

Southend, Essex and Thurrock (SET) Dementia Strategy

2022–2026

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Foreword

This strategy brings together organisations from across Health and Social Care and the Voluntary Sector to speak with one voice on our aspirations for making Southend, Essex and Thurrock places where people can live well with dementia.

The impact on all those who live with dementia, including friends, family and carers, is clear to all. It is critical that we have a strategy that looks at every element, from the very tough nettle of prevention, through early diagnosis into care, support for carers and provision of accommodation.

This updated strategy for Southend, Essex and Thurrock builds on successes and lessons of the past and will be invaluable as we work together in collaboration.

Cllr John Spence, Cabinet Member for Adult Social Care & Health, Essex County Council

After a number of setbacks from the pandemic, it's fantastic to see that the Southend, Essex and Thurrock (SET) Dementia Strategy has been finalised and is ready to share with our residents.

This is a big step for our collective services across Essex as we commit to a joint strategic plan to not only gain a greater understanding of dementia, its causes and development, but also help to adopt a preventative approach that impacts those with the disease and their wider spheres of friends, family and those who care for them.

Following consultation with our residents in Thurrock and across Southend and Essex, we have been able to ensure our approach considers not only the provision of services, but the concerns of those in our communities who are currently facing or aware of the challenges of living with dementia. This is a crucial step to understanding all levels of the disease in our communities and ensuring this direct feedback remains at the heart of our forward-thinking approach for support in the future.

Thank you to everyone whose opinions and expertise fed into the creation of this dementia strategy. Rest assured your views, and the impact of this strategy, will lay the foundations for the best healthcare and support possible for generations to come.

Cllr Deborah Huelin, Thurrock Council Cabinet Member for Adults & Health

The number of people affected by dementia is rising and the government announced a 10-year plan in May 2022 that aims to reduce Dementia by 40%.

The development of this strategy has been delayed through COVID 19 but Southend, Essex and Thurrock (SET) have taken learning from our existing Dementia strategy and developed the new strategy drawing on best practice and consultation.

Current figures using the health census from 2019 show that Greater Essex likely has 21,972 over 65's with dementia and this is set to increase 33% by 2030. The government is projecting that over one million people in the UK could be living with dementia by 2025.

In 2020 Southend G.P. data showed that Southend had a higher prevalence of dementia than the average in England. This strategy has a commitment to research, training, local place-based action, and prevention. It supports our living well priority with 'living well longer' through early diagnosis, support, self-help, the nine priorities identified with stakeholders, and 10 strong commitments by SET. Together these underpin the dementia strategy implementation plan that supports the government's aim of a 40% reduction in dementia and improves quality of life for our residents who have dementia, their families, and carers.

Cllr Kay Mitchell, Southend-on-Sea City Council Cabinet Member for Adult Social Care and Health Integration

Strategy on a Page

Mission: To make sure that:

- Those who experience dementia, and their families and carers feel they are understood and can access the support they need when they need it
- That communities and local organisations are aware of the impact dementia has on those who experience it and their families and carers
- That support for people with dementia and their families and carers is underpinned by levels of training and expertise among professionals and volunteers

And to further promote and enhance the conditions which will contribute to a reduction in prevalence and promoting health improvement in the long-term, recognising health inequalities and the wider determinants of health to promote better health outcomes for people across SET.

