Living well with dementia

A dementia strategy for Essex, Southend and Thurrock

Developed in partnership

Working in partnership:

Essex County Council
Southend-on-Sea Borough Council
Thurrock Council
NHS North Essex
NHS South Essex
North Essex Partnership NHS Foundation Trust
South Essex Partnership University NHS Foundation Trust
Foreword

We are delighted to introduce the final Essex, Southend and Thurrock Dementia Strategy following its public consultation. The Strategy has been developed in partnership to improve 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”1 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.

As a result of the consultation, and responses from organisations and citizens of Essex, Southend and Thurrock we have updated this document to reflect the priorities and future direction of services for people with dementia and their carers. One of the key aims of the strategy is to ensure that all health and social care services continually seek to improve outcomes for people with dementia and their carers. To this end health and social care organisations have developed local action plans which will be available alongside this document.

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

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1 Living well With Dementia – A National Dementia Strategy Department of Health 2009
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.

Approximately two thirds of people with dementia live in their own homes and many are therefore likely to be dependent on the support of their families and informal carers. We have identified that appropriate support for carers is a key priority and are committed to ensuring that health and social care organisations recognise the contribution they make.

This strategy 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. The strategy has been developed against a background of a challenging financial environment and significant change within health and social care. To reflect this it will be necessary to work jointly to deliver effective, efficient and streamlined services as well as working alongside the emerging Clinical Commissioning Groups and citizen engagement forums such as Healthwatch.

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. As health and social care organisations in Essex, Southend and Thurrock we will continue to work together and to involve people with dementia and their carers, in order to realise the vision of delivering improved outcomes and enabling people to live well with dementia.
This Strategy is approved and endorsed by:

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Acknowledgements

Partnership Organisations
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), 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. It 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 (NDS) whilst allowing the flexibility of responding to local needs. It 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 that 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 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 with General Practitioners and

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3 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.
4 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.\(^5\)

This strategy is committed to the quality standard for dementia which requires that dementia services should be commissioned from and co-ordinated across all relevant agencies encompassing the whole dementia care pathway (see figure 1). An integrated approach to the provision of services is fundamental to the delivery of high quality care to people with dementia.\(^6\)

**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\(^7\).

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\(^5\) Wording from South East Essex Draft Local Dementia Strategy, March 2011  
\(^6\) NICE Quality Standard for Dementia 2010  
\(^7\) 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. 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 Alzheimer’s 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. 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.

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8 Healthcare for London Dementia services report
10 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:11

- Alzheimer’s 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.”12 It is, therefore, necessary to pay attention to the overall health and wellbeing of people with dementia.

Many people with dementia are likely to experience some form of sensory impairment. It has been suggested that one in twenty people over 75 are likely to experience both moderate to severe hearing loss and a moderate to severe sight loss. In addition it was found that 220,000 people over the age of 70 living in the UK in 2010 had significant combined visual impairment and hearing loss.13 Therefore it is important to understand how sensory impairments impact upon a person with dementia and to ensure that attention is paid to ensuring that sensory needs are met.

The relationship between dementia and hearing loss is currently being explored. Difficulty in hearing can add to feelings of isolation and confusion for people with dementia.14 People can be supported by ensuring that hearing aids are used appropriately as well as providing a suitable environment without distracting noises and using good communication techniques. There are, however, specific issues for people who are Deaf and use British Sign Language. The Deaf with Dementia Research Project is undertaking three studies; one aimed at identifying the normal ageing milestones in people who are Deaf, as a way of benchmarking the changes that take place and how the symptoms of dementia may be identified; the second is a series of interviews exploring the experiences of Deaf people with dementia; the third is assessing the knowledge of dementia within the deaf community and whether information is accessible to Deaf people. This research is being undertaken by the University of Manchester, City University, UCL and the Royal Association of Deaf people.15

12 Essex, Southend-on-Sea and Thurrock Joint Strategic Needs Assessment 2008, 5.4.5.2
13 Robertson, J & Emerson, E Estimating the Number of People with Co-occurring Vision and Hearing Impairments in the UK CeDR Lancaster (2010)
14 Alzheimer’s Society 2010 Fact Sheet 522 Staying Healthy
15 http://www.nursing.manchester.ac.uk/dealwithdementia/
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 dementia with Lewy bodies. 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. This includes adaptations to the environment, ensuring that appropriate eyewear is used, arranging regular sight checks and ensuring that communication adjustments are made\textsuperscript{16}.

