

NHS Basildon and Brentwood CCG  
NHS Castle Point and Rochford CCG  
NHS Mid Essex CCG  
NHS North-East Essex CCG  
NHS Southend CCG  
NHS Thurrock CCG  
NHS West Essex CCG

Southend, Essex and Thurrock Dementia Strategy 2017-2021

“Let’s Talk”  
...about dementia

Southend, Essex and Thurrock  
**Dementia Strategy**  
2017-2021



6699



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## Living well with dementia *...in Southend, Essex and Thurrock*

This strategy is for everybody in Southend, Essex and Thurrock, (Greater Essex), who is living with dementia or supporting someone who is. It describes what we want support for people with dementia to look like in the future and identifies 9 priorities for action to make this happen.

The strategy has been developed in partnership between Essex County Council, Southend on sea Borough Council, Thurrock District Council, and Clinical Commissioning Groups across Greater Essex. It sits alongside Greater Essex's Mental Health and Wellbeing strategy, to form a new and comprehensive, all-age ambition for mental health and emotional well-being in our county.

There are real opportunities for change and innovation across Greater Essex to ensure that people have the best support available to live well with dementia. We want to make Greater Essex more inclusive for everyone living with dementia and empower people to live the life they want in the community for as long as possible.

Over the past year Essex County Council has worked with partners to talk extensively to people who live with dementia and worked to develop the understanding of people's current experience of dementia in Greater Essex. The Public Office also produced a report following a range of engagement activity in Greater Essex and this insight was used to inform this strategy.

Southend Borough Council also conducted a wide range of public and stakeholder consultation activities. The key themes identified reflected similar challenges and needs to those across Essex, with some local differences.

These engagement activities highlighted some challenging truths about existing systems, which involve all of the partners above who commission dementia services in their specific geographical areas:

- Systems are fragmented and bureaucratic. The "battle" to find what they need wears carers down and professionals find it difficult to navigate too
- Services do not consider people as part of a family – or even in partnership with their carer
- Support is not personalised – and doesn't enable people to maintain their capabilities, interests or relationships
- Systems rely heavily on the carer, but don't support them very well. Carers carry on until they can no longer cope, and then health or care services often need to intervene in the midst of a crisis
- Carers are often unable to access services when they are available and have few options available over night and at weekends
- Current avenues of support don't help people and families to withstand the emotional pressures they face – stress, relationship breakdown, loneliness
- Existing systems push people towards residential care because they can't find the support they need in the community.

These are stark revelations, but ones that emphasise the need and opportunity for change and innovation to ensure that people have the best support available to live well with dementia.

# Rethinking dementia

...a collaborative enquiry

## Together we built a 'case for change':

Current experience of services is poor: quality, inconsistency. Services are fragmented and access is difficult.	Demand is increasing, money is being wasted, and we can't afford to keep doing things the way we currently are.
There is stigma and a lack of awareness understanding of dementia in communities, which can be a barrier to diagnosis.	Existing arrangements do not support whole families or the needs of carers.
Individual needs are not currently sufficiently understood or met.	The world has changed (technology, expectations and nature of families) but services haven't.
Professionals' values, knowledge and skills do not always support good outcomes for people with dementia and their families.	Lack of timeliness is a major issue: diagnosis, availability of quality information & support, planning for the future.

## Critical conclusions we draw included:

<ul style="list-style-type: none"> <li>• We need family-led solutions</li> <li>• Carers lack support and respect: we should be celebrating their role</li> <li>• Current services are women-centric: more balance required</li> <li>• Residential care is the default solution, but is outdated</li> <li>• This needs to be about supporting active citizenship for people with dementia</li> <li>• We have to move away from a professional-driven approach, and think about new roles and networked solutions</li> <li>• There is challenge and complexity in providing information that is, timely relevant and meaningful to individuals.</li> <li>• Where is the positive risk-taking?</li> <li>• There are waiting lists for current services</li> <li>• We are not commissioning for flexibility or personalised approaches</li> </ul>	<ul style="list-style-type: none"> <li>• We don't know how good current provision is, or not the impact it's having</li> <li>• No one organisations is taking responsibility for monitoring and coordinating current provision</li> <li>• We are spending huge resources responding to crisis rather than preventing them.</li> <li>• There are BIG implications for the way we commission: it needs to change</li> <li>• This will require culture change that we need to own</li> <li>• Significant number of staff lack basic training</li> <li>• It's not just about training and skills: it's values. Staff need to tackle attitudes towards older people more generally</li> <li>• What is 'good enough' evidence? We need to understand what we don't know and feel confident to take considered risks on the new.</li> </ul>
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# Vision

Our vision for the future is one in which: People living with dementia are recognised as unique individuals who are actively shaping their lives and their care whilst being able to remain as physically and emotionally healthy for as long as possible.

# Dementia

...a shared strategy

Our strategy to achieve this is organised around nine priorities that reflect specific aspects of people's life with dementia. However there are five key elements to our approach that underpin the whole strategy:

## Features of the new system

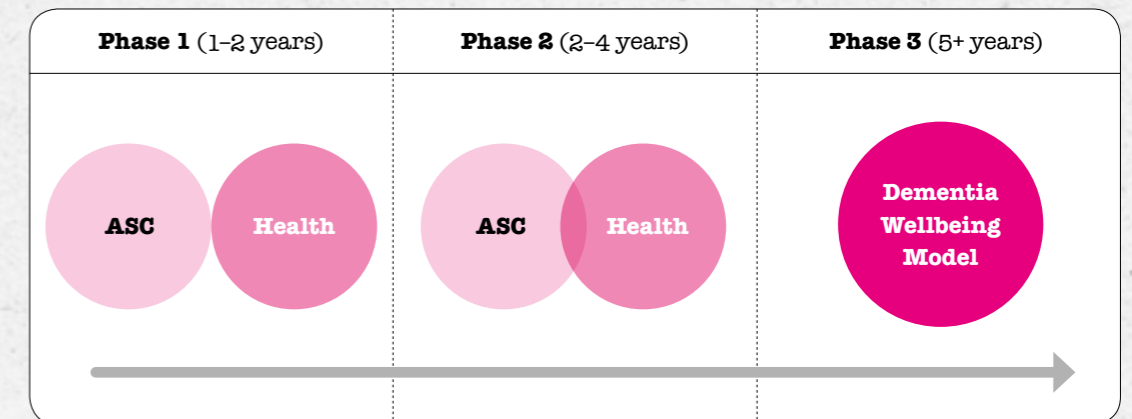
We will...