Priorities	Commitments
1. Prevention: People in Southend, Essex and Thurrock will have good health and wellbeing, enabling them to live full and independent lives for longer	<ul style="list-style-type: none"> • We will work collaboratively within communities and across voluntary, health, care and statutory services to develop and deliver information to improve awareness of dementia, how to prevent dementia and the support available
2. Supporting unpaid carers: Unpaid carers are supported to enable people with dementia to remain as independent as possible	<ul style="list-style-type: none"> • We will involve and seek the views of people living with dementia and their unpaid carers, recognising their role as valued experts and equal partners to ensure carers have increased opportunity to access good quality support
3. Reducing the risk of crisis: All people with dementia receive support to reduce the risk and manage crisis	<ul style="list-style-type: none"> • We will work across our systems to develop an integrated approach within communities to improve timely support following diagnosis to promote independence, optimise strength, build resilience, and prevent unnecessary crises
4. A knowledgeable and skilled workforce: All people with dementia receive support from knowledgeable and skilled professionals where needed	<ul style="list-style-type: none"> • We will develop and build on activities and training that improve professional practice and process
5. Finding information and advice: Everyone with dementia will have access to the right information at the right time	<ul style="list-style-type: none"> • We will work collaboratively with system partners to engage people living with dementia, their families, unpaid carers and wider support networks to better understand how we can improve access to the right information, advice and guidance at the right time to ensure they are fully supported
6. Diagnosis and support: All people with dementia will receive appropriate and timely diagnosis and integrated support	<ul style="list-style-type: none"> • We will improve access to and opportunities for dementia diagnosis at the earliest possible stage for the people of Southend, Essex and Thurrock
7. Living well with dementia in the community: All people with dementia are supported by their Southend, Essex and Thurrock communities to remain independent for as long as possible	<ul style="list-style-type: none"> • We will work with people living with dementia, their families, unpaid carers and wider support networks to build more dementia-friendly and dementia-enabled communities and work to understand what timely support they need in relation to access to housing, transport, employment and technology • We will continue to promote access to care technology to promote health, prevent deterioration and promote independence
8. Living well in long-term care: All people with dementia live well when in long-term care	<ul style="list-style-type: none"> • We will work with the care markets to encourage long-term care settings to promote the knowledge, understanding and skills actively empowering activities and solutions that increase and retain their connections within their communities'
9. End of life: 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"> • We will work with families, communities and palliative specialists to improve information that enables families to plan ahead to make informed decisions that support individuals to remain cared for in their preferred care setting

Introduction

About dementia

Dementia is an umbrella term used to describe a collection of symptoms that affect the brain including memory loss, perception, problems with reasoning and communication skills. Dementia is defined as a progressive disease that affects more than one aspect of daily life and can lead to a reduction in a person's ability to conduct routine tasks such as washing, dressing and cooking.

There are over 200 types of dementia including Alzheimer's, Vascular and dementia with Lewy bodies. Dementia is not a natural part of ageing and does not just affect older people. It has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers¹ (particularly unpaid carers), families and communities.

Government guidance² estimates the number of people living with dementia globally to be 50 million, with this number expected to more than treble by 2050 to 152 million. The guidance highlights that around 850,000 people in the UK are living with dementia, 120,000 of which live alone. By 2025, over one million people could have dementia in the UK and by 2040, this figure will exceed 1.6 million.

Dementia is one of the major causes of disability and dependency among older people with no known cure. It is estimated that a person is formally diagnosed with dementia every three minutes in the UK, that one in three people born this year will develop dementia in their life, that dementia caused more deaths in England in year end March 2021 than Covid-19 and a quarter of all those who died of Covid-19 had dementia.



Image 1, Source – Public Health England³

Annex C: The Impact of Dementia; Data and Insights also offers comprehensive information on the impact of dementia on individuals, families, communities, care and support services.

¹ A 'carer' is someone who - without being paid - regularly looks after, helps or supports someone over the age of 18 who wouldn't be able to manage everyday life without their help.

² Government guidance, *Dementia: applying All Our Health* <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

³ Public Health England: *health matters: midlife approaches to reduce dementia risk* <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

Strategic Context

The national approach

In May 2022, Government announced a new 10-year plan⁴ to tackle dementia and boost the £375m funding already committed for research to better understand neurodegenerative diseases. The plan aims to reduce the 40% of dementia considered to be potentially preventable, including exploration of new technology, science and medicine to help reduce the numbers and severity of dementia.

It also aims to help reduce the NHS backlog as a result of Covid-19 to ensure more timely dementia diagnosis. This strategy will take note and incorporate key initiatives of the Government's dementia plan when published later in 2022.

The strategy takes account of the Public Health England Health matters: public health issues⁵ collection, with particular reference to the dementia section and Health matters: midlife approaches to reduce dementia risk⁶.