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\textsuperscript{17}.

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\textsuperscript{18}.

\textsuperscript{16} Visuoperceptual difficulties in dementia Alzheimers Society Fact sheet 527
\textsuperscript{17} http://findarticles.com/p/articles/mi_m2459/is_1998_Jan/ai_53233904/?tag=content;col1
\textsuperscript{18} 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. 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 are estimated to make up 8 per cent of the total number of people with dementia.

The main causes of young onset dementia differ from the overall figures and are identified as:

- Alzheimer's disease 34%
- Vascular dementia 18%
- Frontal temporal dementia 12%
- Alcohol related dementia 10%
- Dementia with Lewy bodies 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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19 Younger People with Dementia Fact Sheet 440, Alzheimer’s Society www.alzheimers.org.uk
20 Alzheimer’s Research Trust Dementia 2010 - The prevalence, economic cost and research funding of dementia compared with other major diseases.
21 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**

![Comparative Rates of Dementia](image)

*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.\textsuperscript{22}

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 black and minority ethnic 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

\begin{figure}[h]
\centering
\includegraphics[width=\textwidth]{figure3.png}
\caption{Percentage of Total Population BME}
\end{figure}

Source: ONS, MYE 2007

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.\(^{23}\) It is identified in the National Dementia Strategy 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”\(^{24}\). There is research evidence that carers of people with dementia experience greater strain and distress than carers of other older people\(^{25}\). Estimates in 2012 are that there are around 550,000 people in England acting as primary carers for people with dementia\(^{26}\).

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 support and resources available, including short breaks (both within and away from the home), individualised budgets and direct payments, aids and adaptations.

Staff need to be very sensitive to the small number of carers who may find they are unable to continue providing care and support in some situations. 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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\(^{23}\) Institute of Public Care: Pan Essex Strategy Reviewing and Repositioning Older Adults Mental Health Services 2008

\(^{24}\) Department of Health 2009 Living Well with Dementia – A National Dementia Strategy p.10

\(^{25}\) Prime Ministers challenge on dementia: Delivering major improvements in dementia care and research by 2015 Department of Health April 2010.

\(^{26}\) Prime Minister’s Challenge as above.
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 Department 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 national 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. These 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 figure 4, which is sourced from Living well with Dementia, the National Dementia Strategy).
Figure 4 Delivering the National Dementia Strategy - joint commissioning of services along a defined care pathway to enable people to live well with dementia
Professor Banerjee later conducted a review into the use of anti-psychotic 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 government re-iterated its commitment to the needs of people living with dementia and their carers in 2010 and 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 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 older 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 anti-psychotic drugs.

- **Reduced use of anti-psychotic medication.** There are an estimated 180,000 people with dementia on anti-psychotic 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.27

The government 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 them28. 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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27 Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy, Department of Health*, September 2010

28 Quality outcomes for people with dementia: *building on the work of the National Dementia Strategy, Department of Health*, September 2010
There is further information in the form of a chart to show how these outcomes link with the objectives of the National Dementia Strategy and the National Institute for Health and Clinical Excellence (NICE) quality standard 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 Alliance30 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. 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.

29 Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, Department of Health, September 2010
30 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 National Dementia Strategy implementation document.

The Prime Minister’s Challenge on Dementia\(^{31}\) was published in March 2012. This focuses on three key commitments which are specifically aligned to three of the nine quality outcomes as indicated in the table below.

<table>
<thead>
<tr>
<th>Key Commitment</th>
<th>Quality Statement</th>
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<tbody>
<tr>
<td><strong>Driving improvements in health and care.</strong></td>
<td>I get the treatment and support that are best for my dementia and my life.</td>
</tr>
<tr>
<td>This entails improving diagnosis rates; incentives to</td>
<td></td>
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<tr>
<td>hospitals to improve quality of care; an innovation</td>
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<tr>
<td>challenge for NHS staff; a care home and domiciliary</td>
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<tr>
<td>care providers’ compact to deliver high quality</td>
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<tr>
<td>relationship based care; promoting local dementia</td>
<td></td>
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<tr>
<td>services.</td>
<td></td>
</tr>
<tr>
<td><strong>Creating dementia friendly communities that understand how to help.</strong></td>
<td>I know what I can do to help myself and who else can help me. My community is working to help me live well with dementia.</td>
</tr>
<tr>
<td>This includes developing dementia-friendly communities</td>
<td></td>
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<tr>
<td>across the country; involving leading national</td>
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<tr>
<td>businesses, industry, public services and academics in</td>
<td></td>
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<tr>
<td>taking forward this challenge; a sustained awareness</td>
<td></td>
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<tr>
<td>raising campaign.</td>
<td></td>
</tr>
<tr>
<td><strong>Better Research</strong></td>
<td>I wanted to take part in research and was able to do so.</td>
</tr>
<tr>
<td>Doubling research funding; investment in brain scanning;</td>
<td></td>
</tr>
<tr>
<td>increased social science research; development of</td>
<td></td>
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<tr>
<td>dementia research units and centres; opportunities for</td>
<td></td>
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<tr>
<td>people to participate in research via accredited memory</td>
<td></td>
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<tr>
<td>services.</td>
<td></td>
</tr>
</tbody>
</table>