<p><b>Listen to citizens' voices and focus on their strengths &amp; abilities:</b> take time to understand individual desires &amp; needs, as well as their capabilities and respond appropriately as these change over time.</p>	<p><b>Take a holistic approach:</b> work with whole families to build a picture of what support is needed, support independent living as much as possible/appropriate and do all we can to meet the needs of family carers.</p>
<p><b>Work together across the whole system:</b> align resources to best help citizens &amp; families and 'do what needs to be done when it needs.</p>	<p><b>Focus on timely intervention:</b> ensure early diagnosis, support future planning (including for end of life) and offer flexible, responsive help when and where it's needed.</p>
<p><b>Build citizens' and communities' understanding of dementia:</b> reduce stigma and increase opportunities and capacity for people to support one other.</p>	<p><b>Be clear and consistent about outcomes:</b> be ambitious about what should count as 'success', looking to help people live rich, meaningful, independent lives for as long as possible</p>

We will know our system is good if it delivers these outcomes:

<p><b>Citizens with dementia</b></p> <ul style="list-style-type: none"> <li>• Can access help and advice when and where they need it</li> <li>• Remain as physical and emotionally healthy as possible for as long as possible</li> <li>• Are actively shaping their lives and their care</li> <li>• Are supported by their families, their communities and professionals to live active and enriching lives as long as possible.</li> </ul>	<p><b>Communities</b></p> <ul style="list-style-type: none"> <li>• Understand the signs of dementia and how to reduce the risk of developing it by living active and healthy lives</li> <li>• Demand and build a way of life that responds positively to the needs of those living with dementia</li> <li>• Are involved in supporting those living with dementia</li> <li>• Know where to go for advice or help.</li> </ul>
<p><b>Family carers</b></p> <ul style="list-style-type: none"> <li>• Feel supported and informed in their role</li> <li>• Can access help and advice when and where they need it</li> <li>• Are able to plan ahead with confidence</li> <li>• Remain physically and emotionally healthy themselves.</li> </ul>	<p><b>Practitioners</b></p> <ul style="list-style-type: none"> <li>• Have a shared vision and understanding of outcomes and success</li> <li>• Seek to provide integrated care which supports independence, reducing hand-offs and increasing simplicity for citizens</li> <li>• Are skilled, knowledgeable and are co-creating and co-delivering approaches that work</li> <li>• Are confident about diagnosing dementia and build trusted relationships with citizens.</li> </ul>

ThePublicOffice Dementia in Essex



Five Year Forward View

## A joint strategic approach to dementia in Greater Essex

The range of support for people with dementia is fragmented; people often get lost trying to navigate an intricate web of information and services. We know people living with dementia face a spectrum of challenges and have a range of needs; so to achieve our vision it is vital that organisations work together to collectively transform the approach to dementia in Greater Essex.

Our vision aspires to create systems where organisations work towards the same goal; All localities are addressing challenges in both health and social care, and developing Sustainability and Transformation Plans setting the future direction for health and mental health services (including as part of the NHS Success Regime in Mid and South Essex). Supporting people living safely with dementia to remain as physically and emotionally healthy for as long as possible is key to this.

We aim to design systems that reflect the unique local and demographic needs of communities across Greater Essex but are able to:

- Support people to receive a timely diagnosis
- Intervene earlier to inform and support people to adapt to a life with dementia
- Develop communities that are inclusive to people living with dementia.

We want our systems to help families develop support networks to manage, or avoid times of crisis, explore independent living situations and not have to turn to hospital or long term care settings to manage. Collectively, our systems need to be structured to promote solutions that build upon people's strengths and support networks to achieve the outcomes they want, rather than impose service-based solutions.

A single dementia pathway that joins up health and social care services is the aspiration of this strategy; as we recognise the benefits this will bring to people living with dementia and the wider health and social care system. In an agreed locality, we aspire to having a single assessment, a single care plan and clear route to information and support that works around a person, their family and wider network

We recognise the vital role Primary Care play and strive to work with their skills, knowledge and expertise to develop a model that enables closer working between General Practitioners and the wider dementia care system. We recognise these aspirations are transformational changes and plan to approach these changes in phases, to achieve the aspiration of fully integrated models of dementia care within 5 years, across Greater Essex. Equally we recognise these changes should not happen in isolation to the wider health and social care system, and should align with the local priorities set out in Sustainable Transformation Plans as part of the Five Year Forward View.

### A new model of specialist support

People with more complex needs or challenging behaviours cannot always find specialist advice or support when they need it. The lack of specialist advice can also lead to hospital or residential care admission when this might be avoided. Expertise on dementia tends to be concentrated in services for older people, which is not always appropriate for younger people with dementia or people with learning disability.

An integrated all-age dementia service for those with the most complex needs that will provide specialist advice and support across the Health and social care system in Essex, and possibly Southend, will support those that can sometimes be overlooked by the current system of support.

### Support that is personalised and empowers people within an inclusive community

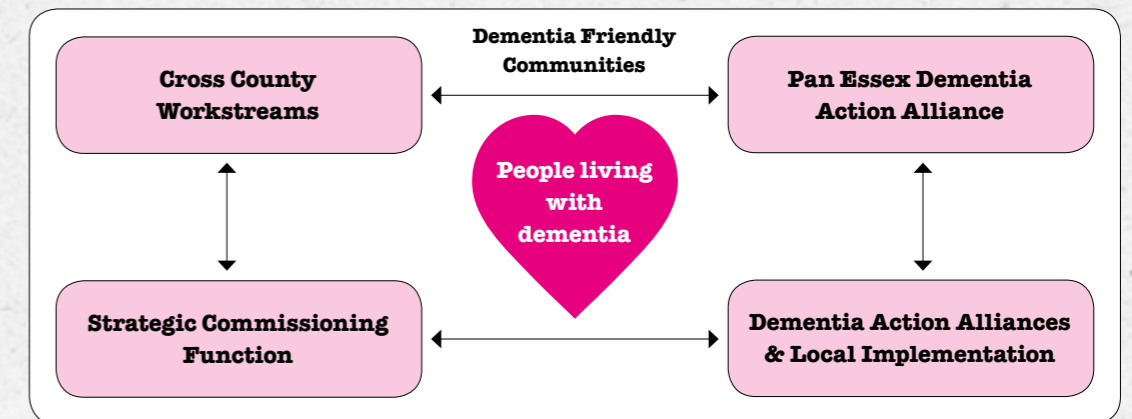
People living with dementia want information and support that enables them to adapt, but keep living the life they led prior to their diagnosis. They often feel isolated from the wider community and many feel scared to go out of their home. We think that a community-wide response is needed to address this problem.

