and intervention for all** (Objective 2). All people with dementia to have access to a pathway of care that delivers: a rapid and competent specialist assessment; an accurate diagnosis sensitively communicated to the person with dementia and their carers; and treatment, care and support provided as needed following diagnosis. The system needs to have capacity to see all new cases of dementia in the area.

The development of memory services at the onset of the dementia journey is fundamental to ensure that people can plan and prepare for the future. It was identified in the strategy that only about one third of people with dementia receive a formal diagnosis or have

contact with specialist services.<sup>61</sup> There are memory assessment services in all Essex, Southend and Thurrock localities which aim to provide a service to all people who require assessment regardless of age. However, the configuration of these services varies from locality to locality.

- Services provided by SEPT in South Essex can all be accessed through a single telephone number.
- Services in Mid Essex and West Essex aim for a Single Point of access to each location via GP referral.
- An age inclusive service with a single point of access is being developed in North East Essex to enhance existing services which started in October 2010 and is being phased in.
- North Essex Partnership Trust also has a neuro-cognitive clinic in the West Essex which provides enhanced diagnostic services for people with complex presentations or where a second opinion is requested.

All memory assessment services include advisors (mostly through the Alzheimers Society) who can support people during the diagnostic process. In some areas, including Southend and Tendring members of the memory service regularly attend the Alzheimer's Society dementia cafés to provide advice and assistance around diagnosis in a non clinical accessible way, encouraging further use of the memory assessment service.

However, any requirements for Social Care support are either referred to the Older Adults Mental Health Teams or Social Care Services as Social Care staff are not integrated with the memory assessment services. Response times from these services vary and further work is required to ensure rapid and consistent access to social care assessment is available when required.

There is a need to ensure that services for assessment and diagnosis are available for younger people with dementia with clear pathways developed to meet the specific needs of this group. Currently services are fragmented as people are often seen within adult mental health services where there is not necessarily access to appropriate and effective ongoing support for people with the complex needs arising from young onset dementia. In order to address this funds have been released from the continuing care service in North East Essex to reinvest in the dementia care pathway with the intention of building expertise in accessing and treating people with young onset dementia across Essex.

Currently people with Learning Disabilities are not seen at the Memory assessment services. Work is being undertaken in some localities with learning disability services to identify appropriate assessment pathways.

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<sup>61</sup> Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy*

### **Good quality information for those with diagnosed dementia and their carers**

(objective 3) 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

The NDS has emphasised the need for people with dementia and their carers to have easy access to care, support and advice following diagnosis. It states that people should be provided with information, a signposting service and support to access services throughout the course of their illness. However, historically dementia services have often been delivered by different organisations in a non-coordinated way. Some people are supported initially in primary care without support from specialist services, others present to hospital services and mental health services in crisis. There has been a lack in consistent pathways to support people to access services that would best support their needs. Work has been undertaken on an Essex, Southend and Thurrock high level pathway within work stream 1 of the OAMH programme which identifies a common pathway across Essex, Southend and Thurrock (See appendix 2). However, it is recognised that the variation between the configuration of services for Older Adults Mental Health in the different PCT areas means that the detail of care pathways will need to be developed at a local level.

Information packs are provided by all Memory Assessment Services following diagnosis. In all areas carers' support and education, or living well with dementia groups are being held to support people recently diagnosed with dementia and their carers which may be run by staff from the mental health trusts or by third sector providers such as the Alzheimer's Society or Carers support agencies. Other organisations such as Southend Carers forum, when registering a carer, will provide a pack of information signposting carers to the right places for help and support. The members work hard to keep this up to date.

The Alzheimers Society is funded across Essex, Southend and Thurrock to provide a support service to people diagnosed with dementia and their carers. This includes providing specialist information about living with dementia as well as information regarding services and benefits with assistance to access these where required. Specific targeted support for people with young onset dementia is provided by West area of NEPFT.

**Enabling easy access to care support and advice following diagnosis** (objective 4) A dementia advisor to facilitate easy access to appropriate care support and advice for those diagnosed with dementia and their carers.

Dementia Advisors Posts are being developed throughout Essex Southend and Thurrock although there are variations in the role in different locations. In most areas they are situated within Memory Assessment clinics and currently provide advice and support during the assessment process and after diagnosis. People are then signposted to ongoing sources of support such as the Dementia Support Services provided by the



Alzheimer's Society and other 3<sup>rd</sup> sector organisations, or to more specialist support through the Older Adults Mental Health teams.