\(^{31}\) Department of Health March 2012 *Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*
Champion groups are being set up to deliver on the key issues for the Prime Minister’s Challenge. The group driving forward health and care improvements will also include:

- Improving end of life care for people with dementia;
- Improving housing and social care accommodation – supporting innovative solutions to support people with dementia to continue to live at home;
- Promoting partnership working between primary and secondary health services and local government;
- Reducing the inappropriate use of antipsychotic medication for people with dementia.
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. A figure which is likely to double over the next 30 years. These figures are now understood in 2012 to be in the region of 670,000 people in England and over 750,000 in the UK as a whole. Two thirds of these people live in their own homes. 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.

Figure 6 Estimated direct cost of dementia


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32 Department of Health March 2012 *Prime Minister’s Challenge on Dementia: Delivering major improvements in dementia care and research by 2015*

Figure 6a Estimated percentage of direct cost of dementia

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

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

Figures 6 and 6a show the total estimated direct cost of dementia in 2009 to have been approximately £10.1 billion. Two-thirds of this (£6.42 billion) relates to the cost of care home provision. 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.

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 the NHS.

According to the Department of Health’s *Impact Assessment of the National Dementia Strategy* around 208,000 people with dementia live in care homes, 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.

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. 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 in 2010 the National Audit Office concluded that improving services and support for people with dementia lacked the urgency and priority that the Committee

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38 Care Quality Commission www.cqc.org.uk/registeredservicesdirectory/13 rsquicksearch.asp (September 2009 data)
had been led to expect and there is a strong risk that value for money will not be significantly improved within the national strategy’s five-year implementation timetable.\textsuperscript{39}

\section*{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:

\textbf{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:\textsuperscript{40}

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, which 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.

\textsuperscript{39} National Audit Office Improving Dementia Services in England – an Interim Report DH 2010
\textsuperscript{40} \url{http://publications.nice.org.uk/dementia-quality-standard-qs1}
8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people’s mental health.

9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.

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

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. This can be viewed clearly in the diagram below.

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

![Diagram of dementia care areas](http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp)
The Equality Act. The Equality Act became law in October 2010 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 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, Southend and Thurrock 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.

End of Life Care Strategy: quality markers and measures for end of life care (DH, 2009). 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.


End of Life Care Strategy Quality Markers and measures for end of life care Department of Health June 2009
The NHS Operating Frameworks\(^{45}\) have 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\(^{46}\). For example, there is already a requirement for primary care trusts 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*\(^{47}\) (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 Framework also emphasises 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). This framework also states 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.

In the 2012/13 framework there is an emphasis on outcomes, and organisations working together to improve the care of older people and those with dementia. Among the systemic things to be achieved are that commissioners should ensure that NICE quality standards are met, initiatives to be in place to reduce the inappropriate prescribing of antipsychotic medication and improvement in diagnosis rates. Additionally there is an emphasis on ensuring that carers are supported in line with the Carers Strategy, which includes carers of people living with dementia.

A Dementia CQUIN payment is in place from April 2012 in response to the evidence that the presence of dementia is associated with longer lengths of stay, delayed discharges, readmissions and inter-ward transfers even though 40% of the medical conditions are those which could be treated at home. The CQUIN is in three stages; case finding of patients aged 75 and over at risk of dementia following admission to hospital; investigation of those identified; referral for specialist diagnosis and follow up.

- There are over 670,000 people in England and over 750,000 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
- It is estimated that 25% of all general hospital beds are occupied by people with dementia; in elderly care wards and those with hip fractures this figure increases to 40% or even higher.