Support should build upon a person's strengths, their skills, their qualities and their own resources. We want to empower people to embrace outdoor space, be physically active and take positive risks that enable them to live the life they want to lead. We recognise early intervention is a key part in achieving this; and strive

to ensure people have access to timely intervention that enables it to happen. We need to change the culture of assessment, support planning and care, through the "Good Lives" approach (or Live Well, the approach used in Thurrock) to ensure that the person, and their family, are kept at the heart of what we do and enable them to live independently in the community for as long as possible. All people with dementia should be offered a personal budget, where applicable under the Care Act to give them maximum control over the kind of help they receive.

We have established a Pan-Essex Dementia Action Alliance to shape and influence a county wide response to dementia in Greater Essex; and worked with District Councils to form local alliances that can drive change in local towns, villages and Greater Essex Communities. We will continue to grow these alliances and aspire to engage a breadth of organisations across the private, public, community, third, health and social care sectors to commit to ways they will transform the lives of people living with dementia.

In Southend people living with dementia and their carers along with 44 businesses, services and community groups are working in partnership with Southend Borough Council to maintain the 'Working towards becoming Dementia Friendly' status awarded in March 2016. Southend is very fortunate to have a variety of members within the Southend Dementia Action Alliance (SDAA), including the UK's first dementia friendly airport, a committed community support approach from Essex Police Southend and Essex Fire & Rescue Southend.



Future Partnership Model

### The voice of lived experience

There are examples of dementia friendly support within Health, with a local GP Surgery working towards becoming a dementia friendly practice and a dedicated team of professionals within Southend Hospital creating dementia friendly wards through changing policies and cultures. Building on this work we feel confident that Southend will be a place where people affected by dementia can live their lives with access to the services and support they need to fully participate in community life.

We want Carers to feel supported in their own right and to be respected as partners in care. We will work with Carers to develop a network that enables their loved one but ensures they remain connected to information and support should they need it.

### Maximise the use of technology

There are a growing number of ways that technology can be used to support people to remain independent, give Carers more freedom and peace of mind and reduce dependence on formal services all of which are outlined in the Dementia Technology. We will work with people to raise their awareness of technology as an enabler to independent living and we will create environments that enable the use of technology. We are working with partners to find and promote new tools that address some of the obstacles to independence faced by people with dementia and their Carers and will align with wider programmes of work taking place across Essex focused on developing digital response to health and social care needs.

We know to really meet the needs of people living with dementia, it's vital we listen to the voice of those living with the condition, not only to better understand the challenges they face but identify solutions to overcoming these challenges. We want to facilitate activity in the community that responds to need, and recognise the only way of doing so is to speak to those that are living with dementia day in, day out. We will involve those living with dementia in helping us achieve the aspirations set out in this strategy and continue to re-visit our vision to ensure the voice of lived experience not only remains central to the transformation within the system, but helps to measure the impact of the new system. To underpin this strategy a sustainable way of engaging with people, in a relevant and meaningful way, will be developed. This, along with the community response, will be supported through the ongoing delivery of local Dementia Action Alliances and specific user groups to support engagement and to change the messaging around dementia in Greater Essex Communities.

To achieve our vision; and drive forward the actions set out in this strategy we recognise the need to bring together the five key elements listed above, to form a whole systems partnership function. A function that is responsible for mobilising activity, and implementing change but one that is accountable to the wider health and social care infrastructure that it works within.

# Priorities

We have worked with our partners and through the Public Office engagement, to identify nine priorities that reflect key aspects of the lives of people living with dementia.

We want to intervene earlier to prevent needs from increasing and help people to continue to live independent lives, building on their strengths and the resources available to them within their personal network and the wider community.

For those who need ongoing support, we want to make sure this responds to the

needs of individuals and supports the wider family network, with the offer of a personal budget to give them maximum control over their care and support.

- **Prevention**
- **Finding Information & Advice**
- **Diagnosis & Support**
- **Living well with Dementia in the Community**
- **Supporting Carers**
- **Reducing the Risk of Crisis**
- **Living well In Long Term Care**
- **End of Life**
- **A Knowledgeable and Skilled Workforce**

Priority	Outcome	Success Measures
<b>Prevention</b>	People in Greater Essex will have good health and wellbeing, enabling them to live full and independent lives for longer.	<ul style="list-style-type: none"> <li>• Using the Making Every Contract Count approach, people understand the link between healthy and active lifestyles and are able to make positive changes in their lives</li> <li>• People have an increased awareness of Mild Cognitive Impairment</li> <li>• People are aware of how to access information and support should they be concerned about dementia</li> <li>• Increased percentage of people diagnosed with dementia receive an annual face to face review of their health needs, including medication, and whose vital health indicators are checked</li> <li>• People in BAME Greater Essex Communities have increased awareness of dementia and the warning signs</li> <li>• Carers have access to annual health check and have access to Improved Access to Psychological Therapies.</li> </ul>
<b>Finding information and advice</b>	Everyone with dementia will have access to the right information at the right time.	<ul style="list-style-type: none"> <li>• A comprehensive whole system Information and guidance offer is available.</li> <li>• People living with dementia will feel supported to navigate the system and access information and support that is relevant to them.</li> </ul>

Priority	Outcome	Success Measures
<b>Diagnosis and support</b>	All people with dementia will receive appropriate and timely diagnosis and integrated support.	<ul style="list-style-type: none"> <li>• GP's across Greater Essex understand the importance of a timely diagnosis and are aspiring to work with the wider system to diagnose within an appropriate timeframe</li> <li>• Professionals across the system are aware of referral pathways and are able to work together to best support the assessment and diagnostic process</li> <li>• There is a clear referral pathway to diagnosis with appropriate information and support offered</li> <li>• BAME Greater Essex Communities are accessing assessment and diagnostic services</li> <li>• There is appropriate screening for people who are considered to be at high risk of dementia</li> <li>• People with dementia have access to post diagnostic support that is relevant and personalised</li> <li>• People living with dementia and their entire network are supported to draw on their strengths and assets to adapt to living a life with dementia, and plan for the future</li> <li>• People are offered a direct payment upon diagnosis of dementia where appropriate.</li> </ul>
<b>Living well with dementia in the community</b>	All people with Dementia are supported by their Greater Essex communities to remain independent for as long as possible.	<ul style="list-style-type: none"> <li>• There is a whole community response to living well with dementia</li> <li>• Environments and physical settings in the community are dementia friendly</li> <li>• People living with dementia are able to take advantage of open space and nature</li> <li>• The voice of lived experience helps to shape how Greater Essex Communities respond to dementia</li> <li>• People living with dementia are encouraged to access information and support that helps themselves to live well and independently</li> <li>• The lives of people living with dementia in the community are transformed through the DAA activity</li> <li>• Young people are part of the community support for people living with dementia</li> <li>• The market is able to respond to people living with dementia and support them to live well</li> <li>• People with dementia have awareness of alternative accommodation options.</li> </ul>