Other initiatives include:

- a joint funded business case which is being considered in North East Essex for a pilot for Dementia Care Advisors based in GP surgeries, where an advisor will provide support and information throughout the dementia journey;
- peer support networks in Southend are evolving to provide signposting/advice services;
- day hospital in West Essex providing outreach into the community in partnership with the Alzheimer's Society.
- In Southend, in addition to the Alzheimer's Society being integrated into memory assessment services they are linking up with primary care in order to work with people to offer help and support from the moment of diagnosis.

**Development of structured peer support and learning** (objective 5). 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 groups are being developed throughout Essex. South East PCT and Southend Borough Council have a programme which is a demonstrator project for the national strategy and is a partnership between the PCT, the Council, and the Alzheimer's Society. This is now fully integrated into local services. Other peer support groups, including some for younger people with dementia are provided through the Alzheimer's Society and Voluntary and Not for Profit Organisations throughout Essex. Dementia cafes offer a valuable source of peer support.

**Improved community personal support services** (Objective 6). 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.

Essex Southend and Thurrock Councils are committed to the personalisation of Adult Social Care which underlines the Department of Health's agenda to transform adult social care. It is an approach that gives people real choice and control over the kind of care they receive. "Personalisation" begins with the person as an individual, with strengths and aspirations as well as a circle of family, friends and other support. The individual is at the centre of the process of identifying their needs and making choices regarding their support and care.

The use of personal budgets improves flexibility, choice and control whereby support is tailored to individual needs. This can be of considerable benefit to people with dementia and their carers. Older Adults CMHT's and Self Directed Support (SDS) practitioners should be able to ensure that people with dementia and their carers benefit from Improved Community Personal Support Services through the development of personal budgets. Across the East of England a Project Manager was appointed with funding for one year from the Joint Improvement Partnership (JIP)<sup>62</sup> to increase the take up of personal budgets for people with dementia and their carers. This provided firm foundations to ensure that people with dementia and their carers are considered and positively encouraged to regain and retain independence, choice and control in their lives. An evaluation report of this work has been written. The benefits of personal budgets are that people can choose the help that they need, delivered where and when they need it.

Essex County Council has made a commitment to increasing the uptake of personal budgets by making the following pledge for 2011/2012

“Increase by a minimum of 20% the uptake of Personal Budgets and/or Assistive Technology by people with Dementia or their Carers”

The NDS refers to emerging research based evidence that there are considerable benefits for people with dementia and their carers who receive specialist dementia home support rather than standard home care services.<sup>63</sup> These seek to overcome traditional problems relating to lack of consistency of workers and task based commissioning. The benefits are cited as including reduced stress and in terms of reduced stress and risk of crises for carers and extended capacity for independent living for people with dementia. There are some providers within Essex Southend and Thurrock who have developed expertise in this area, but further work is needed to ensure that there is access to specialised support across all areas where this is needed.

There remains a range of day services provided through NHS, local authority, Council, independent and voluntary sources. Specialist day services are provided in some areas which have been highly valued but currently there are no other such services being planned. Although there has been a move away from buildings based day services through the Personalisation agenda it must be recognised that many service users do enjoy meeting in groups with others and that there are therapeutic advantages of good day services which provide meaningful activity and support as well as respite for carers. The Alzheimer's Society has also developed a leisure and wellbeing service throughout Essex,

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<sup>62</sup> The Joint Improvement Partnership (JIP) are multi-agency cross sector forums linking together different communities of interest to address personalisation, efficiency and quality agenda in public sector agencies connected to Adult Social Care. .

<sup>63</sup> Ibid Ch 5 para 3 pp47-48.

Southend and Thurrock which aims to support people with dementia to maintain their skills and leisure interests on a one to one basis thereby enhancing their sense of wellbeing and independence. The service supports people in the early stages of dementia who may not be eligible for Social Care Services.

There has been significant investment by some PCT's in Essex to respond to the challenges of the NDS. New services include:

- Provision of memory clinics providing both diagnosis and treatment
- Access to enhanced Liaison Services
- Dementia Advisor Posts
- Peer Support
- Wellbeing and Leisure Services
- Dementia Cafés
- Thinking Fit Project (West Essex)

These new additional services across health and social care are to be welcomed. However, increased awareness coupled with rises in the number of people diagnosed with dementia may impact on the demands on health and social care staff in the Older Adult Community Mental Health Teams.