\(^{45}\) Department of Health Operating Framework for the NHS in England 2010/11, 2011/12 & 2012/13
\(^{46}\) Revision to the Operating Framework for the NHS in England 2010/11 Department of Health 2010
 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

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

Quality, Innovation, Productivity and Prevention
The same key messages keep coming through; training, integration, clear pathways, information, and equality. 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\(^\text{48}\). The key objectives of the QIPP programme which are set out in ‘Inspiring Change in the NHS’\(^\text{49}\) are:

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

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

\(^\text{49}\) http://www.nhsbreakingthrough.co.uk/Pdfs/Inspiring%20Change%20in%20the%20NHS.pdf
transforming support for people with dementia in Essex, Southend and Thurrock 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 200850.

Whilst this report focused on the wider mental health agenda for older adults, it also made 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; 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 Older Adults Mental Health 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 Standard for Dementia, My Home Life, Dignity in Care and Putting People First: A shared vision and commitment to the transformation of adult social care51.

50 http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/Older_Peoples_Mental_Health_Strategy.pdf
51 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 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 include; 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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52 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, Southend and Thurrock Joint Strategic Needs Assessment (JSNA) reports that across the geographical area of 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.\(^{53}\)

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.\(^{54}\)

### 6.2 Impact of Dementia in Essex, Southend and Thurrock

When it was published in February 2009 the National Dementia Strategy\(^{55}\) 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.\(^{56}\) 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 will increase from 22,300 to 35,500\(^{57}\). 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. It is estimated that 79.9% of the people in homes specialising in dementia care,

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\(^{54}\) IPC report Reviewing and Repositioning the Older Peoples Mental Health Services  
\(^{55}\) Department of Health 2009 Living Well with Dementia – A National Dementia Strategy  
\(^{56}\) Alzheimer’s Research Trust 2010 Dementia 2010 – The economic burden of dementia and associated research funding in the UK.  
\(^{57}\) JSNA 2008 quoting POPPI figures
66.9% in nursing homes and 52.2% in care homes have dementia. With 296 residential and nursing homes across Essex, Southend and Thurrock 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**

![Graph showing projected increase in people with dementia from 2010 to 2030 by PCT region.](image)


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**Footnotes:**

58 JSNA 2008 Citing Dementia UK Report 2007
Figure 11 Table showing numbers of people over 65 predicted to have dementia by PCT area

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

Source: POPPI 2010

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

<table>
<thead>
<tr>
<th>PCT Area</th>
<th>to 2015</th>
<th>to 2020</th>
<th>to 2025</th>
<th>to 2030</th>
</tr>
</thead>
<tbody>
<tr>
<td>North East</td>
<td>14%</td>
<td>32%</td>
<td>58%</td>
<td>87%</td>
</tr>
<tr>
<td>South East</td>
<td>12%</td>
<td>30%</td>
<td>51%</td>
<td>76%</td>
</tr>
<tr>
<td>South West</td>
<td>13%</td>
<td>28%</td>
<td>49%</td>
<td>80%</td>
</tr>
<tr>
<td>Mid</td>
<td>17%</td>
<td>40%</td>
<td>68%</td>
<td>102%</td>
</tr>
<tr>
<td>West</td>
<td>12%</td>
<td>27%</td>
<td>46%</td>
<td>69%</td>
</tr>
<tr>
<td><strong>EST Total</strong></td>
<td><strong>14%</strong></td>
<td><strong>31%</strong></td>
<td><strong>55%</strong></td>
<td><strong>83%</strong></td>
</tr>
</tbody>
</table>

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% (i.e. 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 there will still be an increase of over two thirds by 2030.

The prevalence of younger adults who may develop dementia in Essex, Southend and Thurrock has been estimated to be in the region of 800 by the year 2015. 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 who may develop dementia is estimated to be in the region of 500 by 2019.

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60 IPC report *Reviewing and Repositioning the older peoples Mental Health Services*
61 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, Southend and Thurrock aged less than 65 years.

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

![Graph showing the predicted number of people under 65 with dementia in Essex, Southend, and Thurrock from 2010 to 2030 by PCT area.](image)

*Source: PANSI 2010. Based on ONS figures for 2008 published May 2010*

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

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

*Source: PANSI 2010*

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62 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

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

*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, Southend and Thurrock with the 2001 census recording approximately 159,000, which is almost 10% of the Essex population. Some 30,000 of carers 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”\(^6^3\). 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.