Priority	Outcome	Success Measures
<b>Supporting carers</b>	Carers are supported to enable people with dementia to remain as independent as possible.	<ul style="list-style-type: none"> <li>Carers are a driving force behind shaping the response to dementia in Greater Essex</li> <li>Carers of people living dementia are offered information and support relevant to their needs, throughout their experience with dementia</li> <li>Carers are encouraged to build on their own support networks to live well and keep physically and emotionally healthy</li> <li>Carers feel informed and equipped to care for someone living with dementia and able to plan, or flex to increased needs or challenges</li> <li>Carers are able to access a range of opportunities to take a break from their role as a Carer.</li> </ul>
<b>Reducing the risk of crisis</b>	All people with dementia receive support to reduce the risk and manage crisis.	<ul style="list-style-type: none"> <li>All hospitals to aspire to being dementia friendly care settings</li> <li>People living with dementia, with complex needs such as co-morbidities are offered specialist information and support</li> <li>Crisis situations are avoided or managed appropriately - Crisis situations are planned for and responded to effectively</li> <li>Emergency planning, including clinical emergency planning is addressed as part of all carer's assessments</li> <li>The Community and Primary Care are able to respond to episodes of crisis in care homes appropriately</li> </ul>
<b>Living well in long term care</b>	All people with dementia live well when in long term care.	<ul style="list-style-type: none"> <li>All care homes for people with dementia in Greater Essex will be supported to be dementia friendly by 2020</li> <li>People living with dementia, their families and carers understand what high quality care looks like and where to find it</li> <li>People with learning disabilities who have dementia, (or at risk of), are fully supported in long term care settings through linking Dementia in to LD health checks</li> <li>People with dementia in long term care are encouraged to build and maintain networks both in and out of the care setting</li> <li>People assessed as not having capacity, with no family or friends are referred to an Independent Mental Capacity Advocate as appropriate.</li> </ul>

Priority	Outcome	Success Measures
<b>End of life</b>	People with dementia and their families plan ahead, receive good end of life care and are able to die in accordance with their wishes.	<ul style="list-style-type: none"> <li>People living with dementia, their families and carers complete advanced care plans that are recorded and held by the GP</li> <li>People assessed as not having capacity, with no family or friends are referred to an Independent Mental Capacity Advocate as appropriate</li> <li>People are not delayed in being discharged from hospital</li> <li>People are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they choose</li> <li>Carers and families receive bereavement support at a time that is right for the individual or family.</li> </ul>
<b>A knowledgeable and skilled workforce</b>	All people with dementia receive support from knowledgeable and skilled professionals where needed.	<ul style="list-style-type: none"> <li>There is a framework for dementia training across Greater Essex to ensure all people receive training relevant to their role</li> <li>To develop a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia, and is equipped to do so</li> <li>To improve the quality of dementia care across the market, and support people to understand the benefit of positive risk taking to enabling a person to live well.</li> </ul>



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## The stages of dementia

“Dementia” is a term that covers a range of symptoms that result from damage to the brain that can affect memory, attention, communication, problem-solving and behaviour. Every individual’s “dementia journey” is very different. Some people may live for years without any obvious decline, while others experience rapid deterioration. However there are similarities in the challenges and pressures people experience as symptoms develop.

In the early stage, people may dismiss forgetfulness or difficulty concentrating as normal signs of ageing or attribute disorientation and mood swings to stress. Once symptoms begin to impact on normal life, diagnosis can be a relief but also lead to fear and denial about the future. People may feel a sense of loss, a loss of their identity and the person they believe they once were.

People with dementia say that it is important to feel that their life still has meaning. Some achieve this by maintaining relationships with important people in their lives or by keeping up interests. Others struggle through lack of opportunity, lack of confidence or other barriers. In the Alzheimer’s Society Dementia 2014 survey, only 60% said that they left the house every day and 40% said that they felt lonely.

Dementia is a progressive condition which means that the symptoms will become worse over time. People’s ability to make decisions about their lives or even day-to-day situations will decline. To compound these problems, a large proportion of people with dementia

will also have other medical conditions or disabilities, such as arthritis, hearing problems, heart disease or mobility problems. The Alzheimer’s Society found that 72% of respondents to their Dementia 2014 survey were living with another medical condition or disability – some were living with up to twelve conditions.

As the disease progresses, people gradually find normal activities challenging and may fear losing control as they become increasingly dependent on others. People may become depressed and anxious when diagnosed as well as when they begin lose their ability to do everyday things for themselves. In the late stage, people can become totally dependent on others for basic life tasks and this is often when they consider moving into a care home.

### **Ethnicity**

Dementia among black, Asian and minority ethnic (BAME) Greater Essex Communities is significantly under-diagnosed and research by the Social Care Institute for Excellence has found that these groups are less likely to use dementia services. There are low levels of awareness, late diagnosis and a lack of culturally sensitive services. All of which makes it more difficult for people from these Greater Essex Communities to get the support they need. Greater Essex has a relatively small BAME population (5.7% in Essex and 13% in Southend) but the proportion of people receiving services is even smaller (1.2%) suggesting they are under-represented.

### Early onset dementia

Care for younger people (ie. under 65) with dementia is a challenge. Younger people with dementia face different issues, not least that they are more likely still to be working or have a young family. Support designed for older people with dementia is often not suitable for younger adults. This means that people with early onset dementia can find themselves isolated within the community. Those with more challenging needs can find it difficult to find suitable long term care options with the majority of solutions aimed either at older people or people with learning disability. The majority of people with dementia in Greater Essex are over 70 but 7.5% are younger than this and there are a few are under 30. In Southend 98% of people living with dementia are over 65 and just 38 people are registered under the age of 65.