Government guidance Dementia: applying All Our Health⁷ encourages frontline health and care professionals to provide advice and support on dementia risk reduction as part of their daily practice and contact with individuals, framing this around NHS England's Well Pathway for Dementia⁸:

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL Risk of people developing dementia is minimised "I was given information about reducing my personal risk of getting dementia"	DIAGNOSING WELL Timely accurate diagnosis, care plan, and review within first year "I was diagnosed in a timely way" "I am able to make decisions and know what to do to help myself and who else can help"	SUPPORTING WELL Access to safe high quality health & social care for people with dementia and carers "I am treated with dignity & respect" "I get treatment and support, which are best for my dementia and my life"	LIVING WELL People with dementia can live normally in safe and accepting communities "I know that those around me and looking after me are supported" "I feel included as part of society"	DYING WELL People living with dementia die with dignity in the place of their choosing "I am confident my end of life wishes will be respected" "I can expect a good death"
STANDARDS: Prevention ⁽¹⁾ Risk Reduction ⁽⁵⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	STANDARDS: Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽³⁾ Investigation ⁽⁴⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	STANDARDS: Choice ⁽²⁾⁽³⁾⁽⁴⁾ BPSD ⁽⁶⁾⁽²⁾ Liaison ⁽²⁾ Advocates ⁽³⁾ Housing ⁽³⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽⁵⁾ Health & Social Services ⁽⁵⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	STANDARDS: Integrated Services ⁽¹⁾⁽⁵⁾⁽⁵⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽³⁾ Leisure ⁽³⁾ Safe Communities ⁽³⁾⁽⁵⁾	STANDARDS: Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽⁵⁾
References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.				
RESEARCHING WELL • Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change. • Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.				
INTEGRATING WELL • Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.				
COMMISSIONING WELL • Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice. • Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.				
TRAINING WELL • Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community. • Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.				
MONITORING WELL • Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each. • Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.				

Image 2 – NHS England's Well Pathway for Dementia

⁴ Gov press release, *Health secretary announces 10-year plan for dementia* [https://www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia#:~:text=Health%20and%20Social%20Care%20Secretary,to%20better%20understand%20neurodegenerative%20diseases.&text=A%20new%2010%2Dyear%20plan%20to%20tackle%20dementia%20will%20be,\(Tuesday%2017%20May%202022\)](https://www.gov.uk/government/news/health-secretary-announces-10-year-plan-for-dementia#:~:text=Health%20and%20Social%20Care%20Secretary,to%20better%20understand%20neurodegenerative%20diseases.&text=A%20new%2010%2Dyear%20plan%20to%20tackle%20dementia%20will%20be,(Tuesday%2017%20May%202022))

⁵ Gov collection, *Health matters: public health issues* <https://www.gov.uk/government/collections/health-matters-public-health-issues#dementia>

⁶ Gov collection, *Health matters: midlife approaches to reduce dementia risk* <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk>

⁷ Gov guidance, *Dementia: applying All Our Health* <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

⁸ NHS England, *the Well Pathway for Dementia* <https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf>

The Dementia Strategy will align with national approaches as highlighted above, including any forthcoming activities related to the [adult social care reform white paper](#)⁹, [Health and Care Act 2022](#)¹⁰ and the [integration and innovation: working together to improve health and social care for all white paper](#)¹¹.

All of which will enable better links between health and social care systems ensuring that the person is at the centre with local systems designed to deliver seamless care and support, enabling people to retain their independence, health and wellbeing. This includes utilising community assets, building on local delivery plans and placed-based action to ensure a person-centred approach.

A Southend, Essex and Thurrock (SET) approach

The previous SET Dementia Strategy lifecycle ended in 2021 and due to Covid-19 an update was delayed, although partnership activities continued during this period as did evidence gathering to understand the impact and outcomes of the strategy.

Review of the previous strategy highlighted challenges which include:

- The impact of an ageing SET population, with an increase in long-term conditions
- The need to improve timelier dementia diagnosis – through access to diagnostic/memory assessment services and encouraging people to pursue diagnosis, for example where delays or stigma may be present
- The complexities of system change i.e., when new operating models are introduced, or system goals change to address causes rather than symptoms
- The need to enhance alignment of priorities amongst multiple stakeholders
- The need for greater understanding and fulfilment of expectations across the system
- Tackling the stigma associated with dementia
- Cost implications for the wider economy
- Greater understanding of the cost of health and social care to support those living with dementia
- A population needs analysis based upon current and projected dementia diagnosis
- Increased need to share data and insights among multiple stakeholders to enhance diagnosis, support and understand the impact of dementia for organisations and partners
- The impact of Covid-19 such as a lack of face-to-face services, social isolation, loneliness, and increase in digitilisation of services.