\(^6^3\) Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy* p.10
6.3 Bench Marking and Mapping Current Performance

Essex, Southend and Thurrock and the localities of Luton formed an early adopter site for the National Dementia Strategy. 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. This report highlighted the difficulties of obtaining data across the complex health and social care systems in Essex, Southend and Thurrock. However, it did identify the need for organisations to make links with other stakeholders (e.g. libraries) and strategies (e.g. Carers, End of Life) and the need for training within general services to have the skills and knowledge to deliver 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. This also identifies how these services meet the objectives of the National Dementia Strategy, where the gaps are and what the actions should be to fully implement the national strategy. See Appendix 3 for a summary of our findings under each objective which has been updated to take account of developments until April 2012. A separate Mapping and Progress Report contains details of developments in each area.

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 outcomes for 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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64 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. This leads to difficulties in providing accurate signposting, information, and navigation for 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\(^{(65)}\) 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 across Essex, Southend and Thurrock with memory assessment services providing early diagnosis, treatment and support in all locations (NICE quality statement 2, NDS objective 2,). 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. Voluntary organisations such as the Alzheimer’s Society are providing support but this needs to be co-ordinated across Essex, Southend and Thurrock 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, (NDS objective 9). 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 a Joint Improvement Partnership project (see appendix 3, NDS 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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\(^{(65)}\) 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, (NDS objective 9). 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. 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. 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 statements 6 and 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 (Nice quality statement 1, NDS objective 13) and these should be addressed through the Essex, Southend and Thurrock workforce development strategy which was developed in June 2012. Enhanced liaison services (NICE quality statement 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.


67 Department of Health: *Recognised, valued and supported: Next Steps for the Carers’ Strategy* November 2010
8. The Way Forward

Priorities for 2011 – 2014

Following the consultation our priorities for action fall broadly under the headings of raising awareness, early diagnosis and support, and living well with dementia. These are that we should:

1. Ensure that clear pathways are available for all people including those with young onset dementia or learning disabilities to access timely assessment, diagnosis, treatment and support;
2. Ensure that people with dementia are able to access admission avoidance schemes, reablement and intermediate care;
3. Develop an effective, trained and skilled workforce;
4. Ensure that there is appropriate support for carers and to recognise carers as partners in the care of people with dementia;
5. Further develop enhanced liaison and in reach services to acute hospitals and nursing homes which include strategies to reduce the use of anti-psychotic medication;
6. Ensure that people with dementia have access to palliative care and support at the end of their life.
7. Provide clear, consistent and co-ordinated information to support people with dementia and their carers at all stages throughout the dementia journey
8. Continue activities to raise awareness of dementia within health and social care organisations and the wider community to reduce stigma and promote early identification of dementia.

The 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. The links to QIPP are illustrated in figure 16 below.
Figure 16 QIPP and strategy priorities

**Quality**
- Improved quality of care in care homes
- End of life and advance support planning available from point of diagnosis
- Creating an informed workforce
- Ensure equity of access to services and opportunities for personal budgets
- Reduction in the use of anti-psychotic medication

**Innovation**
- Explore ‘Total Place’ thinking in Essex (a ‘dementia care hub’)
- Availability of a range of flexible, reliable and responsive support options
- Increased use of assistive technology

**Prevention**
- Focus on early intervention and prevention to keep people at home
- Review and improve specialist liaison and in reach services
- Develop reablement and intermediate care for people with dementia
- Flexible and timely support for carers and availability of carers breaks

**Productivity**
- Timely intervention from the right person at the right time
- Reduction in acute hospital stays
- Create a single point of access for all
- Improve data collection to identify need
- Reduction in duplication and hand offs between services/teams

Improving the skills and knowledge of the workforce will be a central component to ensure delivery of the QIPP priorities. These priorities are underpinned by a commitment to personalisation and person centred care.
Additionally there is a focus on the three outcome areas of:

- 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, the summary of our findings in Appendix 3 and the outcomes of the public consultation to identify the above priorities. We will also use this information to develop local service action and implementation plans, building on the work that has already been undertaken by the Primary Care Trusts, Mental Health Trusts, the County Council and Unitary Authorities.
## Appendix 1