### Learning disability and dementia

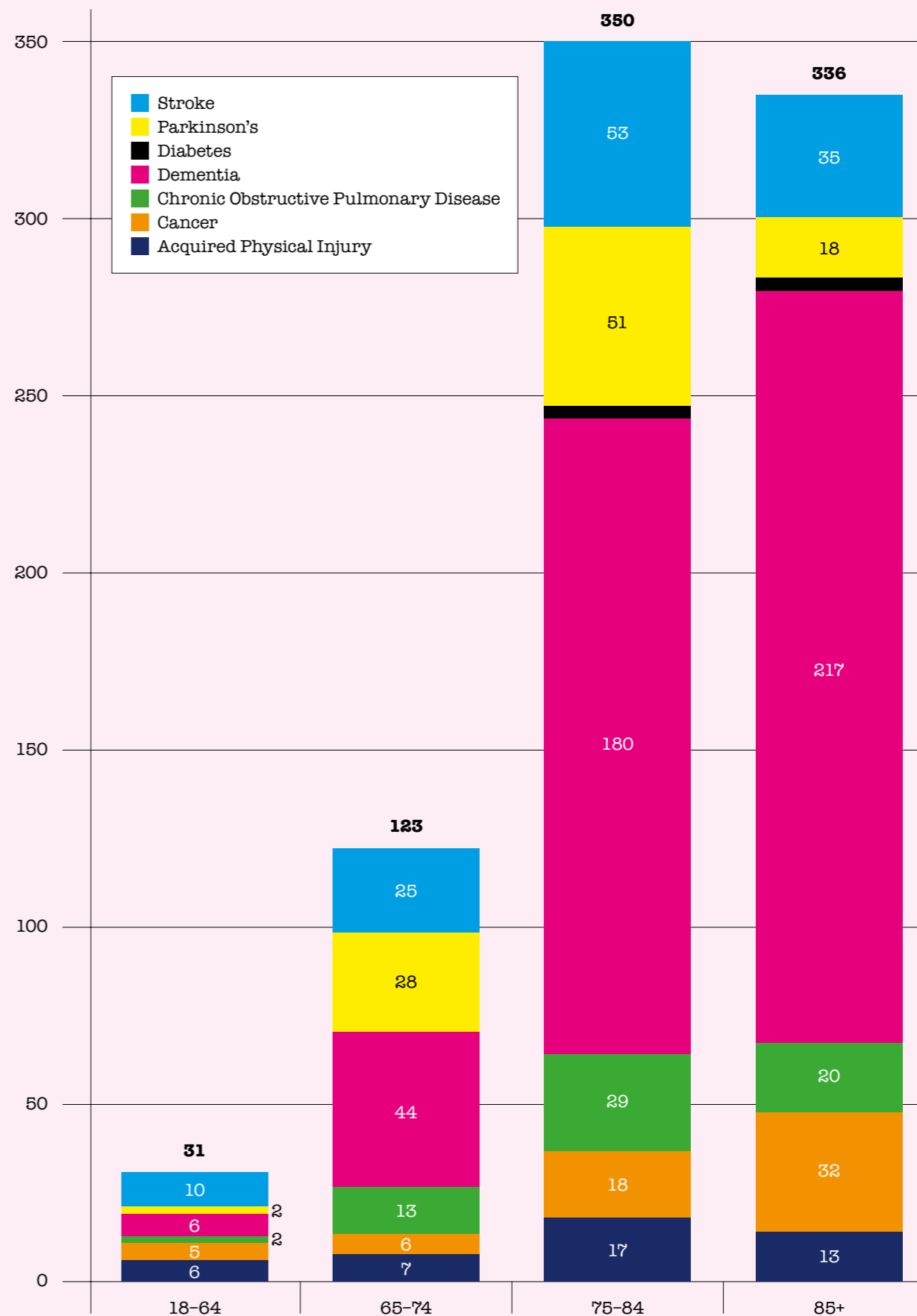
People with learning disabilities have a higher risk of developing dementia than other people and usually develop the condition at a younger age. This is particularly true of people with Down's syndrome, one in three of whom will develop dementia in their 50s. Symptoms of dementia can present differently so that people often don't recognise changes as being dementia related. Because of this, opportunities for early intervention are lost. In Greater Essex we have found that mainstream diagnostic services are not geared up to assess people with learning disability, are not making reasonable adjustments and often refer people back to learning disability services. Likewise, mainstream dementia services are not geared to support people with learning disability or their carers.

### Carers

Over 21 million people in the UK know close friends or family affected by dementia and it is estimated that one in three people will care for a person with dementia in their lifetime (Prime Minister's Challenge on Dementia). Approximately one third receive no support from either social services or the voluntary sector. In Southend, Thurrock and Essex an estimated 145,000 provide care and support for someone who needs help (not specific to Dementia) with their day to day life of which about 32,000 are estimated to provide care for more than 50 hours per week. We know that over half of people who have approached ECC for a social care assessment have an unpaid family carer and there will be even more in the community who have not yet sought support from us (ECC Dementia Specialist Topic Needs Assessment (2015)). The support of family carers is often crucial to enabling people with dementia to remain in their community. They are often the first to spot changes in the person's health or behaviour and can support communication and sharing of information.

However carers of people with dementia can face a particularly challenging range of symptoms and behaviours that can persist over several years. Research shows that carers of older people with dementia experience greater strain and distress than carers of other older people (Carers Trust: The Triangle of Care: A guide to best practice in dementia care). In addition, many carers are themselves older people with physical frailty and health conditions of their own. The graph on the next page has been taken from data provided at assessment.

Types of health conditions that affect older (65+) cared-for





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# Our priorities for action 2015-2020

## Priority 1: Prevention

### The issue

The risk of developing dementia increases with age. Currently we estimate there are 19,000 people in Greater Essex with dementia but predicted to rise to over 25,000 in the next ten years, (based on Office for National Statistics Population 2014 and is higher than the national average). The highest increase is predicted in those over 85, so likely to present with more complex needs suggesting huge implications for the Health and Social Care System.

According to Alzheimer's Society research (Dementia UK Update 2014), as many as 70% of people with dementia will also have other medical conditions or disabilities, such as arthritis, hearing problems, heart disease or mobility problems. Many will have one or two conditions, some will have far more. This emphasises the importance for people to receive advice and support that is tailored to their needs. The ability to measure awareness around cardio vascular risk factors, and general health and wellbeing will be key in supporting people to think in a preventative way.

The Blackfriars Consensus Statement (2014) made clear that the risk of some types of dementia can be reduced but it cannot be eliminated. There is growing evidence that cardiovascular factors, physical fitness, and diet have a major part to play in keeping

the brain healthy and thus reduce the risk of developing dementia in later life. Other lifestyle choices such as not smoking, keeping low cholesterol and blood sugar can also help.

The economic impact of dementia is enormous. The Alzheimer's Society calculate the average annual cost per person with dementia as about £30,000 for those living in the community versus c. £37,000 for those in residential care. For people living in the community, three quarters of the cost relates to the indirect costs associated with the contribution of unpaid family carers. For those people in residential care, £32,700 relates to social care, this is £26.5bn a year, enough to pay for every household's energy bills in the UK. (Source Dementia 2015) Alzheimer's Society.