Access to social care services and social care support can be arranged through Community Assessment Teams or where specialist support is needed, through Community Mental Health Teams for Older Adults. Southend on Sea Borough Council have integrated the Older Adult Mental Health Teams into the Older Peoples Teams. This is to ensure that services to support people with dementia are available when they are needed and also ensuring people with symptoms of dementia who do not have a diagnosis receive the services they need and seek diagnosis. The Borough Council also provides a range a whole suite of services for carers ranging from respite care to carers support groups. Essex County Council and Thurrock Council have integrated Community Mental Health Team for Older Adults. They provide multi-disciplinary assessment, support planning, monitoring and treatment. The team works closely with The Alzheimer's Society.

**Implementing the Carers' Strategy** (Objective 7) The NDS states that active work is needed to ensure that the provisions of the carers strategy are made available to the carers of people with dementia including assessment of needs, support and good quality personalised breaks.

The Carers Strategy for Essex is currently being developed which provides an opportunity to explicitly include the needs of the carers of people with dementia with reference to the NDS. Southend Carers Strategy takes full account of dementia services and is almost ready for consultation and publication.

South West Essex PCT and SEPT is a national demonstrator site for the Carers Strategy and have developed e-learning for carers, a website, and has also been working in schools to raise awareness about young carers. Additionally there was a road-show programme in 2010 which focussed on the needs of carers of people with dementia

The Alzheimer's Society and other voluntary and not for profit organisations are funded throughout Essex to provide support to Carers as well as some respite services. Mental Health services provide support groups for carers in several areas.

Access to a break from caring is fundamental to supporting carers. However, carers should be confident that their loved one is receiving good quality care and support. Suitable breaks may be from as little as 2 hours on a regular basis, to full days or a longer term week or fortnight break, and maybe within the home or in an alternative venue such as a day centre or residential setting. The challenge, however, is to ensure that the support provided is person centred and focussed on the needs of both the person with dementia and their carer. Further work is therefore required to ensure that there is a range of options in place for carers' breaks across Essex.

**Improved quality of care for people with dementia in general hospitals (Objective 8)**  
To achieve improved quality of care the NDS recommends that leadership is identified for dementia in general hospitals with care pathways developed and the commissioning of specialist liaison teams to work in general hospitals.

Enhanced liaison services are at different stages of development across the area. These services provide clinical support to Acute Hospitals and residential providers. An established liaison team is based at the Crystal Centre on the Broomfield hospital site and works across the Mid Essex Hospital trust to assist in the early identification, diagnosis and management of mental health problems of older people. A delirium pathway has been developed which is in use in Mid Essex hospitals. North Essex PCT has obtained QIPP funding to further develop services in Colchester and Tendring.

South West Essex has a Hospital Liaison Dementia Nurse, who is working with the wards to facilitate discharge and to provide support and advice in understanding behaviour in dementia in an acute setting. There is also a Clinical Lead identified within the Acute Hospital. In West Essex a liaison nurse works in acute and community hospitals to provide advice, support and clinical consultation.

Further work is required to identify and review the care of people with dementia in general hospitals and this will form part of the work of work stream 2 of the Essex Southend and Thurrock OAMH programme.

It should be noted that the Primary Care Trusts are developing in two “clusters”; the North Essex Cluster which includes North East Essex, Mid Essex and West Essex and the South Essex Cluster comprising NHS South East Essex and NHS South West Essex.

**Improved intermediate care for people with dementia, (objective 9).** Intermediate care which is accessible to people with dementia and meets their needs.

The NDS identifies that people with dementia are often excluded from pathways out of hospital or to avoid hospitalisation such as intermediate care, rehabilitation and reablement. However it refers to good clinical evidence that people with mild or moderate dementia with physical rehabilitation needs do well if given the opportunity.

The current Reablement Schemes in Essex (County Council) are available for people with dementia but are mostly appropriate for people with physical disabilities or who are physically frail. People with dementia may need longer than 6 weeks for rehabilitation and reablement and staff working in intermediate care need to have access to training in dementia and access to specialist advice in order to enable people with dementia to benefit from rehabilitation and reablement. A pilot Reablement scheme for people with dementia is being developed in Mid Essex and there are identified intermediate care beds in South West Essex. Reablement services are being developed in Southend and Thurrock which are expected to be inclusive of people with dementia. A joint initiative between South West Essex Community Services, the PCT and SEPT is to develop a pathway for people with dementia in intermediate care settings.

