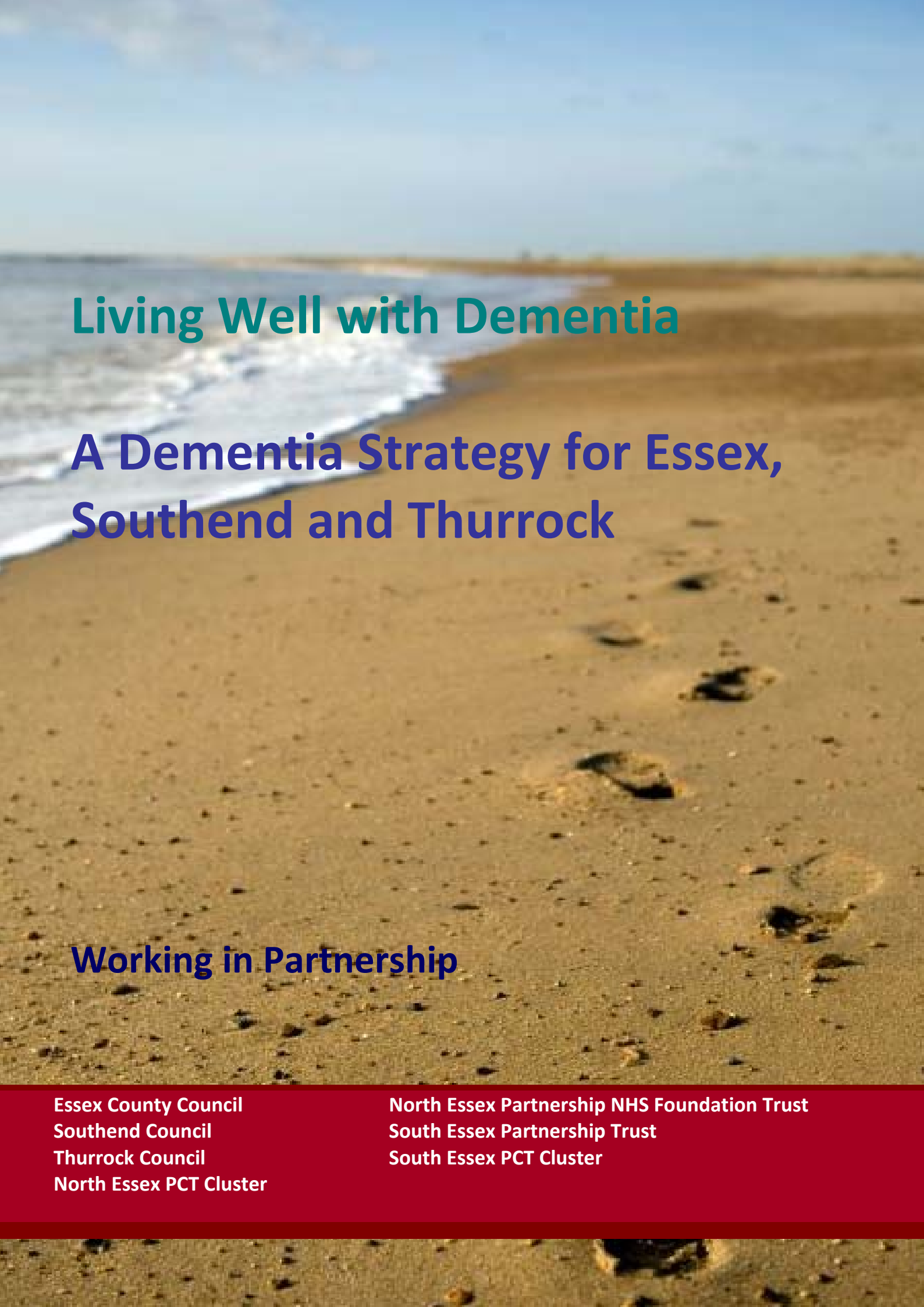

Living Well with Dementia

A Dementia Strategy for Essex, Southend and Thurrock

Working in Partnership

Essex County Council
Southend Council
Thurrock Council
North Essex PCT Cluster
North Essex Partnership NHS Foundation Trust
South Essex Partnership Trust
South Essex PCT Cluster

Foreword

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

Since the publication of *"Living well with dementia: A National Dementia Strategy"*[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 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.

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 coordinated across, all relevant agencies encompassing the whole dementia care pathway. At all stages people should receive health care and social support from staff that has the skills and training to provide the best quality care.

This Strategy is designed to meet this challenge and is inclusive of all citizens who

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

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

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

Sheila Bremner
Chief Executive
North Essex PCT Cluster

Andrew Geldard
Chief Executive
North Essex Partnership NHS Foundation Trust

Dr. Patrick Geoghegan
OBE,
Chief Executive, Professor of Mental Health and Social Care
South Essex Partnership Trust

Simon Leftley
Corporate Director of Adult and Community Services

Jenny Owen CBE
Deputy Chief Executive and Commissioning Director,
Adult Social Services

Lorna Payne
Corporate Director of Community Wellbeing

Andrew Pike
Chief Executive
South Essex PCT Cluster

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1. Introduction

This document forms the Essex, Southend and Thurrock Strategy for Dementia 2010-2014. It is based on national guidance, set out in "Living well with dementia: A National Dementia Strategy" (2009)[2], a local needs assessment and review of current provision, encompassing the three local authorities, two mental health trusts and five PCTs in Essex and supports the strategies which are being developed in each of the PCT localities. The Strategy aims to provide an overarching statement of how we can collectively meet the objectives of the National Dementia Strategy whilst allowing the flexibility of responding to local needs and has been developed by the Older Adults mental Health Programme Board in partnership with Essex Adult Services, NHS , The North Essex Partnership NHS Foundation Trust, South Essex Partnership and University NHS Foundation Trust and third sector organisations.

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

The Strategy is designed to be inclusive of all citizens in Essex, 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.

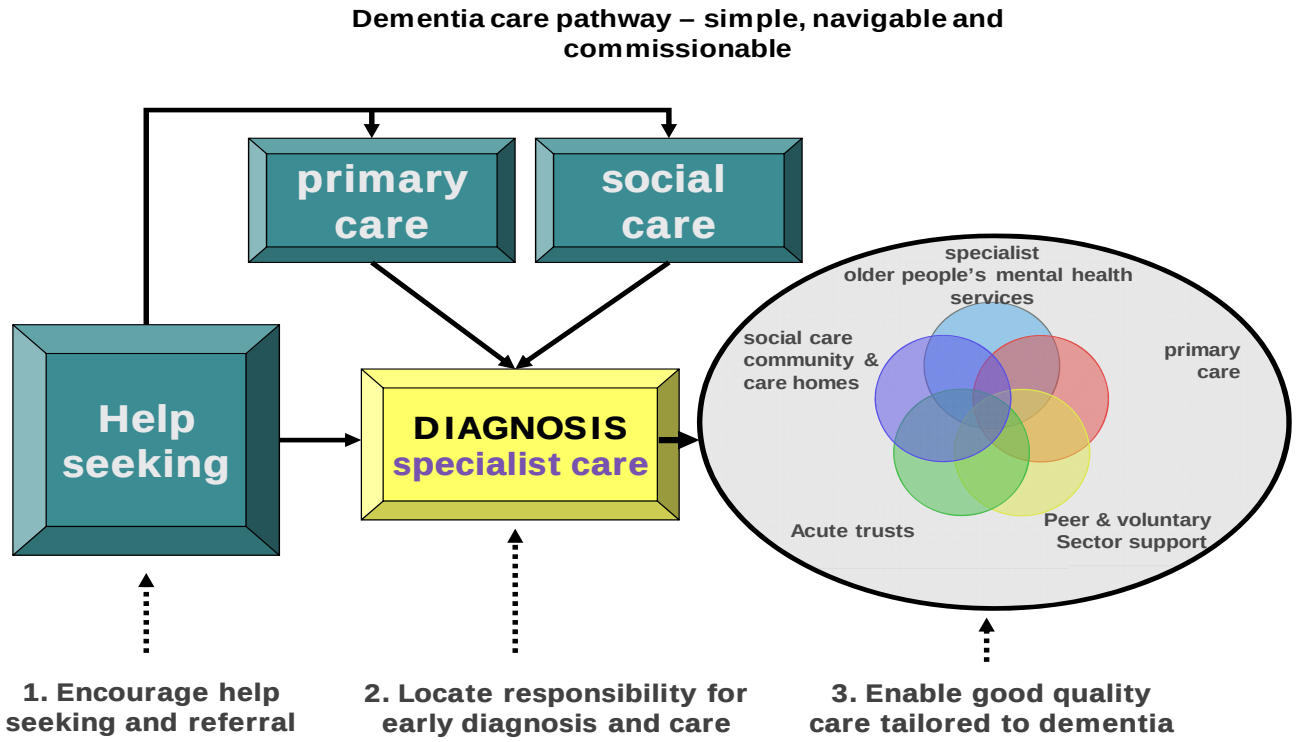
Underpinning the Strategy and providing a framework for delivering high quality services is the rigour of world class commissioning and the philosophy of Putting People First, which is a National initiative for the personalisation of Adult Social Care. Putting People First puts the person who receives care at the heart of the process, ensuring 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.

This strategy is committed to the quality standard for dementia which requires that dementia services should be commissioned from and coordinated across all relevant agencies

[2] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_094058

encompassing the whole dementia care pathway (see Fig 1). An integrated approach to provision of services is fundamental to the delivery of high quality care to people with dementia.[3]

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[4].

[3] NICE Quality Standard for Dementia 2010
[4] *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 is part of the work of the Older Adults Mental Health Programme Board with representatives from, Southend and Thurrock Unitary Councils, Essex County Council the five Essex PCTs, the North Essex Partnership NHS Foundation Trust, the South Essex Partnership University NHS Foundation Trust, and the Alzheimer's Society.

- 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.[5] In addition, individuals may experience behavioural and psychological symptoms at any stage in their illness. The wellbeing of people with dementia is affected by environmental, psychological and biological factors and people can easily become disoriented in strange surroundings such as hospital or when being cared for by different people.