To maintain independence and quality of life as long as possible, it is essential we prioritise the health and wellbeing of people with dementia and that of their carers and support them to self-manage any co-existing health problems. Social isolation and loneliness can be a significant problem and can lead to anxiety and depression. However in Greater Essex the percentage of those diagnosed with dementia receiving an annual review from their GP or recording of vital health indicators is currently among the lowest in the country.

**Outcome**

People in Greater Essex will have good health and wellbeing, enabling them to live full and independent lives for longer.

**Success measures**

- Using the Making Every Contract Count approach, people understand the link between healthy and active lifestyles and are able to make positive changes in their lives
- People have an increased awareness of Mild Cognitive Impairment
- People are aware how to access information and support should they be concerned about dementia
- Increase percentage of people diagnosed with dementia receive an annual face to face review of their health needs, including medication, and whose vital health indicators are checked
- People in BAME Greater Essex Communities have increased awareness
- Carers have access to annual health check and have access to Improved Access to Psychological Therapies.

“We estimate there are 19,000 people in Greater Essex with dementia but predicted to rise to over 25,000 in the next ten years.”

Based on Office for National Statistics Population 2014

**Priority 2: Finding information and advice**

**The issue**

Information and advice is fundamental to enabling people, carers and families to take control of their care and make well-informed decisions about the support they need. We need to help people find and connect to resources and support that will help them get on with their life and develop technological solutions that make it easier for them to do this. However people tell us that they struggle to navigate the large amount of information available about dementia and identify the right support in their area. This can be really distressing when people are at a vulnerable point, such as when they have just received a diagnosis or when they have an immediate need for help. The offer of information and advice needs to be personalised because people will have different preferences for how they want to receive information.

GP's and their surgeries can be key sources of information but the quality and availability of information available is variable. From April 2015, everyone with dementia should have access to a named GP with overall responsibility for their care.

**Outcome**

Everyone living dementia will have access to the right information at the right time.

**Success measures**

- A comprehensive whole system Information and guidance offer is available
- People living with dementia will feel supported to navigate the system and access information and support that is relevant to them.

“There's so much information, where am I supposed to start?”

Carer

“I have been given a lot of information, cannot make head nor tail of it and not sure what it all means.”

Carer

“It is difficult for carers to find out what help is out there and how to access it.”

Counsellor

### Priority 3: Diagnosis and assessment

#### The issue

Early diagnosis of dementia is vital because it helps people to understand what is happening to them, make plans and gain access to the most appropriate support and treatment. Some professionals can be reluctant to refer people for diagnosis because of a perceived lack of post-diagnostic support, amongst other reasons. In Essex, 52% of the estimated dementia population have a diagnosis. In Southend the diagnosis rate at December 2016 was 72.6%. The national target is 67%.

Some groups are at higher risk of not being diagnosed. Greater Essex has a relatively low BAME population (5.7%) but the proportion of people of BAME origin receiving services generally, is even lower (1.2%), suggesting they are underrepresented. In Southend the BAME population in the 2011 census was 13%.

Early onset dementia can be harder to recognise and diagnose and people may still be working and have young children. In Greater Essex 7.5% of those with dementia are under 70 and a few are under 30. Finally, people with learning disabilities are at significantly higher risk of developing dementia and at a younger age. There are no specialist services for people with both LD and dementia in Greater Essex.

Following diagnosis, people need personalised ongoing support and advice both to understand their condition; the support available (including for their carers) and the importance of planning in advance. They should have an assessment of their needs and a personalised care plan covering both health and social care.

#### Outcome

All people with dementia will receive appropriate and timely diagnosis and integrated support.

#### Success measures

- GP's across Greater Essex understand the importance of a timely diagnosis and are aspiring to work with the wider system to diagnose within an appropriate timeframe
- Professionals across the system are aware of referral pathways and are able to work together to best support the assessment and diagnostic process
- There is a clear referral pathway to diagnosis with appropriate information and support offered
- BAME Greater Essex Communities are accessing assessment and diagnostic services
- There is appropriate screening for people who are considered to be at high risk of dementia
- People with dementia have access to post diagnostic support that is relevant and personalised
- People living with dementia and their entire network are supported to draw on their strengths and assets to adapt to living a life with dementia, and plan for the future
- People are offered a direct payment upon diagnosis of dementia.

“

Getting a diagnosis took so long. It was a huge relief when it finally came. I knew then I wasn't imagining it. We could start to make plans.”

Carer

“

I was given this devastating news, given a folder of stuff and left to get on with it in the darkness.”

Carer

“

At the point of diagnosis we need someone who is there for the family. Not just bits of paper and a crisis line. We need practical, real advice from someone who knows what we're experiencing.”

Carer

#### Priority 4: Living well with dementia in the community

##### The issue

Especially in the early stages, people with dementia tell us that they want to continue to live their life as normally as possible. This means staying in their own home, being included in their local community, maintaining friendships and interests. As people's symptoms worsen they become more dependent on others for transport and general help to be able to do this. Fear about becoming confused or getting lost also leads to people going out less and restricting themselves to less demanding activities, which can lead to them becoming more isolated from the community. Loneliness is an increasing problem and can lead to depression or anxiety – over half of those we support who have dementia are widowed and about 4% live alone.

We know that there are gaps in the support available for people with dementia in Greater Essex. Greater Essex is above average in providing equipment or adaptations to help people stay in their own homes but below average in its provision of home care. Services are also not personalised. They often group people together without taking account of their individual capability or their personal preferences, experiences or personality. There is a limited range of activity to choose from in some areas and few services at evenings or weekends. Transport is a problem, particularly in more rural parts of the county. There is little support to help people maintain friendships or relationships or make new ones.

The traditional approach to assessing people's needs can be too focused on assessing for services. In fact formal services are just part of a wider network of community support which encompasses other public services, voluntary and commercial services, local amenities and the informal help and support that Greater Essex residents give to each other.

We want to promote a more inclusive approach to help people live independently in their community, maintaining the relationships and activities that matter to them. We will do this by helping people and their families to use their existing strengths and resources and connect to things that will help them get on with their lives. Where people need more intensive support we will make sure this is tailored to their individual needs and preferences, with the option of a personal budget to give them maximum control over the kind of help they receive.