**Considering the potential for housing support, housing related services and Telecare to support people with dementia and their carers (objective 10).** The needs of people with dementia 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.

Recent extra care developments in Witham and Basildon have included units which are designed to suit the needs of people with dementia. Housing strategy plans include needs of people with dementia. The Southend on Sea housing strategy links in with the National Dementia Strategy and includes Dementia needs in the Homes for the Future programme to fit assistive technology. In NE Essex a telecom pilot using a medicines prompting device is planned.

Assistive Technology provision is identified as one of the first interventions that should be considered for vulnerable people. AT can be used to great effect to support the independence of people with dementia as well as supporting carers. The service is pan age and disability and has particular solutions available for people with dementia. These range from simple low cost memo minders to personal location devices intended to promote safer walking. Other solutions include bed exit alarms, doors opened (or left

open) alarms, smoke and CO detectors, and a range of medication prompting support methods.

A joint initiative between ECC and NEPFT is piloting a buddy system within the CMHT and day hospital and the use of assistive technology in clinical ward areas to promote follow on use in the community.

As mentioned earlier Essex County council has made the following pledge for 2011/2012 to support the use of assistive technology for people with dementia.

“Increase by a minimum of 20% the uptake of Personal Budgets and/or Assistive Technology by people with Dementia or their Carers”

**Living well with dementia in care homes** (objective 11). Improved quality of care for people with dementia in care homes through the development of explicit leadership for dementia within care homes, defining the care pathway there, the commissioning of specialist in-reach services from community mental health teams and through inspection regimes.

OAMH services should provide support to residential and nursing homes. This support is configured differently across the localities and further review into the effectiveness of this support is required.

- A specific liaison service is set up in Mid Essex that provides support and advice to care homes.
- In South Tendring a CMHN provides support to care homes in the locality which aims to enable people with complex need to be understood and has given residential staff a greater degree of confidence in managing behaviours.
- West Essex NEPFT have a nursing and residential homes liaison project where an identified nurse provides intervention for specific individuals and training and advice is provided to staff.
- Mid NEPFT liaison service has a remit to support care homes.
- Southend on Sea Borough Council also provides Dementia Champion training to care home staff and
- Thurrock Council has a specific Dignity programme involving Care Homes as well as other services.

Quality Improvement Standards in Essex CC specifically require that all residential homes which provide care to older people must have core dementia training. However, changes to the monitoring process may impact on this requirement being followed up.

A project has been undertaken in South West Essex within one care home to develop a training strategy particularly in relation to medicines management which will be rolled out to other homes. A QIPP bid has been successful in relation to this and is coupled with support from SEPT to review medication. Audits have identified gaps in Community

support for people with dementia in care homes. South West Essex is funding the Alzheimers and SEPT to deliver training in local residential homes in Thurrock and Essex.

All localities are prioritising the use of anti-psychotic medication. This is particularly relevant in residential care settings.

Other initiatives which may support this objective are:

- Dignity in Care<sup>64</sup>
- End of Life Strategy<sup>65</sup>.
- My Home Life Programme<sup>66</sup>

My Home Life Essex has been developed by Essex County Council following the National My Home Life initiative involving Care UK, The Joseph Rowntree Foundation and the care home sector with the aim of improving the quality of life for people living in residential care homes. My Home Life Essex offers "the local care home community the opportunity to develop a programme whereby they can learn from the research and each other, share good practice, pool ideas and to make residential care for older people in Essex the best that it can be"<sup>67</sup>.

A review of care in residential and nursing homes is part of the work programme of work stream 2 of the OAMH programme. An Essex wide group has been set up to look at standards in care homes to ensure consistent high levels of care are provided.

**Improved end of life care**, (objective 12). 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.

End of Life strategies are being developed in each of the PCT localities. Links are being made to the National Dementia Strategy. At least one area (SW PCT) has developed an end of life pathway for people with dementia. The Preferred Priorities of Care document is being used in some areas for people with dementia but the timing of when these should be used appears to vary between services. There are specific issues relating to pain management, advance care planning and mental capacity for people with later stage dementia.