3.2 Who is affected?

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

The latest figures published by the Alzheimers Society suggest that 1 in 14 people over the age of 65 and 1 in 6 people over 80 years has some form of dementia.[6] 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.[7]

Alzheimers disease is the most common form of dementia. The proportions of those with different forms of dementia are broken down as follows:[8]

[5] Healthcare for London Dementia services report
[6] Alzheimers Society Website, accessed 9/07/2010; *Alzheimers Society position statement on demography.*
[7] JSNA 2008 citing Alzheimers society Dementia UK (2007)
[8] Alzheimers Society Website, accessed 9/07/2010; *Alzheimers Society position statement on demography.*

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

Dementia can also occur alongside other long term conditions. As the Joint Strategic Needs Assessment (JSNA) states "dementia is a fast growing problem which is likely to put a huge strain on local authorities and the NHS as people are living longer and surviving common forms of cancer and heart disease." (JSNA 5.4.5.2). It is therefore necessary to pay attention to the overall health and wellbeing of people with dementia.

Sight loss in people with dementia exacerbates problems of disorientation and confusion. People may not only experience age related changes in vision but the affects of some types of dementia cause additional difficulties. In Alzheimers disease the proximity of the brain areas to the visual pathways may result in these becoming damaged through the spread of plaques and tangles and in PCA (posterior cortical atrophy) damage to the visual system is characteristic of the disease. Visuo-perceptual difficulties such as hallucinations are also experienced particularly in people with Lewy Body Dementia. Changes can occur to visual pathways following strokes, thus affecting people with vascular dementia. An awareness of age related sight loss is important for those who support people with dementia as much can be done to lessen the impact of these conditions through adaptations to the environment, ensuring that appropriate eyewear is used, arranging regular sight checks and ensuring that communication adjustments are made[9]

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[10].

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[11].

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.

[9] *Visuoperceptual difficulties in dementia* Alzheimers Society Fact sheet 527
[10] http://findarticles.com/p/articles/mi_m2459/is_1998_Jan/ai_53233904/?tag=content;col1
[11] http://www.biomedcentral.com/1471-2318/8/36

In 2010 there were thought to be 64,037 people under 65 with dementia in the UK compared with just 16,737 in 1998. The majority of those affected in this younger age group – 70 per cent – are men. Younger people with dementia were estimated to make up 8 per cent of the total number of people with dementia.[12]

The main causes for of young onset dementia differ from the overall figures and are identified as:[13]

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

This group of people have specific needs as they and their carers may still be working when they receive a diagnosis and may also have dependent children living with them. Dementia therefore impacts upon the family, work and income in addition to the difficulties associated with late onset dementia. The presentation of early onset dementia may also be complex leading to difficulties in diagnosis. This can lead to delays in early 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. The high prevalence of these forms of dementia for younger people is therefore a significant issue for this group.

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 Downs Syndrome are particularly affected. About 20% of people with a learning disability have Downs Syndrome. This group of people often have complex needs arising as dementia impacts upon their pre-existing psychological and physical health conditions.

[12] Alzheimer's Research Trust *Dementia 2010 - The prevalence, economic cost and research funding of dementia compared with other major diseases.*
[13] Harvey et al 2003 *The prevalence and causes of dementia in people under the age of 65.*

Figure 2 Comparative rates of Dementia – Down's syndrome, Learning disabilities,

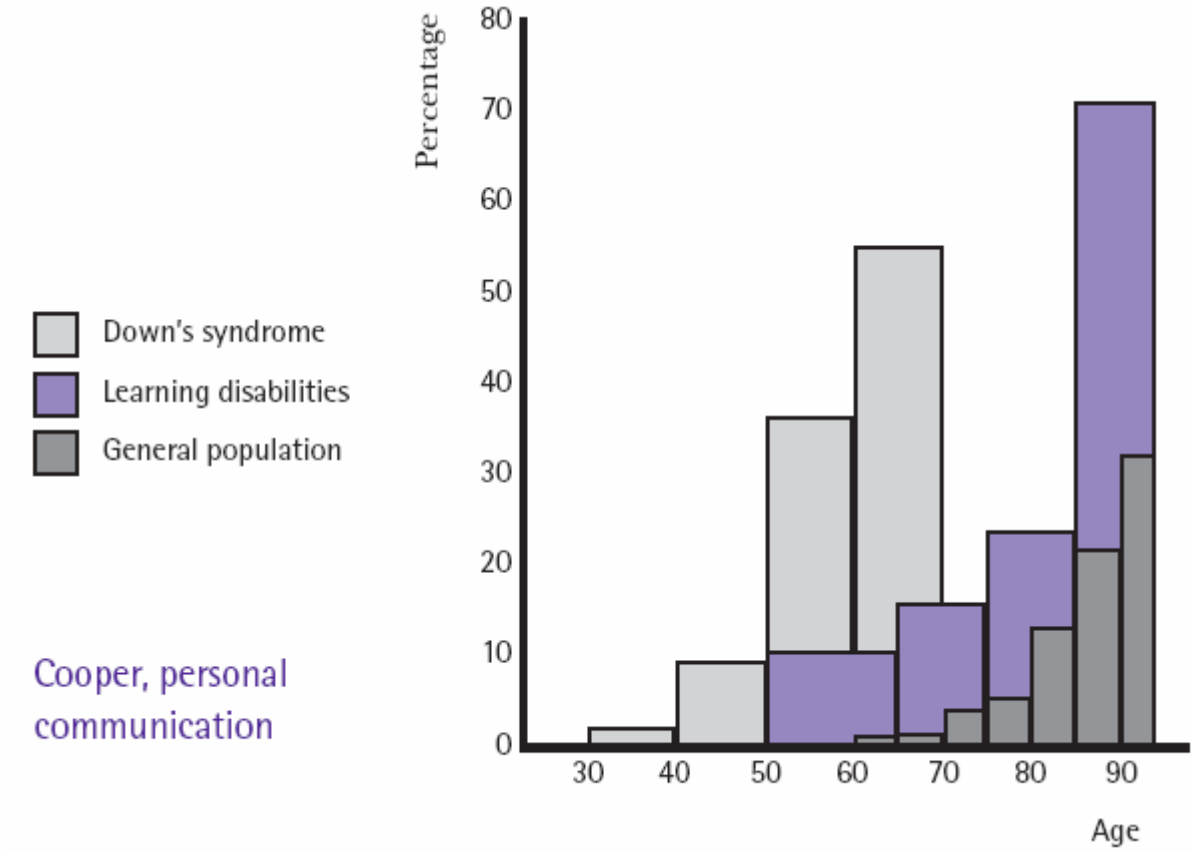


Figure 1 above, summarises the age-related prevalence rates of dementia in people with Down's syndrome, those with learning disabilities without Down's syndrome, and in the general population[14]. The exact rates have to be considered with caution but the trend represented in this figure is now increasingly accepted. The early presentation and course of dementia is now well established for people with Down's syndrome. For those with learning disabilities but without Down's syndrome, age-related prevalence rates 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. This latter group would appear to have a uniquely early risk for developing dementia, almost invariably of the Alzheimer's-type. For the former group the full range of causes of dementia is observed.

Key points:

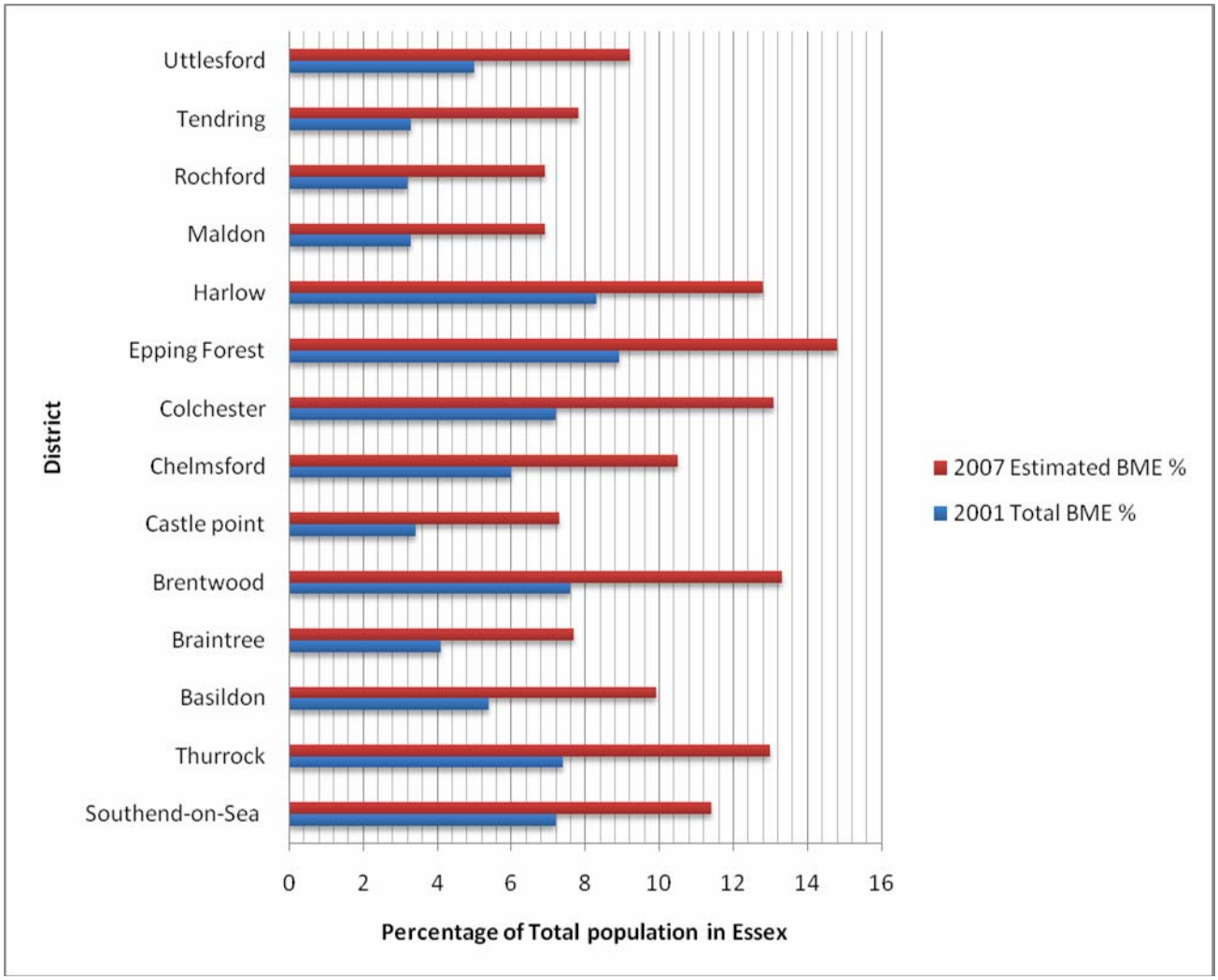
- People with learning disabilities have a higher risk of developing dementia compared to the general population, with a significantly increased risk for people with Down's syndrome and at a much earlier age.
- Life expectancy of people with Down's syndrome has increased significantly.
- The incidence and prevalence of Down's syndrome is not decreasing.