### Quality Outcomes for People with Dementia

<table>
<thead>
<tr>
<th>Outcome</th>
<th>Descriptor</th>
<th>NICE Quality Standard</th>
<th>National Dementia Strategy Objective</th>
</tr>
</thead>
<tbody>
<tr>
<td>I was diagnosed early</td>
<td>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.</td>
<td>2, 3</td>
<td>1, 2</td>
</tr>
<tr>
<td>I understand, so I make good decisions and provide for future decision making</td>
<td>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.</td>
<td>3, 5</td>
<td>3, 4, 5</td>
</tr>
<tr>
<td>I get the treatment and support which are best for my dementia, and my life</td>
<td>Everyone living with dementia will receive the best dementia treatment and support, no matter whom 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.</td>
<td>1, 4, 5, 7, 8</td>
<td>2, 6, 8, 9, 10, 11, 13, 18</td>
</tr>
<tr>
<td>I am treated with dignity and respect</td>
<td>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.</td>
<td>1</td>
<td>1, 13</td>
</tr>
<tr>
<td>Outcome</td>
<td>Descriptor</td>
<td>NICE Quality Standard</td>
<td>National Dementia Strategy Objective</td>
</tr>
<tr>
<td>---------</td>
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</tr>
<tr>
<td>I know what I can do to help myself and who else can help me</td>
<td>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.</td>
<td>1, 3, 4, 5</td>
<td>3, 4, 5, 6, 13</td>
</tr>
<tr>
<td>Those around me and looking after me are well supported</td>
<td>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.</td>
<td>3, 4, 6, 10</td>
<td>3, 4, 5, 7</td>
</tr>
<tr>
<td>I can enjoy life</td>
<td>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.</td>
<td>3, 4</td>
<td>1, 4, 5, 6</td>
</tr>
<tr>
<td>I feel part of a community and I’m inspired to give something back</td>
<td>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</td>
<td>1, 5, 16</td>
<td></td>
</tr>
<tr>
<td>I am confident my end of life wishes will be respected. I can expect a good death</td>
<td>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.</td>
<td>5, 9</td>
<td>12, 13</td>
</tr>
</tbody>
</table>

Appendix 2  Essex, Southend and Thurrock Dementia Care Pathway – Agreed Principles

This is an integrated pathway agreed by all stakeholders across the geographical areas of Essex, Southend 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 e.g. 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

**Prevention and Identification**
- **Promote Health and Wellbeing**
  - Raising Awareness
- **Case Finding**
  - Vulnerable Groups
  - Referral: Self, family, carer, other
- **GP**
  - History taking, Physical examination, Initial blood tests, exclude other conditions, Delirium pathway, Refer to Memory Assessment Service
- **Acute/Community Hospital**
- **Older People’s Hospital Liaison Service**
  - Dementia Diagnosed by other route i.e. Private referrals, Neurology or Psychiatrist (not connected to memory services)

**Assessment & Diagnosis**
- **Memory Assessment & Support Service (MASS)**
  - Cognitive and mental state examination
  - Assess medical and psychiatric comorbidity
  - Further tests and scans, neuroassessment for atypical presentation

**Early Intervention and Treatment**
- **If appropriate**, prescribe dementia medication as per NICE guidelines.
  - Follow up with Medication monitoring.
  - Awareness/training sessions for people with dementia and carers.
  - Cognitive Stimulation Therapy
  - Carers’ initial assessment
  - Provide information pack
  - Assistive Technologies assessment

**Diagnosis of Dementia**
- **Refer to Dementia advisor/support worker** or other service to maintain contact and signpost patient/carers, consider Mental Capacity Act 2005.

**Living well with Dementia**
- **Regular review of:**
  - Cognition and mood state
  - Medications in line with NICE guidelines
  - Patient’s and carer’s support network
  - End-of-life and Advance Care Plans

**Follow up in accordance with local protocols e.g. CMHT, Primary Care,**
- **Carers**
  - Assessment
  - Ensure carer on carer’s register
  - Support and counselling
  - Peer support networks
  - Carers Breaks

**Support to stay independent**
- **Finance & Benefits Advice, LPAs Direct Payments/Personal Budgets/PHB’s**
- **Community Support Services**
  - Psychology & Psychotherapy & Social Work interventions,
  - Speech & Language Therapy,
  - Dietician
  - Assistive Technology, Occupational Therapy/Equipment Services
  - Continence Service, Falls prevention
  - Reablement/Intermediate care

**Voluntary Organisations**
- Information & signposting
- Outreach support worker
- Support groups and activities

**End of life**
- **GP/ CMHT/Other**
  - Recognise dementia as terminal illness
  - Involve carers and family
  - Exercise mental capacity act
  - Identify if the person with dementia already has a plan and act on that plan
  - Add patient to supportive care register
  - Follow guidance in DH End of life care strategy
  - Equal access to palliative care and hospice services