By adopting a SET approach that builds on learning and best practice from the previous strategy and takes account of other key SET strategies, this will build on community assets and drive development of a high-quality dementia support offer for the residents of SET. In doing so, the Dementia Strategy will provide an overarching ambition and nine priority areas for delivery through local partnerships and place-based plans focusing on local delivery and place-based action.

⁹ Gov policy paper: *adult social care charging reform: further details* <https://www.gov.uk/government/publications/build-back-better-our-plan-for-health-and-social-care/adult-social-care-charging-reform-further-details>

¹⁰ Parliamentary bills: Health and Care Act 2022 <https://bills.parliament.uk/bills/3022>

¹¹ Gov policy paper: *integration and innovation: working together to improve health and social care for all* <https://www.gov.uk/government/publications/working-together-to-improve-health-and-social-care-for-all/integration-and-innovation-working-together-to-improve-health-and-social-care-for-all-html-version>

Essex County Council strategic approach

The Dementia Strategy will take account of and incorporate Everyone's Essex¹² four areas of focus, with emphasis on promoting the health, care and wellbeing of all Essex residents. The four areas of focus are:

1. The economy
2. The environment
3. Children and families
4. Promoting health, care and wellbeing for all parts of our population who need support

The Dementia Strategy will build on the Joint Health and Wellbeing Strategy¹³ 2022-2026 (JHWS) areas of focus (including any subsequent updates), which are:

1. Improving mental health and wellbeing
2. Physical activity and Healthy weight
3. Supporting long term independence
4. Alcohol and substance misuse
5. Health inequalities & the wider determinants of Health

The JHWS references the 2019 Joint Strategic Needs Assessment¹⁴ (JSNA) where it was identified that dementia diagnosis is not as good as it could be and that there is an ageing population with more people with long-term conditions.

The JSNA notes that over the last three years the estimated dementia diagnosis rate in people aged 65 and over in Essex is estimated to have risen from 60.5% in 2017 to 64.5% in 2019. Despite this positive increase in diagnosis, diagnosis rates remain lower than the England average of 68.7% with only 2 districts (Epping Forest 81.7% and Rochford 81.7%), having diagnosis rates over the England level (Maldon is the lowest at 57.6%).

POPPI (Projecting Older People's Population Information) projections using health and census data estimate that in 2019 there are likely to be 21,972 people across Essex over the age of 65 with dementia and that this figure could increase by 33% by 2030 to 29,437 people. Tendring currently has the highest number of estimated people with dementia (3,104) whilst Harlow has the lowest (1,018).

In addition to the above, the refreshed Dementia Strategy will work alongside other key strategies to include (but not limited to):

- Essex Joint Health and Wellbeing Strategy 2022-2026
- Thurrock Health and Wellbeing Strategy 2022-2026
- Southend on Sea Health and Wellbeing Strategy 2021-2024
- Essex All Age Carers Strategy 2022–2026
- Meaningful Lives Matter, including the Essex Learning Disabilities and Autism Transformation programme and Supported Living Provider Forum
- Essex JSNA and district profiles
- District/borough/city Local Plans

¹² Essex County Council: *Everyone's Essex: our plan for levelling up the county 2021-2025* <https://www.essex.gov.uk/everyones-essex-our-plan-for-essex-2021-2025>

¹³ Essex County Council: *Essex Joint Health and Wellbeing Strategy 2022-2026* [Essex Joint Health and Wellbeing Strategy 2022 - 2026 \(ctfassets.net\)](https://www.essex.gov.uk/essex-joint-health-and-wellbeing-strategy-2022-2026)

¹⁴ Essex County Council, *Essex JSNA and district profile reports 2019* <https://data.essex.gov.uk/dataset/exwyd/essex-jsna-and-district-profile-reports-2019>

Southend City Council Strategic Approach

The Southend Essex and Thurrock Dementia Strategy will work alongside other Key Southend City Council strategies such as (but not limited to):

'Ageing Well', 'Caring Well', and 'Living Well'.

The council's overall direction for adult social care, which is built on these three core strategies, setting out priorities over the next five years 2022-2027.