In a Dementia Friendly Community people are empowered to have aspirations and feel confident, knowing they can contribute and participate in activities that are meaningful to them. But we know that there is still stigma and misunderstanding in our Greater Essex Communities and that people are not knowledgeable about dementia or how to help someone with the disease live well. Key services including blue light services, supermarkets, banks, etc. do not always have staff able to recognise and support people with dementia.

##### Outcome

People living with dementia feel able to access and contribute to their community, undertaking day to day tasks that supports them to remain as independent for as long as possible.

##### Success measures

- There is a whole community response to living well with dementia
- Environments and physical settings in the community are dementia friendly
- People living with dementia are able to take advantage of open space and nature
- The voice of lived experience helps to shape how Greater Essex Communities respond to dementia
- People living with dementia are encouraged to access information and support that helps themselves to live well and independently
- The lives of people living with dementia in the community are transformed through the DAA activity
- Young people are part of the community support for people living with dementia
- The market is able to respond to people living with dementia and support them to live well
- People with dementia have awareness of alternative accommodation options.

“At first I didn't think 'activity centres' were really for people like him. Who else is a grown up and goes to an 'activity centre'?”

Carer

“People don't know what to say or do, your world gets very small all of a sudden.”

Carer

## Priority 5: Supporting carers

### The issue

The impact on the family of a person diagnosed with dementia is significant, especially on family members who take on the responsibility of caring for the person. Diagnosis can be a difficult time for the carer as much as for the person with dementia. The condition can have a major impact on their relationship as the person becomes more dependent on their family for day to day support. Carers tell us they need help to understand the condition and how it is likely to affect their family member and may need help to find support for them both.

People with dementia become increasingly dependent on others and in the later stages may develop behaviours and psychological symptoms that make them among the most challenging to care for. Many carers gain personal satisfaction from caring and want to continue but caring comes at great personal cost. 40% of carers experience psychological distress or depression with those caring for people with behavioural problems experiencing the highest levels of distress (Carers Trust: Triangle of Care: Best practice for dementia care). Yet their ability to continue caring may be essential to the person being able to remain in the community. Carers tell us that they need practical support and reassurance in caring and someone to turn to when things get tough.

Carers find it difficult to take time for themselves, whether to take a break or for essential activities such as their own health appointments, because it can be hard to find others they trust who are willing or able to look after someone with dementia. Services are not always the best answer. They are often at the wrong time or place and may not offer things that people really want. But carers of people with dementia often end up relying on a narrow range of day services and dementia cafés for lack of alternative forms of support.

When it comes to longer breaks, carers evidently find it hard to find suitable options and gain access to them. In addition there are limited options for people with more complex needs or who are more challenging to care for. We need to work with people with dementia and their carers to understand what they need and examine the full range of options within their own network and the wider community that would allow them to take a break, whether on their own or with the person they care for.

It is also important that health and care professionals listen to the carer and work with them to support the person with dementia. As well as giving the carer peace of mind, working in partnership with the carer can achieve better outcomes for the person with dementia and ensure services have a fuller picture of the person's needs. Yet carers report feeling disconnected from the process and frustrated that they are not listened to.

### Outcome

People caring for someone living with dementia feel informed and able to support their loved one, whilst able to maintain their own health and wellbeing

### Success Measures

- Carers are a driving force behind shaping the response to dementia in Greater Essex
- Carers of people living dementia are offered information and support relevant to their needs, throughout their experience with dementia
- Carers are encouraged to build on their own support networks to live well and keep physically and emotionally healthy
- Carers feel informed and equipped to care for someone living with dementia and able to plan, or flex to increased needs or challenges
- Carers are able to access a range of opportunities to take a break from their role as a Carer.

“ I have to stop myself from thinking about more than one day ahead because if you try, it overwhelms you. It destroys you.”

Carer

“ The diagnosis was a difficult experience. I walked in a daughter and walked out a carer.”

Carer

## Priority 6: Reducing the risk of crisis

### The issue

Dementia is not a generic condition. People with dementia can develop a wide range of symptoms that are particularly challenging for carers and put unprecedented demand on services. These can include aggression, agitation, delusions, wandering, night time waking, hoarding, loss of inhibition and shouting. Behavioural and Psychological Symptoms of Dementia (BPSD) can lead to crisis and care breakdown resulting in admission to acute services or residential care. Some people with dementia also have other conditions, such as learning disability or long term health problems, that can make their condition even more complex.

Other crises can occur as a result of the carer themselves becoming injured, ill or unable to continue caring, leaving the person with dementia unsupported. Carers can be at increased risk of becoming ill as a result of caring. Studies have shown that providing carers with breaks from caring, emotional support and access to training can significantly delay the need for the person receiving care to go into residential care. It may also prevent emergency hospital admission.

Finally, people with dementia can experience other physical or mental health problems which, if not identified and addressed, can lead to admission to acute hospital or mental health services. Nationally, 25% of hospital

beds are thought to be occupied by someone with dementia (Fix Dementia Care; Hospitals Report 2016 (Alzheimer's society), and in Greater Essex we know that people living with dementia stay in hospital 50% longer than those without. Care Managers say that it can take days or even weeks for mental health services to respond to a referral. Social workers told us that mental health teams are focused on preventing escalation to residential and acute services but that we need to identify and support people earlier and look at the role of community psychiatric support to keep people out of hospital.

### Outcome

All people with dementia receive support to reduce the risk and manage crisis

### Success Measures

- All hospitals to aspire to being dementia friendly care settings
- People living with dementia, with complex needs such as co-morbidities are offered specialist information and support
- Crisis situations are avoided or managed appropriately – Crisis situations are planned for and responded to effectively
- Emergency planning, including clinical emergency planning is addressed as part of all carer's assessments
- Primary Care are able to respond to episodes of crisis in care homes appropriately.

“

I was so exhausted by it all I almost gave in and said “do what you want” but I managed to make it in the end.”

Carer

“

She called us because she wanted someone to talk to. As her condition was progressing she felt scared. She had gone into her local town shopping as she always had but had got lost and was found walking round the roundabout.”

Carer

“

People don't contact us until they're in crisis. And when they do contact us, there are often two people in crisis, the individual with dementia and their carer. We wait for people to come to us and by then the dementia has progressed quite far, we have to be more proactive.”

Paid carer



## Priority 7: Living well in long term care

### The issue

In 2014 the Care Quality Commission found that whilst many hospitals and care homes deliver excellent care, the quality of care for people with dementia varied greatly. A key issue was that some hospitals and care homes did not comprehensively identify all of a person's care needs and there was variable or poor staff understanding and knowledge of dementia care.