[14] Cooper, S.A. (1997). Epidemiology of psychiatric disorders in elderly compared with younger adults with learning disabilities. *British Journal of Psychiatry, 170*, 375–380

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. As the current population ages it is therefore likely that the number of people from these communities will also rise. It is therefore important that services are able to be flexible to meet the needs of this group. Essex has become more diverse with the areas closest to London and those containing the largest towns tending to have the highest concentrations of people from BME groups. The highest proportions of people from all BME groups are residing in Epping Forest, Harlow and Brentwood as Figure 2 illustrates.

Figure 3 Essex concentrations of BME groups, 2007



Source: Resident population estimates by ethnic group (percentages) 2001 and 2007 NeSS, Neighbourhood Statistics; http://www.statistics.gov.uk/STATBASE/Product.asp?vlnk=14238

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.[15] 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” .

Family carers need specific emotional and practical support. Many family carers find the diagnosis of dementia traumatic. Where the family are the main carers, they must be offered a comprehensive Carer’s Assessment. Many carers, particularly the parents of people with Down’s syndrome, may themselves be at risk of developing dementia or other age-related conditions. Services need to be sensitive to the needs and beliefs of carers, and to see things from their perspective. Some carers believe that it is their duty to care and may find it very difficult to accept support and help into their own home. Carers need to have prompt access to appropriate information about supports and resources available, including short breaks (both within and away from the home), individualised budgets and direct payments, and aids and adaptations.

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

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

[15] Institute of Public Care: Pan Essex Strategy Reviewing and Repositioning Older Adults Mental Health Services 2008

4 Living Well with Dementia – A National Strategy

4.1 National Context

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

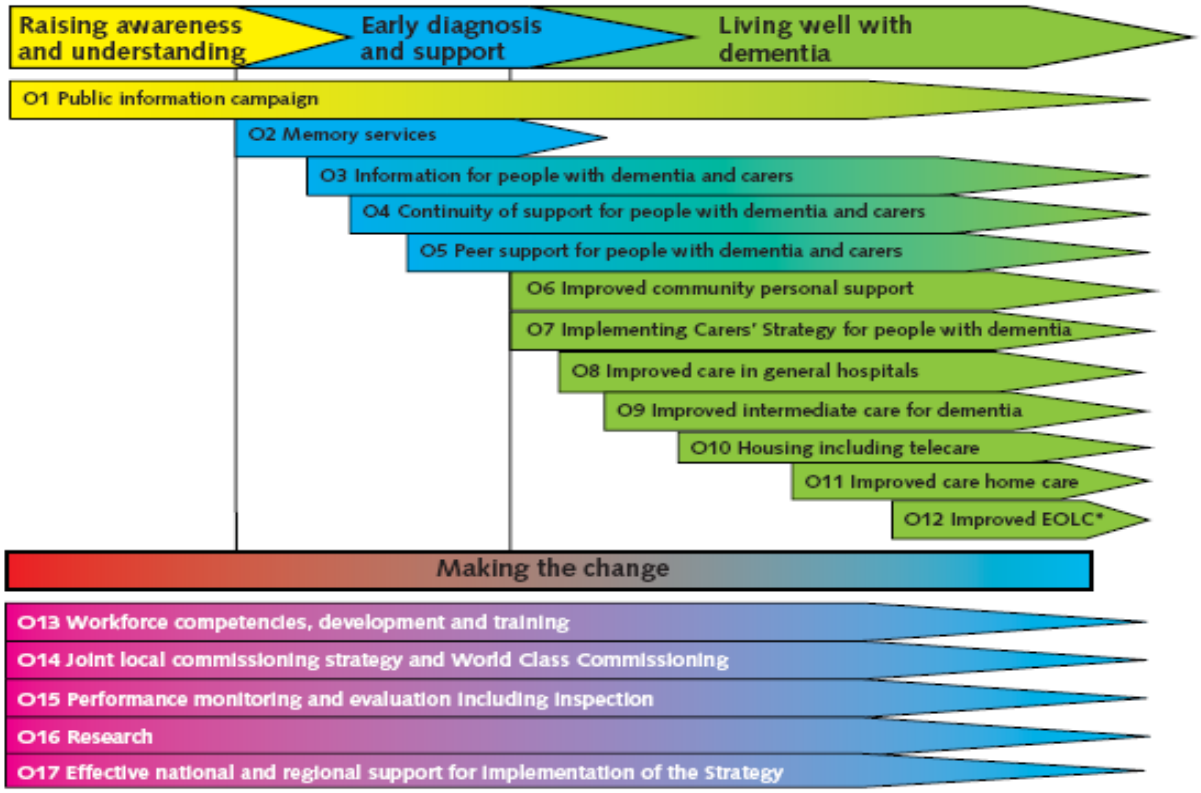
The strategy identified seventeen objectives to raise awareness and understanding of dementia, promote early diagnosis and support and to enable people living with dementia and their carers to continue to enjoy a good quality of life, no matter what the stage of their condition or where they are in the health and social care system.

The vision in the NDS is that services and society should transform their approach and attitudes to enable people with dementia and their carers to live well with dementia. This is in contrast to the current situation, where in many services people with dementia are simply 'managed'.

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

In order to achieve this vision 17 key objectives were identified specifying improvements of 3 key areas. Objectives 1 to 12 are grouped under the 3 main headings to support a defined pathway for commissioning services; raising awareness and understanding, early diagnosis and support; and living well with dementia. The remaining 5 objectives are cross cutting objectives which enable change to be implemented which include workforce development, commissioning, performance monitoring and evaluation, and research. In addition, there is a commitment to ensuring both national and regional support for the implementation of the strategy. (See fig 1.)

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



*End of life care

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

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

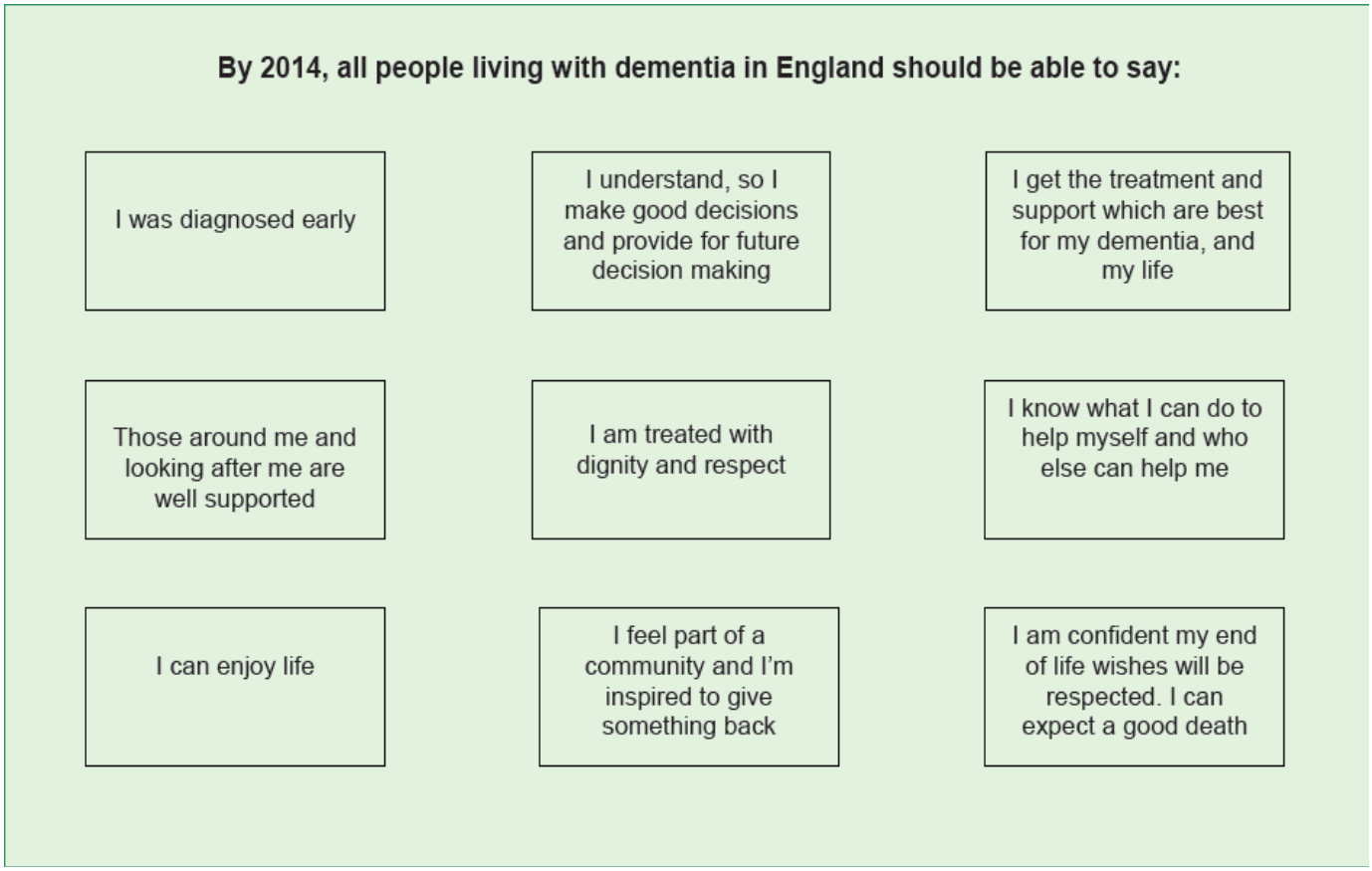
- **Early diagnosis and support** - Two thirds of people with dementia never receive a diagnosis; the UK is in the bottom third of countries in Europe for diagnosis and treatment of people with dementia; only a third of GPs feel they have adequate training in diagnosis of dementia.
- **Improving the quality of acute hospital care** - 40% of people in hospital have dementia; the excess cost is estimated to be £6m per annum in the average General Hospital; comorbidity with general medical conditions is high, people with dementia stay longer in hospital.
- **Improving care home quality** - Two thirds of people in care homes have dementia; dependency is increasing; over half are poorly occupied; behavioural disturbances are highly prevalent and are often treated with antipsychotic drugs.