The three strategies were co-designed with people who use services and their friends and families. They focus on how the council will support people across the city, whether they are older people, those with a care and support need with learning disabilities, mental health challenges, autism, living with additional physical or sensory difficulty, or the friends and family of people with additional needs.

All three social care strategies are relevant to the work around dementia, and as such will be absorbed under these partnership groups.

Health and Wellbeing Strategy 2021- 2024

Helping people live a meaningful and quality life is really important. Through the new Health and Wellbeing Strategy for Southend, the vision will be as follows:

to support and enable the people of Southend to have the best possible physical and mental health, wellbeing, and quality of life

to promote good healthcare, to enhance health and wellbeing for all ages

Informing our strategies are Joint Strategic Needs Assessments (JSNA) which are used to describe the characteristics of a place and its residents, offering relevant information to inform commissioning and planning decisions. The 'Southend JSNA' isn't a single document, it is a collection of reports and tools describing different aspects of the factors which influence our residents' lives. Work is currently in progress to refresh the Southend JSNA and this will include further information relating to Dementia

Thurrock Council Strategic Approach

Thurrock's Health & Wellbeing Strategy 2022-26 sets a vision of Levelling the Playing Field and sets goals to address a range of inequalities across Thurrock. It comprises 6 Domains of action, and Domain 3 ("Person-Led Health and Care") includes development of a Dementia Strategy to support Dementia Friendly Communities.

Thurrock Integrated Care Alliance (TICA) has recently produced a Better Care Together Thurrock (BCTT) strategy for adult health and care. The strategy aims to transform adult health and social care in line with the Human, Learning, Systems (HLS) approach to system transformation. The HLS focus on cultural change and empowering the workforce to adopt a strengths-based approach, a learning culture and act as system stewards, offers opportunities to develop sustainable approaches to delivering holistic care. The strategy seeks to align current community NHS health provision with each PCN health and care locality network. This will include enabling integrated care and support plans and a blended roles approach. This approach will encompass specialist condition-specific teams such as the Older Adults Health and Wellbeing Team and Dementia Crisis Support

What are the problems we need to address?

Support for Unpaid Carers:

An estimated 540,000 people in England act as primary carers for people with dementia; half of these are employed, 112,540 have needed to leave employment to meet their caring roles and 66,000 carers have cut their working hours.

In Essex carers have highlighted a lack of respite, awareness of services and availability of information, and feelings of isolation as key issues.

Prevalence and modifiable risk:

Most recent figures from NHS Digital highlight that there are 24,578 people (over 65) in SET living with dementia. **If the prevalence remains constant, for SET as a whole, there will be an additional 10,554 people aged 65+ with dementia in 2030.**

Evidence shows that 40% of dementias are preventable through action across the life course. A 20% reduction in risk factors per decade could reduce the UK prevalence by 16.2% (300,000 cases) by 2050.

Loneliness and Isolation:

Public Health England suggests that **60% of people with dementia are more likely to be lonely.** Approximately 60% of people with dementia go out of their houses less than once a week and in sparsely-populated rural areas, it is harder for older people living alone to find the opportunity to mix with others.

Essex has **an increasing older population and nationally up to 14% of older people report feeling lonely all the time.** With **loneliness and depression increasing the risk of dementia by up to 50%** this is a pressing issue for SET.

Research:

Climate Change/Air pollution: Epidemiological evidence is suggestive of an association between exposure to ambient air pollutants and both the risk of developing dementia and acceleration of cognitive decline.

Research collaborative: Build on opportunities with local research partners develop, support and implement evidence based, best practice which underpins delivery of the SET Strategy.

Addressing inequalities:

Dementia is the **leading cause of death for women in the UK since 2011**, not only are they at greater risk of dementia, but they are also more likely to be impacted in other areas of their lives such as through caregiving to a family member with dementia, financial stability, mental wellbeing and career progression.

People with **learning disabilities are at greater risk of developing dementia**, are likely to develop the condition at an earlier age and can have a faster rate of progression.

A growing prevalence of young onset dementia, with **over 42,000 people in the UK estimated to be living with a diagnosis.** People with young onset dementia tend to have additional complexities, particularly regarding diagnosis and a lack of appropriate services.