The government wants to avoid people with dementia requiring long term care by improving the provision of local community services, education and training. The majority (85%) of people with dementia say that they would prefer to remain in their own home. In Greater Essex over 80% of people with dementia live in the community but the proportion of people with dementia supported in residential care is still higher in this county than in similar local authorities.

There are currently 252 care homes and 81 nursing homes for people with dementia across the county. There is a lack of data about the quality of residential care in the market and carers and families tell us that they struggle to find appropriate care for the person they care for.

The government wants all hospitals and care homes to meet agreed criteria to become dementia friendly by 2020.

### Outcome

All people with dementia live well when in long term care and able to access their community as appropriate

### Success Measures

- All care homes for people with dementia in Greater Essex to be dementia friendly by 2020
- People living with dementia, their families and carers understand what high quality care looks like and where to find it
- People with learning disabilities who have dementia, (or at risk of), are fully supported in long term care settings through linking Dementia in to LD health checks
- People with dementia in long term care are encouraged to build and maintain networks both in and out of the care setting
- People assessed as not having capacity, with no family or friends are referred to an Independent Mental Capacity Advocate as appropriate.

“

I can't trust that they're going to follow his care plan. I can't switch off.”

Carer

“

I had to place someone four times due to his dementia. His behaviour wasn't difficult – he just needed personalised support. His behaviour deteriorated due to the transfers but this should have been anticipated.”

Carer

“

Care homes need to be enabled to provide outings, passionate about taking people outside, but I accept care homes are not staffed to provide regular outings for people in their care. We need to find another way to ensure people have a life.”

Carer

### Priority 8: End of life

#### The issue

It is important to have early conversations with people with dementia about advance planning and end of life care so that people can plan ahead and ensure that their wishes are known and acted upon. The government has said that all people with a diagnosis of dementia should be given the opportunity for advance care planning early on to ensure the person and their carer are fully involved in decisions on care at end of life.

The aim should be to maximise the person's quality of life and support carers. All people with dementia and their carers should receive coordinated, compassionate and person-centred care towards the end of their life. This includes palliative care for the person with dementia and bereavement support for carers.

#### Outcome

People with dementia and their families plan ahead, receive good end of life care and are able to die in accordance with their wishes

#### Success Measures

- People living with dementia, their families and carers complete advanced care plans that are recorded and held by the GP
- People assessed as not having capacity, with no family or friends are referred to an Independent Mental Capacity Advocate as appropriate
- People are not delayed in being discharged from hospital
- People are informed of options about end of life and are given the appropriate support, respect and dignity to die in the place they choose
- Carers and families receive bereavement support at a time that is right for the individual or family.

“People’s wishes are not known. We need to get this information earlier.”

Social worker

“People don’t plan. We need to help people plan for the inevitable whilst they’ve still got the capability.”

Social worker

### Priority 9: A knowledgeable and skilled workforce

#### The issue

If health and care professionals and all other care workers understand the complexity of dementia; its impact upon the person and their family and know how to provide effective help and support, this will improve the quality of information, advice and care that people receive in all areas. Poor quality care has a major, negative impact on the quality of life of the person with dementia and causes stress and anxiety for their carer. It can also lead to higher care costs when health and social care professionals do not know how to support people to maintain their independence and quality of life in the community.

Across health and social care there is a lack of consistency or a clear pathway around dementia training. Training is provided at different levels and there is no clear picture of what the training is meant to deliver.

#### Outcome

All people with dementia receive support from knowledgeable and skilled professionals where needed

#### Success Measures

- There is a framework for dementia training across Greater Essex to ensure all people receive training relevant to their role
- To develop a workforce across the dementia care system that has the right skills, behaviours and values to support people living with dementia, and is equipped to do so
- To improve the quality of dementia care across the market, and support people to understand the benefit of positive risk taking to enabling a person to live well.

“People think you can’t communicate with people with dementia; there is a general lack of awareness.”

Support worker

“The biggest impact that could happen to assist those living with dementia is education. To educate people and eradicate the stigma.”

Care home manager

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## Key documents

Alzheimer's Society (2010). My name is not dementia

Alzheimer's Society (2013). Building dementia-friendly Greater Essex

Greater Essex Communities: a priority for everyone

Alzheimer's Society (2014). Dementia 2014: Opportunity for Change

Carers Trust & Royal College of Nursing (2013). The Triangle of Care: Carers Included: a Guide to Best Practice for Dementia Care

Department of Health (February 2015): Prime Minister's Challenge on dementia 2020

Greater Essex County Council (April 2015). Carers count in Greater Essex: Greater Essex Carers Strategy 2015-2020

Greater Essex County Council (June 2015). Dementia specialist topic needs assessment.

Greater Essex County Council (June 2015): Literature review of interventions to support the dementia needs assessment

ESRO and ThePublicOffice (2015). Living well with dementia in Greater Essex: ethnographic research findings

Joint Commissioning Panel for Mental Health (2013). Guidance for commissioners of dementia services

National Institute for Health and Care Excellence (2006, modified March 2015). Clinical Guideline 42: Dementia: supporting people with dementia and their carers in health and social care

National Institute for Health and Care Excellence (April 2013). Quality Standard 30: Supporting people to live well with dementia

The Princess Royal Trust for Carers and the Royal College of General Practitioners (2011). Supporting carers: an action guide for general practitioners and their teams

Public Health England and UK Health Forum (2014). Blackfriars Consensus on promoting brain health: reducing risks for dementia in the population.

Royal College of General Practitioners (2013). Commissioning for Carers

Southend on sea borough Council (Jan 2016) Themes From the Consultation Workshops

Southend on sea Borough Council (December 2016) Dementia JSNA (draft)

Technology Charter <https://www.alzheimers.org.uk/technologycharter>

# Glossary and appendix

## Glossary

<b>ASC</b>	Adult Social Care
<b>BAME</b>	Black and minority ethnic groups
<b>BPSB</b>	Behavioural and psychological symptoms of dementia
<b>DAA</b>	Dementia Action Alliance
<b>GP</b>	General Practitioner
<b>LD</b>	Learning Disability
<b>MCI</b>	Mild Cognitive Impairment
<b>Good Lives</b>	ECC approach to Social Care

## Appendix - Implementation Plan

The following activity will help us delivery our aspirations and vision set out in the strategy but will required addition investment to deliver. It is expected that an Outline Business Case (OBC) will be developed to request the level of investment needed to improve the lives of people living with dementia, the families and carers. Again, you can see from the table how the activity links in to the priorities and outcomes outlined in the strategy as well as how we propose we will measure whether or not we are successful. At this time the level of investment/cost is not given as a financial figure as this will be part of the OBC.

6699