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

All of these are to be underpinned by personalisation and personal support in the community.[16] Improved community support services, are integral to each of the four priorities as they support early intervention; prevent premature admission to care homes and impact on inappropriate admission to hospital and length of stay.

The government has also stated its commitment to ensuring there is a greater focus on accelerating the pace of improvement in dementia care, through local delivery of quality outcomes and local accountability for achieving them[17]. 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 by the department, which capture what people with dementia have said they aspire to in terms of their health and social care systems.

Figure 4 Draft synthesis of outcomes desired by people with dementia and their carers



[16] *Update for Dementia Services Development in the East of England August 2010* Maureen Begley (Dementia Programme Manager NHS East of England)

[17] 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 NDS and NICE quality standards in *Appendix 1*

Public and political commitment to dementia has grown significantly in recent years to a position where dementia is now a major strand of public policy discussion. To continue and progress the momentum the Dementia Action Alliance[18] was launched on 26 October 2010. The Alliance is a coalition of 45 organisations committed to improving quality of life for people with dementia and their carers in England by 2014 (the date when the National Dementia Strategy comes to an end). On the launch date, the Alliance published a National Dementia Declaration explaining the outcomes they seek to deliver for people with dementia and their carers. In addition, each signatory organisation has published an action plan setting out what their role is in delivering better quality of life for people with dementia, their carers, and the actions they intend to take in order to help deliver those outcomes. The seven agreed outcomes come under the following headings:

1. I have personal choice and control or influence over decisions about me

2. I know that services are designed around me and my needs

3. I have support that helps me live my life

4. I have the knowledge and know-how to get what I need

5. I live in an enabling and supportive environment where I feel valued and understood

6. I have a sense of belonging and of being a valued part of family, community, and civic life

7. I know there is research going on which delivers a better life for me now and hope for the future

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

[18] http://www.dementiaaction.org.uk/

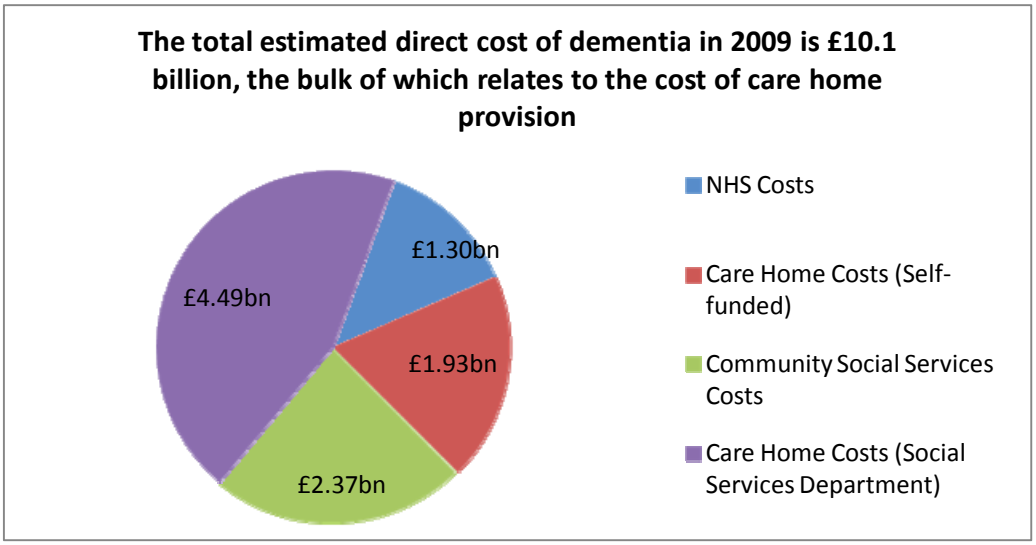
5 Organisational Challenge and Policy

5.1 The Challenge

We recognise that councils need to be fully engaged and ensure people living with dementia are included because; two thirds of the estimated 700,000[19] people living with dementia in England live in their own homes. This figure is likely to double over the next 30 years, hence it is important to ensure 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 5 shows the total estimated direct cost of dementia in 2009, which was £10.1 billion, the bulk of which relates to the cost of care home provision[20]. Two-thirds of the direct costs, £6.42 billion, relates to the provision of care home places for people with dementia and those costs are split between families, the NHS and social services. NHS and social services provision outside care homes (costing £3.68 billion) accounts for the remaining one third of direct costs.

Figure 5 Estimated Direct Cost of Dementia



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

[19] Knapp M, Prince M, Albanese E et al (2007). *Dementia UK: The full report*. London: Alzheimer's Society.
[20] *Knapp et al (2007) Dementia UK and The King's Fund (2008) Paying the Price*

According to the Department of Health's impact assessment of the National Dementia Strategy, around 208,000 people with dementia live in care homes,[21] of whom 91,000 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.[22]

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 per cent in the North East and London.[23] Around 59,000 people with dementia receive domiciliary care – quality inspectors rated between 10 (North West region) and 18 per cent (West Midlands) of providers as poor to adequate. The impact assessment identifies savings of £130 million a year from 2013-14, based on delaying entry into care homes through early diagnosis and intervention.

In a report released earlier this year the National Audit Office concluded that improving services and support for people with dementia lacks the urgency and priority that the Committee had been led to expect, and there is a strong risk that value for money will not be significantly improved within the Strategy's five-year implementation timetable.[24]

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 strategy to ensure our approach is joined up and fit for the future, these include the following:

NICE Dementia Quality Standard which provides clinicians, managers, and service users with a description of what a high-quality dementia service should look like, identifying the following key priorities for implementation:[25]

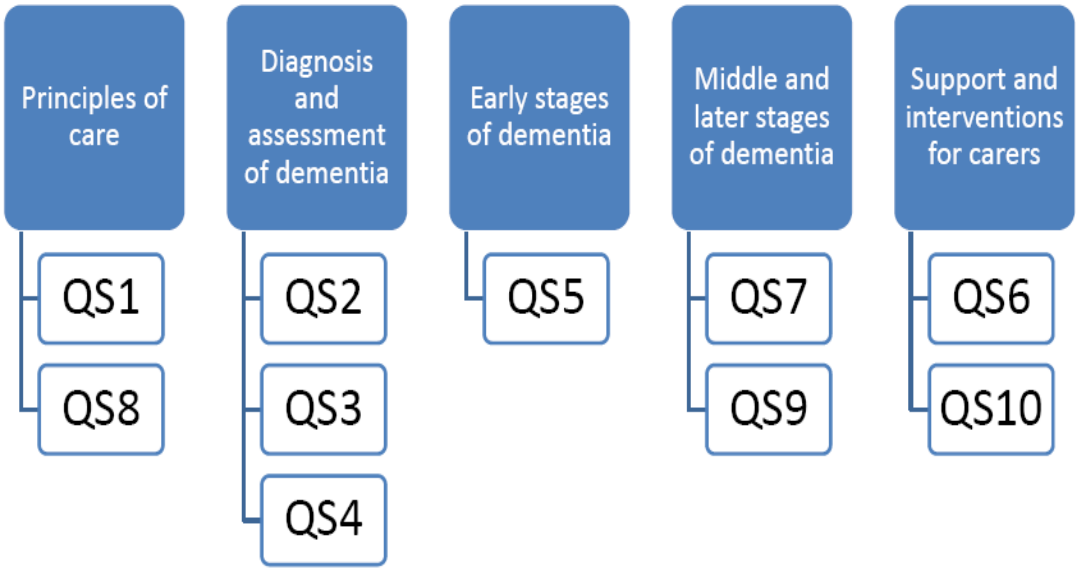
1. People with dementia receive care from staff appropriately trained in dementia care.
2. People with suspected dementia are referred to a memory assessment service specialising in the diagnosis and initial management of dementia.
3. People newly diagnosed with dementia and/or their carers receive written and verbal information about their condition, treatment and the support options in their local area.
4. People with dementia have an assessment and an ongoing personalised care plan, agreed across health and social care that identifies a named care coordinator and addresses their individual needs.

[21] Department of Health (2009) Impact Assessment of National Dementia Strategy.
[22] Report by the Comptroller and Auditor General (2007) Improving Services and 3 Support for People with Dementia HC 604 Session 2006-2007.
[23] Care Quality Commission www.cqc.org.uk/registeredservicesdirectory/13 rsquicksearch.asp (September 2009 data)
[24] National Audit Office Improving Dementia Services in England – an Interim Report
[25] http://www.nice.org.uk/aboutnice/qualitystandards/dementia/

5. People with dementia, while they have capacity, have the opportunity to discuss and make decisions, together with their carer/s, about the use of: advance statements, advance decisions to refuse treatment, Lasting Power of Attorney, Preferred Priorities of Care.
6. Carers of people with dementia are offered an assessment of emotional, psychological and social needs and, if accepted, receive tailored interventions identified by a care plan to address those needs.
7. People with dementia who develop non-cognitive symptoms that cause them significant distress, or who develop behaviour that challenges, are offered an assessment at an early opportunity to establish generating and aggravating factors. Interventions to improve such behaviour or distress should be recorded in their care plan.
8. People with suspected or known dementia using acute and general hospital inpatient services or emergency departments have access to a liaison service that specialises in the diagnosis and management of dementia and older people´s mental health.
9. People in the later stages of dementia are assessed by primary care teams to identify and plan their palliative care needs.
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 standards for dementia are based on the understanding that dementia services are commissioned from and coordinated 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.[26] This can be viewed clearly in the diagram below

Figure 6 Dementia, areas of care map



[26] http://www.nice.org.uk/aboutnice/qualitystandards/dementia/dementiaqualitystandard.jsp

Age Equality and the Equality Act. The Equality Act became law in October 2010[27] 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. Banning age discrimination in the provision of goods, facilities, or services and tackling unjustifiable age discrimination where it has negative consequences. There will be further consultation on this and a transition period before it is implemented, but we need to ensure that services for people with dementia in Essex are age inclusive, providing equity of available resources to achieve identified outcomes. The aim of the age equality agenda is for services to be of equivalent good quality for people of all ages.