Diagnosis Rates:

Dementia diagnosis rates in Essex remain below the national average (62%).

Engagement sessions and workshops with partners across the SET highlighted the need to coordinate timelier diagnosis. Support in the key weeks after diagnosis is also recognised as a critical window for early support and intervention that promotes a positive view of diagnosis, facilitating access to timely care and support thus enabling people to live well with dementia in their preferred place of residence.

It is estimated that **2 in 10 people over the age of 65 have mild cognitive impairment.** Although the mild form of this condition often has little effect on daily life, **5 to 10% of people with it will develop dementia.**

Awareness and Dementia Friendly Communities and Services

Dementia does not just impact the person – everyone around them, from family members to friends, is affected in some way. The impact on those living with dementia, including their family and carers, cannot be underestimated and demonstrates the need for a whole system approach to awareness, care and support including diagnosis. 1 in 3 people born in the UK will develop dementia in their lifetime, the importance of increased awareness and understanding of dementia throughout our communities again, cannot be underestimated given the anticipated rise in the number of people living with dementia.

Housing, Health and care providers through to education, transport and leisure services all have roles in the planning and development of neighbourhoods creating **environments, support and opportunities in which people become and remain socially connected and are enabled to live well with dementia.**

Our Mission, Priorities and Commitments

Our mission

Building on the previous strategy, consultation and engagement activity and national guidance and best practice, the refreshed Dementia Strategy sets out to make sure that:

- Those who experience dementia, and their families and carers feel they are understood and can access the support they need when they need it
- That communities and local organisations are aware of the impact dementia has on those who experience it and their families and carers
- That support for people with dementia and their families and carers is underpinned by levels of training and expertise among professionals and volunteers

And to further promote and enhance the conditions which will contribute to a reduction in prevalence and promoting health improvement in the long-term, recognising health inequalities and the wider determinants of health to promote better health outcomes for people across SET.

Our nine priorities

The mission will be achieved through delivery of our nine strategic priorities which, following stakeholder engagement, were agreed as:

1. **Prevention:** People in Southend, Essex and Thurrock will have good health and wellbeing, enabling them to live full and independent lives for longer
2. **Supporting unpaid carers:** Unpaid carers are supported to enable people with dementia to remain as independent as possible
3. **Reducing the risk of crisis:** All people with dementia receive support to reduce the risk and manage crisis
4. **A knowledgeable and skilled workforce:** All people with dementia receive support from knowledgeable and skilled professionals where needed
5. **Finding information and advice:** Everyone with dementia will have access to the right information at the right time
6. **Diagnosis and support:** All people with dementia will receive appropriate and timely diagnosis and integrated support
7. **Living well with dementia in the community:** All people with dementia are supported by their Southend, Essex and Thurrock communities to remain independent for as long as possible
8. **Living well in long-term care:** All people with dementia live well when in long-term care
9. **End of life:** People with dementia and their families plan ahead, receive good end of life care and are able to die in accordance with their wishes

Our commitments

Following stage two consultation activity and aligned to the nine priorities, the strategy sets out **10 commitments** informed by the people of Southend, Essex and Thurrock:

1. We will **work collaboratively within communities** and across voluntary, health, care and statutory services to develop and deliver information **to improve awareness of dementia, how to prevent dementia and the support available**
2. We will **involve and seek the views of people living with dementia and their unpaid carers**, recognising their role as valued experts and equal partners to **ensure carers have increased opportunity to access good quality support**
3. We will **work across our systems in to develop an integrated approach** within communities **to improve timely support following diagnosis** to promote independence, optimise strength, build resilience, and prevent unnecessary crises
4. We will **develop and build on activities and training that improve professional practice and process**
5. We will work collaboratively with system partners to **engage people living with dementia, their families, unpaid carers and wider support networks to better understand how we can improve access to the right information, advice and guidance at the right time** to ensure they are fully supported
6. We will **improve access to and opportunities for dementia diagnosis at the earliest possible stage** for the people of Southend, Essex and Thurrock
7. We will **work with people living with dementia, their families, unpaid carers and wider support networks to build more dementia-friendly and dementia-enabled communities** and work to **understand what timely support they need** in relation to **access to housing, transport, employment and technology**
8. We will continue **to promote access to care technology** to promote health, prevent deterioration and promote independence
9. We will **work with the care markets to encourage long-term care settings** to promote improving knowledge, understanding and skills actively empowering activities and solutions that **increase and retain their connections within their communities'**
10. We will **work with families, communities and palliative specialists** to improve information that **enables families to plan ahead to make informed decisions** that support individuals to remain cared for in their preferred care setting