**Personalisation agenda to deliver person centered care to everyone**
- Follow Delirium pathway where identified
- Inclusive of all people with dementia including Younger People (under 65 years) and people with a Learning Disability
- Awareness and use of the Mental Capacity Act 2005
Appendix 3

Summary of progress in respect of the objectives of the National Dementia Strategy across Essex, Southend and Thurrock April 2012

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 all three local authorities and the primary care trusts in Essex, Southend and Thurrock to provide information via its network of services throughout Essex and through its Countywide Information Service. Staff from all areas and the mental health trusts have supported the dementia awareness campaigns in their localities with ongoing awareness raising activities in residential homes, sheltered accommodation and other public venues. There has been an Essex Southend and Thurrock wide focus on GP training to raise awareness, increase referrals and utilise memory services as a single point of contact.

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 has contact with specialist services. 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. The configuration of these services varies from locality to locality. The diagnosis gap across Essex Southend and Thurrock is an average of 64%, i.e. only 36% of people estimated to have dementia are currently diagnosed. All areas are working towards closing this gap as a priority. New services include improved follow up services, dementia support services and liaison services in General Hospitals to promote diagnosis and accurate assessment. Pathways are being developed for young onset dementia and people with learning disabilities and dementia.

69 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

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.

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.

In all areas people who are diagnosed with dementia receive information packs about the condition and where to get help. Work is being undertaken to streamline the information to ensure consistency.

From 1st April 2012 Memory Services across Essex, Southend and Thurrock will be supported by dementia support workers/dementia advisors through Department of Health funding for social care awarded in September 2011.

Ongoing sources of support and information about living with dementia is provided through voluntary and not for profit organisations with more specialist support through the Older Adults Mental Health teams.

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 available throughout Essex, Southend and Thurrock. These are for people with dementia and their carers of any age including groups for younger people with dementia. They are provided through the mental health trusts and voluntary and not for profit organisations throughout Essex. Dementia cafes offer a valuable source of peer support.

70 Department of Health; Gateway 16406, NHS Support for Social Care; Provision of Support for Memory Services, September 2011.
**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. There has been a drive by the Essex, Southend and Thurrock local authorities to increase the take up of personal budgets by people with dementia and their carers. It is acknowledged that there must be a range of good quality personal support options available which are responsive, reliable and flexible.

**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.

Carers remain a priority for all organisations to ensure that people can access both carers’ support and carers’ breaks. In North Essex, Admiral Nurses have been employed to provide additional support. In Southend work is being undertaken to develop a single point of contact and signposting for the carers of people with dementia.

The challenge remains 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, Southend and Thurrock.

**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 have been developed across all general hospitals. These have improved links between the mental health and acute trusts and enabled greater understanding between services. A Dementia Intensive Support Team is in place in South Essex which aims to prevent inappropriate hospital admissions, reduce length of stay and increase the numbers of people who return home instead of admission to residential care.
**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.

Reablement schemes across Essex, Southend and Thurrock are available for people with dementia. Plans are in place to develop the Dementia Intensive Support Teams across South Essex so that they can specifically assist where people with dementia are participating in a reablement programme. Step-down/reablement placements are available across Essex, Southend and Thurrock and a dementia pathway has been developed for people in community hospitals.

**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 Essex and Southend have included units which are designed to suit the needs of people with dementia. Housing strategy plans and the developing Essex County Council commissioning strategy for housing related support include needs of people with dementia. A recent development in some areas has been the introduction of dementia awareness raising sessions within sheltered accommodation to increase residents’ understanding of their neighbours who have dementia.

The use of assistive technology has been actively promoted across Southend, Essex and Thurrock. The Southend on Sea Council’s housing strategy includes dementia needs in the Homes for the Future programme to fit assistive technology easily and without disruption.

**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.

Liaison Community Mental Health Nurses are working with care homes throughout Essex Southend and Thurrock in order to improve outcomes for people with dementia in their care setting.
Liaison nurses support care homes to reduce the use of medication and to avoid unnecessary admission to hospital by helping them to develop strategies for supporting people who are experiencing behavioural and psychological symptoms of dementia. In addition they can assist care homes to recognise when physical health problems are causing distress.

Dignity initiatives, My Home Life Essex and the Relatives and Residents Association are all beneficial in improving the quality of residential care for people with dementia.