A national study of older people's mental health services highlighted likely age discrimination within services. It found: older people's services were falling behind those for working age adults; clear evidence of age discrimination in access to services; and a lack of age appropriateness. New Horizons/Healthcare Commission (2009) [28]

The NHS Operating Frameworks for 2010-11 and 2011-12 identified dementia as an area for local prioritisation. Getting dementia care right should be a priority for local services from an efficiency as well as quality perspective[29]. For example, there is already a requirement for PCTs to publish locally how they are delivering services in line with the *Quality outcomes for people with dementia: Building on the work of the National Dementia Strategy*[30]. That requirement holds – wherever possible commissioners must be accountable to the people they serve, not the centre.

The 2011-2012 NHS Operating Frameworks also emphasis the point 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. While also stating that NHS organisations should agree with their social care commissioning partners the aspects of the strategy that could be delivered by using section 75 flexibilities[31].

- There are over 570,000 people in England with dementia – and numbers are expected to double in the next thirty years
- Direct costs of dementia to the NHS and social care are in the region of £8.2bn annually
- 40% of people admitted to hospital have dementia

[27] http://www.legislation.gov.uk/ukpga/2010/15/contents
[28] Healthcare Commission (2009) *Equality in Later Life: A National Study of Older People's Mental Health Services*
[29] Revision to the Operating Framework for the NHS in England 2010/11 Department of Health 2010
[30] *http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_119827*
[31] *http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_122738*

- 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.

End of Life Care Strategy: quality markers and measures for end of life care (DH, 2009)[32] 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. Directly linking in with many of the NDS objectives but particularly objective 12 of the NDS – *Improved end of life care for people with dementia.*
The following are the seven EOL markers:

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

.

Quality, Innovation, Productivity and Prevention
The same key messages keep coming through, training, integration, clear pathways, information, and equality; now we need to make sure that, we know how we are going to implement them. The tool to drive through this transformation change is the QIPP - Quality, Innovation, Productivity and Prevention (QIPP) programme[33]. The key objectives of the QIPP programme, set out in 'Inspiring Change in the NHS' are:

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

[32] End of Life Care Strategy *Quality Markers and measures for end of life care* Department of Health June 2009
[33] http://www.improvement.nhs.uk/QIPP/tabid/61/Default.aspx

Figure 7 QIPP key objectives

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

5.3 Essex Position

Essex has been developing its understanding of the impact of dementia and the wider mental health agenda for Older Adults for a number of years. In 2006 Essex County Council and the five PCT's jointly commissioned the Institute of Public Care to review its Older Adult Mental Health Strategy and following a consultation exercise the final report, *Essex County Council and Primary Care Trusts - Reviewing and Repositioning the Older Peoples Mental Health Services* was produced in August 2008[34].

34 http://www.essexcc.gov.uk/vip8/ecc/ECCWebsite/content/binaries/documents/Older_Peoples_Mental_Health_Strategy.pdf

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

Other policies and strategies which impact on the Essex, Southend and Thurrock Dementia Strategy include the County Council's and Unitary Authorities' local Carers Strategies, the PCT End of Life Strategies, NICE Quality Standards for Dementia, My Home Life, Dignity in Care and Putting People First: *A shared vision and commitment to the transformation of adult social care*[35].

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

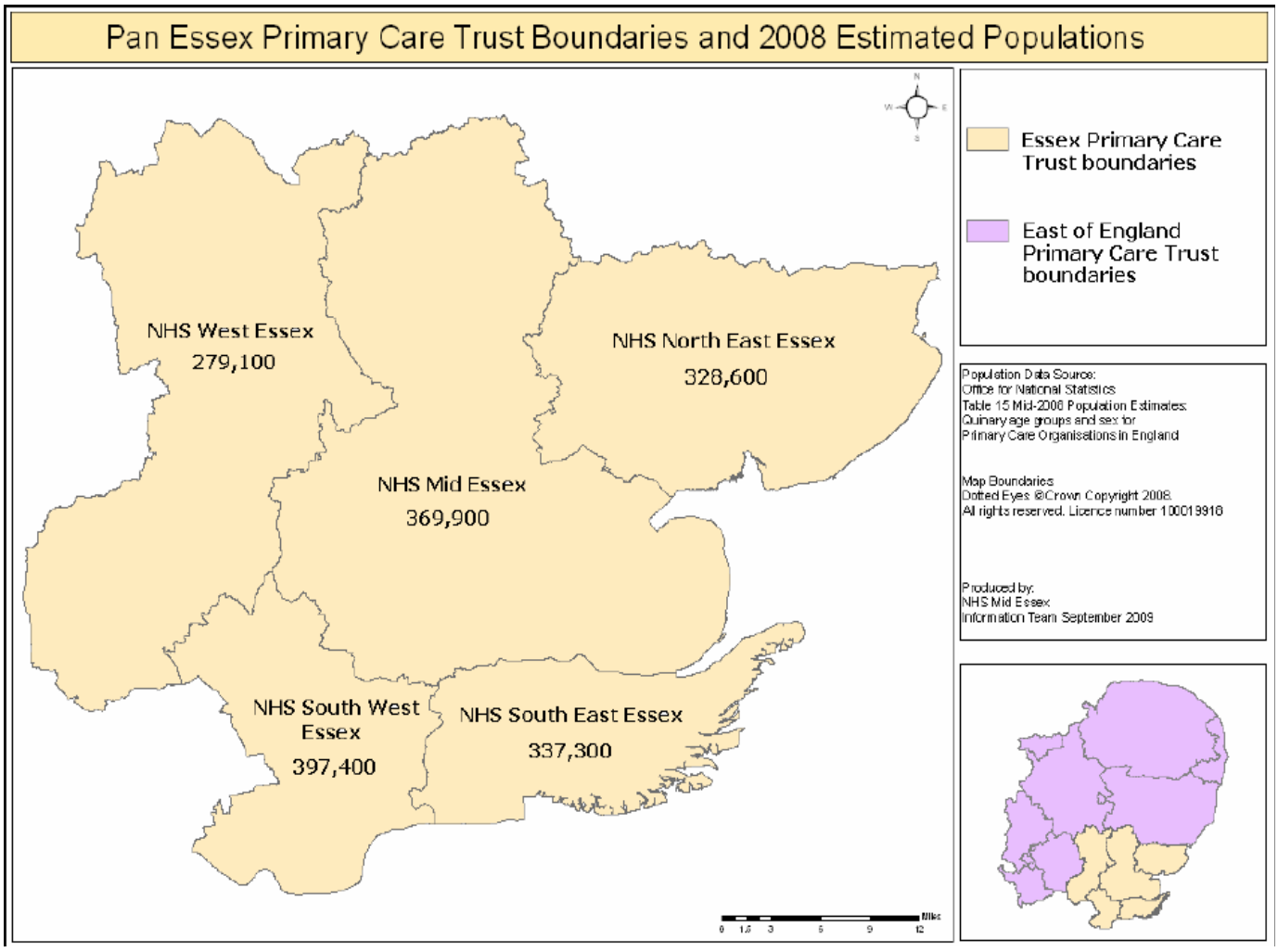
6 The Current Position

6.1 Current Needs and Services

6.1.1. Demographic Information

Essex is the sixth largest county in England and which borders Southend, Thurrock, 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.

Figure 8 Population by PCT area



A number of health and social care organisations work together to deliver a range of services to the people of Essex, which includes, 12 District and Borough Councils, 2 Unitary Authorities, 1 County Council, 5 PCT's, 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.

Despite its population Essex remains largely rural but has a higher than average population of both people aged over 65 and over 85. The Essex Joint Strategic Needs Assessment reports that across Essex the population aged over 65 is expected to increase by 45% by 2021, with the numbers of people aged 85 expected to rise by 75%. This is recognised as presenting one of Essex's most significant challenges with an associated risk of developing long term conditions including dementia.[36]

The proportion of people from groups other than white British is approximately 9.7 percent, which is lower than the national average which is 15.8 percent. 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

Life expectancy can vary greatly as Essex has both socio-economically deprived 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.[37]

6.2 Impact of Dementia in Essex

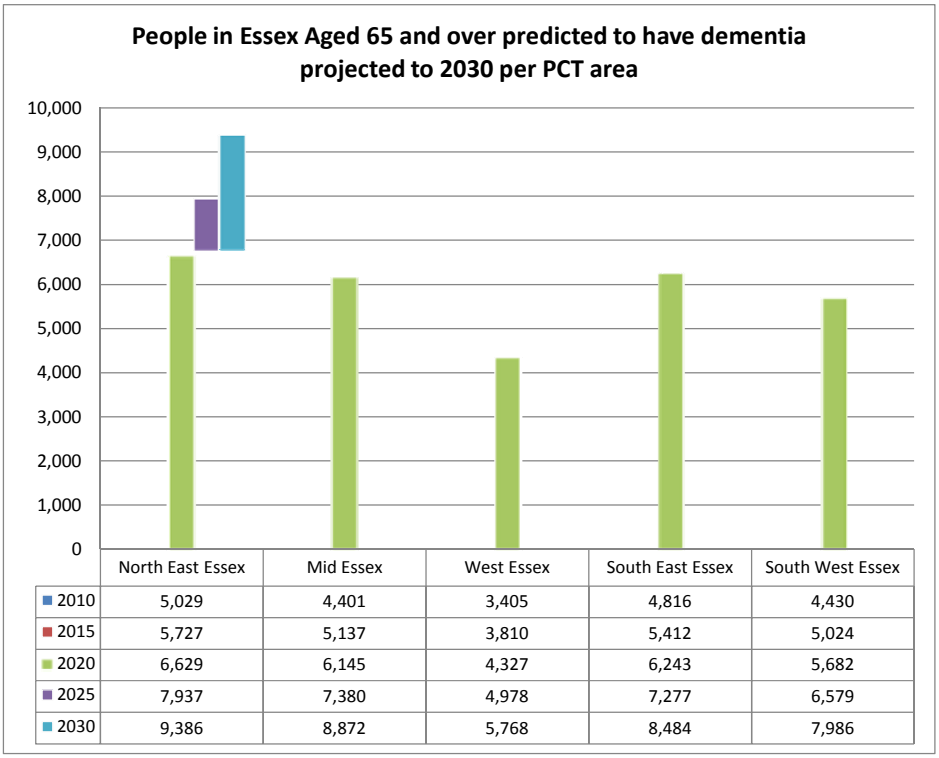
When it was published in February 2009 The National Dementia Strategy[38] stated that there were 570,000 people in England living with dementia and over the next 30 years that figure would double. However the Alzheimer's Research Trust in February 2010[39] suggested that the original figures of people living with dementia were under represented and that the figure in the UK is closer to 820,000 people. This figure is about 15% higher than originally estimated.