End of life issues are included in the SEPT dementia e-learning tools and SWIFT funding has been obtained from the Strategic Health Authority for End of Life e-learning to be

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<sup>64</sup> <http://www.dignityincare.org.uk/>

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[http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH\\_086277](http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277)

<sup>66</sup> <http://myhomelifemovement.org/>

<sup>67</sup> Quote: Jan Lockyer My Home Life Essex Project Manager

rolled out across Essex for both NHS and Care Home staff. This training will incorporate supporting people with dementia.

**An informed and effective workforce for people with dementia, (Objective 13)** All health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality 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.

A dementia training needs and skills gap analysis was undertaken for the Eastern Region in November 2009.<sup>68</sup> This identified common themes across the region. The main findings were that there was more training available to staff in social care rather than in health settings but that there was little evidence of this being mandatory training in either setting; the biggest training gaps were for GPs, district and practice nurses, those working in acute general wards including medical, nursing and non-medical staff; there were gaps in the skills and knowledge of some trainers and many trainers were failing to meet the criteria for the East of England Integrated Commissioning Strategy; training from the Alzheimers Society was highly valued. The priorities for learning were identified as ensuring that a person centred approach is firmly embedded in training and evidenced in dementia care; younger people with dementia communication skills: working with carers and families; maintaining independence; end of life care.

An e-learning training package has been developed by SEPT which is available to NHS staff with a plan to roll this out across the Region to include Local Authority staff during 2011. In addition an enhanced training package is being developed by Essex CC which will be available within this financial year. Dementia champion training is being commissioned in Southend which also has a programme of training for health and social care staff. Mid Essex is developing training for GPs and South West has arranged awareness training for hospital staff and paramedics.

A task and finish group is being set up to explore dementia training needs in Essex, Southend and Thurrock. This group aims to complete its report and recommendations by June 2011

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<sup>68</sup> *Dementia training and Development, Training needs and skills gap analysis.* The Office of Public Management 2009



**A joint commissioning strategy for dementia.** (Objective 14) Local commissioning and planning mechanisms to be established to determine the services needed for people with dementia and their carers, and how best to meet these needs.

The Essex, Southend and Thurrock strategy supports the local strategies which are being developed. The current position is:

- North East Essex PCT draft strategy has been completed and actions are being implemented.
- South East. Southend on Sea Borough Council, Essex County Council and NHS South East Essex have been working on pulling all the achievements so far in achieving the objectives of the National Dementia Strategy into a strategic document to understand the future direction of dementia services and put the necessary plans and services in place to ensure that people with dementia and their carers are able to live well with dementia, both now and in the future as the population of Southend changes.
- South West Essex PCT strategy is being developed.
- A Thurrock Action Plan is being developed taking account of consultation on this document
- West Essex strategy is being developed and a Dementia Profile has been published.
- Mid Essex has produced a position statement in relation to the NDS.
- Local delivery plans are being developed. ECC is developing a specific delivery and action plan in relation to the national and Pan Essex strategies.
- A Mapping and progress report has been developed to record our progress against the Objectives of the National Strategy. This will be updated every 6 months.

**The Reduction in the use of Anti-psychotic Medication** An action plan has been published with the aim of reducing the use of anti-psychotic medication and making this a key priority across the NHS.

All PCTs are prioritising this work. South West PCT has carried out an audit of the use of anti-psychotic medication within all residential and nursing homes. West PCT has been carrying out an exercise regarding the prescribing of these drugs. A key issue is the training of staff who are working with people with behavioural symptoms and also raising awareness among the staff who prescribe them.

#### **Research (Objective 17)**

Two research projects are being carried out in West Essex. A study on the use of Anti-psychotic medication and Memantine in nursing and residential homes and the Thinking Fit project which is studying the benefits of physical and mental fitness programmes for people with early dementia.

## Acknowledgements

We are grateful to the following people who have supported the development of this strategy

### Older Adults Mental Health Programme Board

Chris Martin	Essex County Council
April Lawlor	Essex County Council
Geoff Smith	NHS North East Essex, North Essex PCT Cluster
David Maby	NHS North East Essex , North Essex PCT Cluster
Jan Cheng	NHS West Essex, North Essex PCT Cluster
David Bush	NHS South East Essex and Southend on Sea Borough Council
Linda Flynn	Essex County Council
Richard Gill	NHS Mid Essex, North Essex PCT Cluster
Roger Harris	Thurrock Council
Tina Lightfoot	Essex County Council
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**This document has been produced in partnership but for the purposes of collating feedback from this consultation please contact**

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Published May 2011