Strategy Monitoring and Review

Review and monitoring of the strategy, unless otherwise stated, will take place annually across Southend, Essex and Thurrock. See **Annex A: Implementation Plan** The plan will sit as a separate document to be reviewed and refreshed throughout the life of the strategy enabling it to respond to changing needs and emerging issues in the future. For further details on delivery of actions and outcome measures against the agreed priorities and commitments.

However, it is recognised that local action plans to help deliver the Dementia Strategy will be developed by partners based on population need, local pathways and priorities, building on known community assets and initiatives identified at locality level. Monitoring and review of local action plans will also take place at local level, to be agreed at their discretion and underpinned by local processes and governance.

Governance and oversight

The Dementia Strategy will align to existing internal and external governance, oversight and partnership boards. It is acknowledged that Integrated Commissioning Boards (ICBs) will be implemented in July 2022. The introduction of ICBs, Local Alliances and subsequent governance structures may result in changes to existing governance, oversight and partnership arrangements.

Review of the previous strategy highlighted the need to further embed the strategic approach to dementia within existing plans. As a result, a framework (Image 8) has been developed based upon NHS England's Well Pathway for Dementia and Livewell themes to support health and wellbeing and outlines the building blocks for change which can be aligned to the emerging ICBs, Local Alliances and wider partnerships.

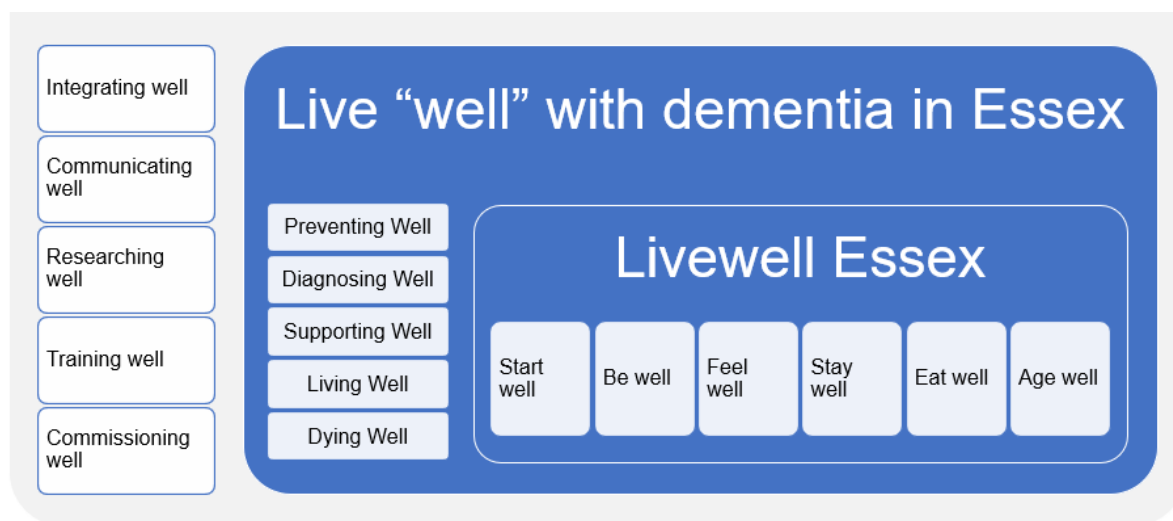


Image 8 – Living well with dementia in Essex framework

Wider initiatives

There is a range of important wider activity and initiatives being undertaken across public and private sector organisations with the aim to improve health and wellbeing outcomes for those living with dementia, their family and carers.

Southend City Council, Essex County Council & Thurrock Council and ICBs commission a range of Dementia Support Services providing personalized support and advice to anyone affected by dementia. These commissioned services are accessible by anyone across community, from local help and community activities to phone and online advice, working with people worried about their memory, people with dementia, carers and family members.