With an increasing ageing population, the numbers of people in Essex living with dementia is set to rise by a higher rate than across England. By 2025 it is estimated that the number of people with dementia in Essex will increase from 22,300 to 35,500[40]. 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.

[36] Essex Southend and Thurrock *Joint Strategic Needs Assessment 2008* para 5.7.
[37] IPC report *Reviewing and Repositioning the Older Peoples Mental Health Services*
[38] Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy*
[39] Alzheimer's research trust 2010 *Dementia 2010 – The economic burden of dementia and associated research funding in the UK.*
[40] JSNA 2008 quoting POPPI figures

There are high numbers of people over 65 living with dementia in residential and nursing settings. 79.9% of the people in Dementia registered homes, 66.9% in nursing homes and 52.2% in care homes have dementia[41]. With 296 residential and nursing homes across Essex which cater for older people and people with dementia with approximately 11,582 places, this is a significant number of people in Essex living with dementia in residential care.

The tables below are adapted from the POPPI figures for the projected growth in dementia among people in Essex. These are based on the Alzheimers 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 figures for Districts in Essex and the unitary councils of Southend and Thurrock. However, it is important to acknowledge that to date; data on figures relating to prevalence of dementia locally and nationally are based on best estimates and can vary significantly.



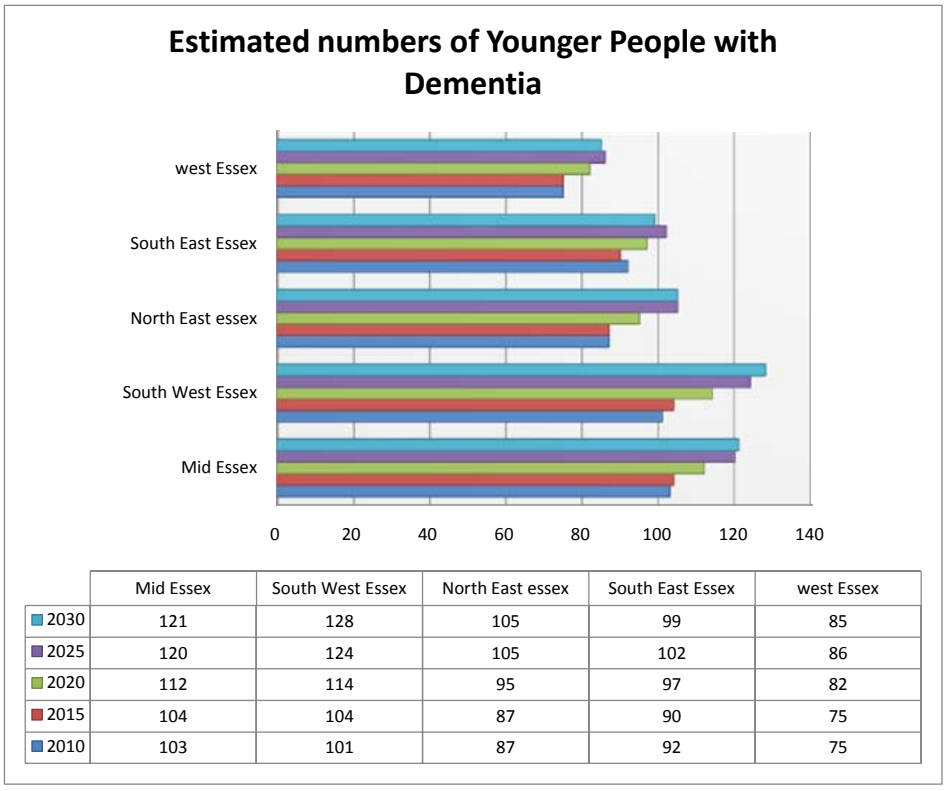
	North East Essex	Mid Essex	West Essex	South East Essex	South West Essex
2010	5,029	4,401	3,405	4,816	4,430
2015	5,727	5,137	3,810	5,412	5,024
2020	6,629	6,145	4,327	6,243	5,682
2025	7,937	7,380	4,978	7,277	6,579
2030	9,386	8,872	5,768	8,484	7,986

[41] JSNA 2008 Citing Dementia UK Report 2007

The estimated average cost of caring for a person with dementia is £25,500 per year. 36% of those costs fall on informal carers, 41% on accommodation, 19% on social care and 8% on NHS.[42]

The prevalence of younger adults who may develop dementia in Essex has been estimated to be in the region of 800 by the year 2015.[43] The numbers of men who develop early onset of dementia is higher than the numbers of women. This may be significant in terms of preventive strategies that may be developed in relation to some types of dementia. The number of people with learning disabilities in Essex who may develop dementia is estimated to be in the region of 500 by 2019[44].

The figures below have been drawn from the PANSI projections for the prevalence of dementia among people in Essex aged under 65 years.



	Mid Essex	South West Essex	North East essex	South East Essex	west Essex
2030	121	128	105	99	85
2025	120	124	105	102	86
2020	112	114	95	97	82
2015	104	104	87	90	75
2010	103	101	87	92	75

[42] Mitchell-Baker, A., Greene, R. *Health and Social care best practice Catalogue. Older Peoples Services Essex. Version 6* (July 2010)
[43] IPC report *Reviewing an Repositioning the older peoples Mental Health Services*
[44] Estimates quoted in IPC report *ch 3*

The JSNA identifies that there are high numbers of people who are unpaid carers in Essex with the 2001 census recording approximately 159,000 – almost 10% of the Essex population. Some 30,000 of these spend 50 hours or more on caring tasks every week and almost half of this group are themselves aged over 60.

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" 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 Bench Marking and Mapping Current Performance

Southend, Essex and Thurrock and the localities of Luton formed an early adopter site for the NDS. Mental Health Strategies was commissioned to undertake a benchmarking and mapping exercise of the services available for people with dementia and their carers related to the objectives of the strategy.[45] This report highlighted the difficulties of obtaining data across the complex health and social care systems in Essex. However, it did identify the need for organisations to make links with other stakeholders (e.g. libraries) and strategies (carers, end of life) and the need for training within general services to have the skills and knowledge to deliver a person centred care.

In producing this strategy, a mapping exercise was undertaken to identify what was available for people with dementia in Essex and their carer's, how these services met the objectives of the NDS, where the gaps were and what the actions should be to fully implement the NDS. See Appendix 3 for a summary of our findings under each objective.

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

[45] 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 this is a significant challenge for the health and social care economy of Essex. Preliminary analysis reveals that services for people with dementia often lack a whole system approach, resulting in fragmentation and inconsistencies in pathways. Leading to difficulties in providing accurate signposting, information, and navigation to the person who is on their journey into dementia. Care Management/care coordination is provided in a vast array 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 pockets of innovative practice and progress in supporting people with dementia and their carers across the region, 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[46] whereby investment in early diagnosis and support will reduce the need for costly crisis intervention and premature residential, nursing or inpatient care. To date there has been progress in Essex with memory assessment services providing early diagnosis, treatment and support in all locations. However there remain challenges in respect of ensuring a single point of access for all referrals, and ensuring that services are available to all those who need them including people with young onset dementia and learning disabilities.

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

Although considerable investment has been made on a regional basis through the JIP the uptake of direct payments and is still lower for people with dementia and their carers so that more people with dementia are likely to receive managed services. It is therefore 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 either in 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

[46] 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

reablement which are not readily available for people with dementia in all areas. Currently we do not have a full picture of 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.[47] There is therefore a need to ensure that there is a range of personalised breaks available which meet the needs of carers and the people with dementia who they are caring for. Whilst Carers Assessments are routinely offered and undertaken further work is required to ensure that carers emotional, psychological and social needs are met and to increase the availability of appropriate breaks. (NICE quality standards 6 &10)

Improving the quality of care within residential and nursing homes and in general hospitals are current national priorities. Further work is required to identify the current position regarding skills and staff development within these areas and these should be addressed through the Pan Essex workforce development strategy which will complete its work in March 2011, (Quality standard 1). However, enhanced liaison services (QS 8) 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 5 PCTs. 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.