**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 care initiatives have taken place across Essex, Southend and Thurrock. Use of the Preferred Priorities of Care document appears to vary between services. An end of life care pathway for people with dementia has been developed with the aim of making this available in all areas. In all areas and services staff are being encouraged to initiate discussions regarding end of life planning and advance statements, directives and care planning at an early stage.

End of life facilitators are now in place throughout Essex, Southend and Thurrock. They provide training to health and social care staff in residential, domiciliary and health settings. The support of people with dementia at the end of their life is included in this training.

**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 task and finish group explored dementia training needs in Essex, Southend and Thurrock. As a result of this a workforce strategy and training pathway has been developed. The pathway highlights the diverse groups of staff who require training and the content and level of training required.

A range of training initiatives and opportunities have been made available for health and social care staff in a variety of formats and at different levels. These include face to face awareness and more in depth training, e-learning, workbooks (Essex County Council staff), academic training through partnerships with universities, specific focussed training e.g. initiatives within care homes to reduce the use of anti-psychotic medication. Meeting training needs remains a key challenge for this strategy.
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.

Work has commenced to explore opportunities for joint commissioning that deliver the outcomes of this strategy. We will be using the responses to the public consultation to inform the implementation of the strategy. Commissioning plans will support the Quality Outcomes identified by the Department of Health. 71

Improved assessment and regulation of health and care services and of how systems are working for people with dementia and their carers (objective 15). Inspection regimes for care homes and other services that better assure the quality of dementia care provided.

Improved processes are in place to safeguard people who use health and social care services through the Southend, Essex and Thurrock (SET) Safeguarding Guidelines 72 and the Ask Sal helpline. The Local Authorities gather the experience of people using services and their carers via their Quality Improvement or Contracts teams.

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

Research is among the key commitments of the Prime Minister’s Challenge (April 2012). 73 Planned developments include a research proposal between NEPFT and Essex University and research around a carer’s assessment tool by NHS South Essex and SEPT.

Current research includes; the Thinking Fit project which is being undertaken by NEPFT and Essex County Council to study the benefits of physical and mental fitness programmes for people with mild cognitive impairment or early symptoms of dementia; NEPFT are contributing to the National Institute for Health Research CBT project; West Essex psychiatrists and teams are involved in research with University College London.

Effective national and regional support for implementation of the Strategy (objective 17). Appropriate national and regional support to be available to advise and assist local implementation of the Strategy. Good-quality information to be available on the development of dementia services, including information from evaluations and demonstrator sites.

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71 Quality outcomes for people with dementia: building on the work of the National Dementia Strategy, Department of Health, September 2010
72 Southend Essex and Thurrock Safeguarding Adults Guidelines December 2010
73 Prime Ministers challenge on dementia: Delivering major improvements in dementia care and research by 2015 Department of Health April 2010.
An East of England group meets regularly which provides a regional support network for health and social care commissioners in delivering the national and local strategies. This is also a forum for sharing good practice across the region.

**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.

Guidance on the use of anti-psychotic medication for people with dementia has been produced for both North and South Essex and is being rolled out to services by pharmacists. Audits of practice in primary and secondary healthcare have been completed. The introduction of specialist nurses to provide in-reach advice and support to care homes throughout Essex, Southend and Thurrock is having a significant effect in enabling staff to develop alternative interventions for the behavioural and psychological symptoms of dementia, thereby reducing the inappropriate use of anti-psychotic medication.
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Essex County Council
Essex County Council
Publications, Essex County Council
Design Team, Essex County Council
Partnership Organisations

**Essex County Council**
County Hall
Market Road
Chelmsford
CM1 1QH
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www.essex.gov.uk

**Southend on Sea Borough Council**
Civic Centre
Victoria Avenue
Southend on Sea
SS2 6ER
Email: council@southend.gov.uk
www.southend.gov.uk

**Thurrock Council**
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New Road
Grays
RM17 6SL
Email: general.enquiries@thurrock.gov.uk
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**NHS South Essex**
Phoenix Court
Christopher Martin Road
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www.southessex.nhs.uk

**NHS North Essex**
Email: me-pct.communications@nhs.net
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3 Headquarters listed below:

**NHS North East Essex**
Colchester Primary Care Centre
Turner Road
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**SEPT**
Trust Head Office
The Lodge
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**NHS Mid Essex**
Swift House
Hedgerows Business Park
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CM2 5PF

**North Essex Partnership NHS Foundation Trust**
Trust Headquarters
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103, Stapleford Close
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**NHS West Essex**
Building 4
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The Plain
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