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

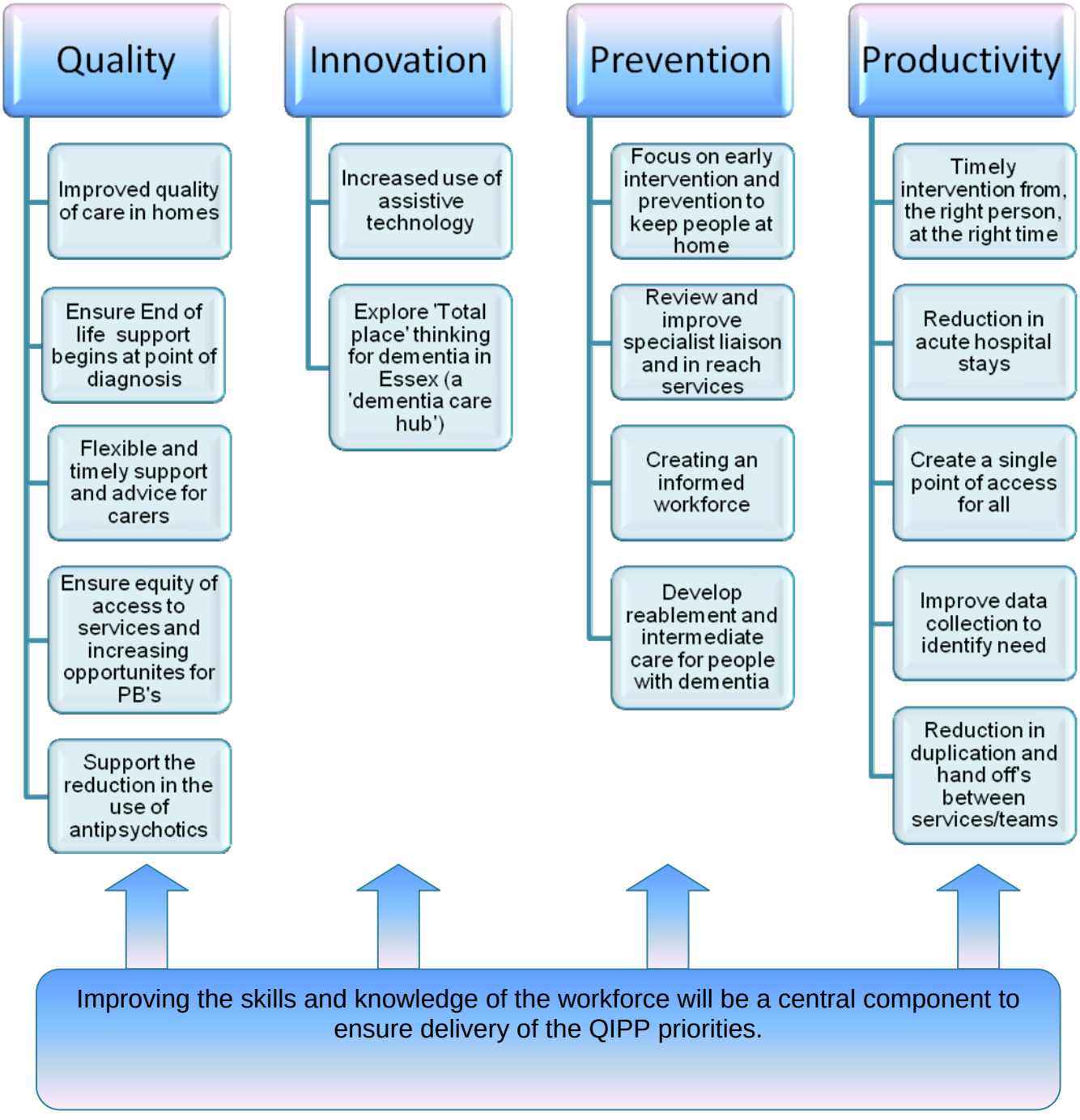
[47] Mitchell-Baker, A., Greene, R. *Health and Social care best practice Catalogue. Older Peoples Services Essex. Version 6* (July 2010)

8. The Way Forward

Priorities for 2010 – 2014

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

Figure 5 QIPP and strategy priorities



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

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

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

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

We have used the information gathered in the Mapping and Progress report and the summary of our findings in Appendix 3 to identify the above priorities. We will also use this information to develop local service plans, building on the work that has already been undertaken by the PCT's, Mental Health Trusts and Unitary authorities.

Appendices

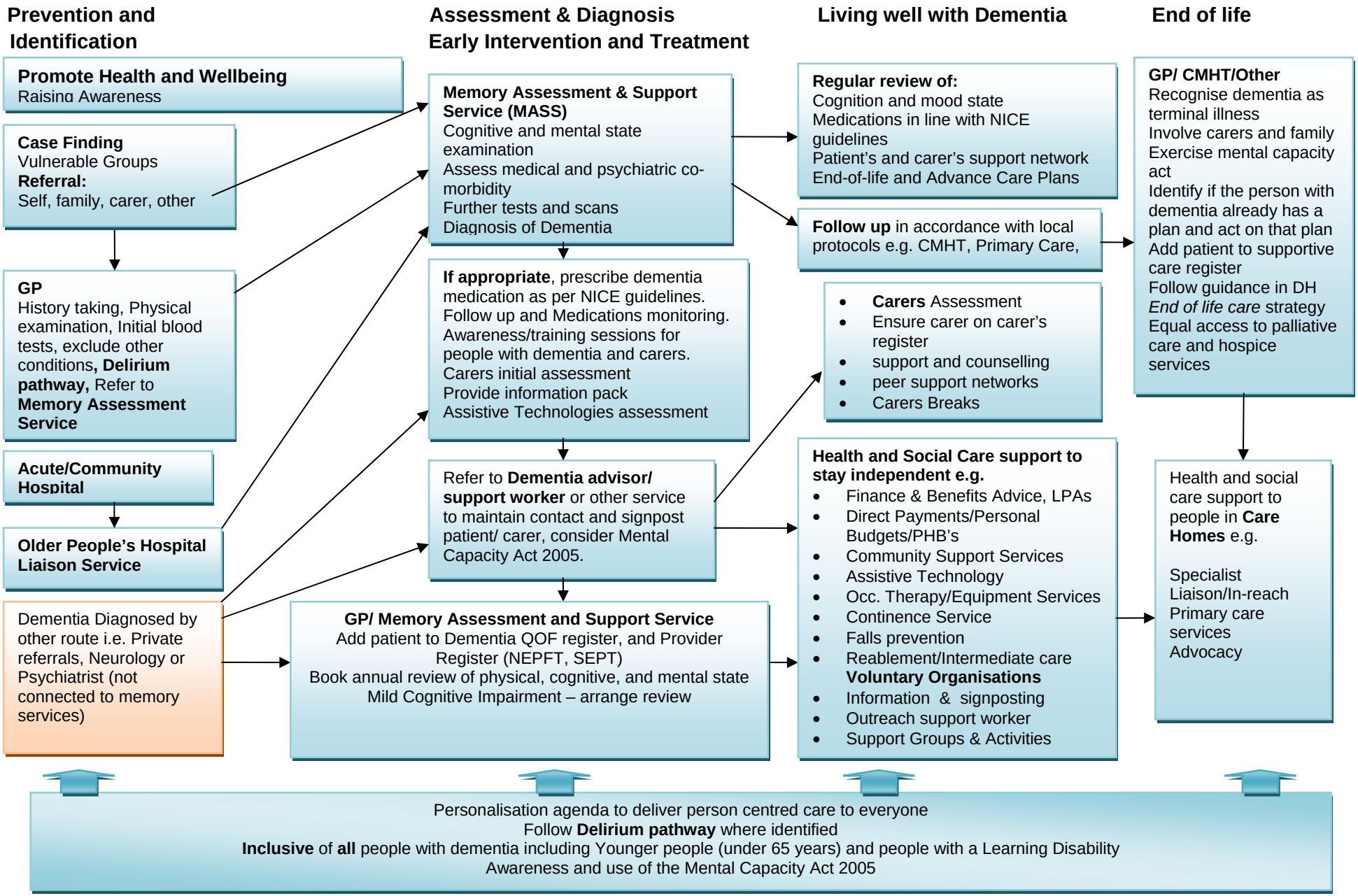
Appendix 1

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

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

Appendix 2

Essex, Southend and Thurrock Dementia Care Pathway



Essex, Southend and Thurrock Dementia Care Pathway – Agreed Principles

- This is an integrated pathway agreed by all stakeholders across the geographical areas of Southend, Essex and Thurrock
- The integrated pathway includes access to primary care, social care and voluntary agency support, secondary mental health support and prevention.
- All parties acknowledge the importance of delivering all parts of the pathway, but that local arrangements to achieve the stated goals may vary.
- The pathway aims to be clear, understandable and useable to all people who read it. This includes individuals and their carers as well as those working with people with dementia in health, social care and allied professions.
- The pathway relates to consistent standards which support quality outcomes for people with dementia and are in line with the NICE Dementia Quality Standard and the values of dignity and respect.
- The principles of Personalisation and person centred support are integral to all stages of the pathway to maximise opportunities for independence and improved quality of life.
- Individual needs and identified outcomes should dictate the level of support required across the pathway.
- Carers' needs are integral to the care pathway.
- There will be a single point of access identified for access to Memory Assessment Services
- The pathway identifies key points for identification and review in order to prevent people being lost in the system 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.

Appendix 3

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

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

In addition to the national public information campaign the Alzheimer's Society is funded by Local Authorities and PCT's in Essex to provide information via its network of services throughout Essex and through its Countywide Information Service. Other initiatives have taken place in most areas. South West PCT held a series of Dementia Roadshows which aimed to provide information for people with dementia, their carers and all those who work in this area. South Essex Partnership Trust has produced DVDs which raise awareness about memory services and the experience of people affected by dementia. North Essex partnership Trust in Mid Essex is currently developing a DVD about working with people with dementia. Dementia cafes are being developed in many areas which are a source of information and advice. Plans are being made to increase training and awareness for GPs across Essex. Liaison and inreach services to residential homes also improve awareness among residential and nursing home staff.

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

The development of memory services at the onset of the dementia journey is fundamental to ensure that people can plan and prepare for the future. It was identified in the strategy that only about one third of people with dementia receive a formal diagnosis or have contact with specialist services.[48] There are memory assessment services in all Essex localities which aim to provide a service to all people who require assessment regardless of age. However, the configuration of these services varies from locality to locality. Services provided by SEPT in South Essex can all be accessed through a single telephone number. Services in Mid Essex and West Essex aim for a Single Point of access to each location via GP referral. An age inclusive service with a single point of access is being developed in North East Essex to enhance existing services which started in October 2010 and is being phased in. North Essex Partnership Trust also has a neuro-cognitive clinic in the West Essex which provides enhanced diagnostic services for people with complex presentations or where a second opinion is requested.

All memory assessment services include advisors (mostly through the Alzheimers Society) who can support people during the diagnostic process. However, any requirements for Social Care support are either referred to the Older Adults Mental Health Teams or Social Care Services as

[48] Department of Health 2009 *Living Well with Dementia – A National Dementia Strategy*

Social care staff are not integrated with the memory assessment services. Response times from these services vary and further work is required to ensure rapid and consistent access to social care assessment is available when required.

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

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

Good quality information for those with diagnosed dementia and their carers (objective 3) Providing people with dementia and their carers with good quality information on the illness and on the services available both at diagnosis and throughout the course of their care

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

Information packs are provided by all Memory Assessment Services following diagnosis. In all areas carers support and education, or living well with dementia groups are being held to support people recently diagnosed with dementia and their carers which may be run by staff from the mental health trusts or by third sector providers such as the Alzheimer's Society or Carers support agencies. The Alzheimers Society is funded across Essex, Southend and Thurrock to provide a support service to people diagnosed with dementia and their carers. This includes providing specialist information about living with dementia as well as information regarding services and benefits with assistance to access these where required. Specific targeted support for people with young onset dementia is provided by West nepft.

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

Dementia Advisors Posts are being developed throughout Essex Southend and Thurrock although there are variations in the role in different locations. In most areas they are situated within Memory Assessment clinics and currently provide advice and support during the assessment process and after diagnosis. People are then signposted to ongoing sources of support such as the Dementia Support Services provided by the Alzheimers Society and other 3rd sector organisations, or to more specialist support through the Older Adults Mental Health teams.

Other initiatives include: a joint funded business case which is being considered in North East Essex for a pilot for Dementia Care Advisors based in GP surgeries, where an advisor will provide support and information throughout the dementia journey; peer support networks in Southend are evolving to provide signposting/advice services; day hospital in West Essex providing outreach into the community in partnership with the Alzheimers Society.

Development of structured peer support and learning (objective 5). The establishment and maintenance of such networks will provide direct local peer support for people with dementia and their carers. It will also enable people with dementia and their carers to take an active role in the development and prioritisation of local services.

Peer Support groups are being developed throughout Essex. South East PCT and Southend Borough Council have a programme which is a demonstrator project for the national strategy and is a partnership between the PCT, the Council, and the Alzheimer's Society. This is now fully integrated into local services. Other peer support groups, including some for younger people with dementia are provided through the Alzheimer's Society and voluntary and not for profit organisations throughout Essex. Dementia cafes offer a valuable source of peer support.

Improved community personal support services (Objective 6). Provision of an appropriate range of services to support people with dementia living at home and their carers. Access to flexible and reliable services, ranging from early intervention to specialist home care services, which are responsive to the personal needs and preferences of each individual and take account of their broader family circumstances. Accessible to people living alone or with carers, and people who pay for their care privately, through personal budgets or through local authority-arranged services.

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

The use of personal budgets improves flexibility, choice and control whereby support is tailored to individual needs. This can be of considerable benefit to people with dementia and their carers. Older Adults CMHT's and Self Directed Support (SDS) practitioners should be able to ensure that people with dementia and their carers benefit from Improved Community Personal Support Services through the development of personal budgets. Across the East of England a Project

Manager was appointed with funding for one year from the Joint Improvement partnership (JIP)[49] to increase the take up of direct payments and personal budgets for people with dementia and their carers. This provided firm foundations to ensure that people with dementia and their carers are considered and positively encouraged to regain and retain independence, choice and control in their lives. An evaluation report of this work has been written. The benefits of personal budgets are that people can choose the help that they need, delivered where and when they need it.

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

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

The NDS refers to emerging research based evidence that there are considerable benefits for people with dementia and their carers who receive specialist dementia home support rather than standard home care services.[50] These seek to overcome traditional problems relating to lack of consistency of workers and task based commissioning. The benefits are cited as including reduced stress and in terms of reduced stress and risk of crises for carers and extended capacity for independent living for people with dementia. There are some providers within Essex Southend and Thurrock who have developed expertise in this area, but further work is needed to ensure that there is access to specialised support across all areas where this is needed.

There remains a range of day services provided through NHS, local authority, Council, independent and voluntary sources. Specialist day services are provided in some areas which have been highly valued but currently there are no other such services being planned. Although there has been a move away from buildings based day services through the Personalisation agenda it must be recognised that many service users do enjoy meeting in groups with others and that there are therapeutic advantages of good day services which provide meaningful activity and support as well as respite for carers. The Alzheimers Society has also developed a leisure and wellbeing service throughout Essex, Southend and Thurrock which aims to support people with dementia to maintain their skills and leisure interests on a one to one basis thereby enhancing their sense of wellbeing and independence. The service supports people in the early stages of dementia who may not be eligible for Social Care Services.

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

- Provision of memory clinics providing both diagnosis and treatment
- Access to enhanced Liaison Services
- Dementia Advisor Posts
- Peer Support
- Wellbeing and Leisure Services

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

[50] Ibid Ch 5, para. 3 pp47-48.

- Dementia Cafés
- Thinking Fit Project (West Essex)

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

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

The Carers Strategy for Essex is currently being developed which provides an opportunity to explicitly include the needs of the carers of people with dementia with reference to the NDS. The Carers Strategy in Southend is being updated to take account of new legislation.

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

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

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

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

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

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

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

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

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

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

Considering the potential for housing support, housing related services and Telecare to support people with dementia and their carers (objective 10). The needs of people with dementia should be included in the development of housing options, assistive technology and Telecare. As evidence emerges, commissioners should consider the provision of options to prolong independent living and delay reliance on more intensive services.

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

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

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

As mentioned earlier Essex County council has made the following pledge for 2011/2012 to support the use of assistive technology for people with dementia.
"Increase by a minimum of 20% the uptake of Personal Budgets and/or Assistive Technology by people with Dementia or their Carers"

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

OAMH services should provide support to residential and nursing homes. This support is configured differently across the localities and further review into the effectiveness of this support is required. A specific liaison service is set up in Mid Essex that provides support and advice to care homes. In South Tendring a CMHN provides support to care homes in the locality which aims to enable people with complex need to be understood and has given residential staff a greater degree of confidence in managing behaviours. West Essex NEPFT have a nursing and residential homes liaison project where an identified nurse provides intervention for specific individuals and training and advice is provided to staff. Mid NEPFT liaison service has a remit to support care homes.

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

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

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

Other initiatives which may support this objective are:

- Dignity in Care[51]
- End of Life Strategy[52].
- My Home Life Programme[53]

[51] http://www.dignityincare.org.uk/
[52] http://www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_086277
[53] http://myhomelifemovement.org/

My Home Life Essex has been developed following the National My Home Life initiative involving Care UK, The Joseph Rowntree Foundation and the care home sector with the aim of improving the quality of life for people living in residential care homes. My Home Life Essex offers "the local care home community the opportunity to develop a programme whereby they can learn from the research and each other, share good practice, pool ideas and to make residential care for older people in Essex the best that it can be"[54].
A review of care in residential and nursing homes is part of the work programme of work stream 2 of the OAMH programme.

Improved end of life care, (objective 12). People with dementia and their carers to be involved in planning end of life care which recognises the principles outlined in the Department of health End of Life Care Strategy. Local work on the End of Life care Strategy to consider dementia.

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

End of life issues are included in the SEPT dementia e-learning tools and SWIFT funding has been obtained from the Strategic Health Authority for End of Life e-learning to be rolled out across Essex for both NHS and Care Home staff. This training will incorporate supporting people with dementia.

An informed and effective workforce for people with dementia, (Objective 13) All health and social care staff involved in the care of people who may have dementia to have the necessary skills to provide the best quality of care in the roles and settings where they work. To be achieved by effective basic training and continuous professional and vocational development in dementia.

A dementia training needs and skills gap analysis was undertaken for the Eastern Region in November 2009.[55] This identified common themes across the region. The main findings were that there was more training available to staff in social care rather than in health settings but that there was little evidence of this being mandatory training in either setting; the biggest training gaps were for GPs, district and practice nurses, those working in acute general wards both medical, nursing and non-medical staff; there were gaps in the skills and knowledge of some trainers and many trainers were failing to meet the criteria for the East of England Integrated Commissioning Strategy; training from the Alzheimers Society was highly valued. The priorities for learning were identified as ensuring that a person centred approach is firmly embedded in training and evidenced in dementia care; younger people with dementia communication skills: working with carers and families; maintaining independence; end of life care.

An e-learning training package has been developed by SEPT which is available to NHS staff with a plan to roll this out across the Region to include Local Authority staff by the end of March 2011. In addition an enhanced training package is being developed by Essex CC which will be available

[54] Quote: Jan Lockyer My Home Life Essex Project Manager
[55] *Dementia training and Development, Training needs and skills gap analysis.* The Office of Public Management 2009

within this financial year. Dementia champion training is being commissioned in Southend which also has a programme of training for health and social care staff. Mid Essex is developing training for GPs and South West has arranged awareness training for hospital staff and paramedics.

A task and finish group is being set up to develop a dementia training strategy for Essex. This group aims to complete its report and recommendations in March 2011

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

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

- North East Essex PCT draft strategy has been completed and actions are being implemented.
- South East Essex PCT draft strategy is being consulted upon with a view to sign off in November 2010
- South West Essex PCT strategy is being developed. It is planned to present this to PCT board in October.
- West Essex strategy is being developed and a Dementia Profile has been published.
- Mid Essex has produced a position statement in relation to the NDS.
- Local delivery plans are being developed. ECC is developing a specific delivery and action plan in relation to the national and Pan Essex strategies.

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

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

Research (Objective 17)
Two research projects are being carried out in West Essex. A study on the use of Anti-psychotic medication and Memantine in nursing and residential homes and the Thinking Fit project which is studying the benefits of physical and mental fitness programmes for people with early dementia.

Consultation Questions

a) Is there anything that has been missed to help us to deliver the Pan Essex Dementia Strategy?

b) Does this Strategy fully address issues of equality and diversity and the needs of particular groups?

c) What are your priorities for implementation? What can and should be done first?

d) What can you or your organisation do in partnership to help deliver the outcomes?

Please send responses to;

Dementia.Strategy@essex.gov.uk