Southend, Essex and Thurrock partners are together working towards becoming dementia friendly communities with a network of Dementia Action Alliances who are working in local areas to drive dementia awareness and enable communities to be accessible and support people living with dementia. Dementia Action Alliances work with local groups, retailers and businesses to be more aware of issues people with dementia face and offer better services.

Consultation feedback tells us that levels of support are not consistent across Southend, Essex & Thurrock, therefore throughout the life of the strategy partners will continue to explore opportunities to develop integrated care and support systems for people affected by dementia building on the successes to date.

To share knowledge, best practice and monitor progress across a range of partners and key stakeholders, **Annex B: Wider Initiatives Linked to Dementia Strategy Priorities** offer further detail of the range of partner activities underway across SET. This will be reviewed and updated throughout the strategy lifecycle to complement activity undertaken alongside the Dementia Strategy.

Best practice exemplar – case study

In May 2022 as part of the Essex Year of Reading campaign, Essex Education Taskforce at Essex County Council partnered with Wayback, virtual reality technology specialists and winner of the 2018 Essex Dementia Challenge Prize. The partnership worked with the James Hornby School and residents at Woodbury Court Dementia Care Home to deliver a intergenerational reminiscence project to celebrate the Queen's Platinum Jubilee. The project went Wayback to the Queen's Coronation using memory films and books to trigger memories, connection and conversation across young and older generational groups including people living with dementia.

This project sought to inspire a love of books and conversational storytelling to help people share first-hand accounts of events whilst bringing different generations together. The day was a huge success and built upon Everyone's Essex initiatives to help citizens to better understand and have compassion for others, as well as reduce feelings of loneliness and isolation across all ages.



Image 7 – selection of photographs from the intergenerational reminiscence project

Benefits of the project for children and young people included increased self-confidence, self-efficacy and wellbeing, promoting of positive relationships and positive changes in perceptions and attitudes about older people. For older people, benefits included enhancement of emotional wellbeing, reading to reignite memories, wider cognitive stimulation and mitigating the impact of social isolation and loneliness to aid recovery.

As part of the ongoing commitment to supporting innovative approaches, we will continue to promote opportunities for knowledge exchange in pilot activity and research projects. In particular, activities that support collaboration through research with a focus on dementia and ageing well initiatives with aims that seek to share knowledge and promote evidence-led approaches within place-based activities.

Annex B: Wider Initiatives Linked to Dementia Strategy Priorities also offers comprehensive information on a range of advice, guidance and initiatives focused on overall health and wellbeing or support for those with dementia, their carers, and families.

Annexes

Annex A: Dementia Strategy Implementation Plan

Whilst the implementation plan aligns to the lifecycle of the strategy, it is acknowledged that Integrated Commissioning Boards (ICBs) will be implemented from July 2022. As such, the introduction of ICBs, Local Delivery Plans and subsequent governance structures may result in amendments to the implementation plan.

Action/s	Outcome Measure	Owner/Contributor	Timescale
Priority 1 – Prevention: People in Southend, Essex and Thurrock will have good health and wellbeing, enabling them to live full and independent lives for longer			
Commitment 1 – We will work collaboratively within communities and across voluntary, health, care and statutory services to develop and deliver information to improve awareness of dementia, how to prevent dementia and the support available			
Development and delivery of a dementia awareness activities. Work with Public health colleagues to develop consistent messaging around how to prevent dementia	<ul style="list-style-type: none"> • People will have a greater understanding of the effectiveness and impact of healthy lifestyle on modifiable risk factors to reduce the risk of developing dementia, including stop smoking, be more active, reduce alcohol consumption, improved diet, lose weight if necessary and maintain a healthy weight • We will work with partners in Public Health to understand the effectiveness and impact of healthy lifestyle campaigns on raising awareness of modifiable risk factors 	<ul style="list-style-type: none"> • Active Essex – Find Your Active Programme • Strengthening communities – Essex Wellbeing Service • LA commissioned dementia support services 	<ul style="list-style-type: none"> • Sep 2023 and annual reviews
Essex Dementia Intergenerational programme (EDIP) activities to increase children and young people's knowledge and understanding of dementia to support improved awareness of dementia in younger age-groups	<ul style="list-style-type: none"> • Children and young people will have an increased knowledge and understanding of actions they can undertake in support of healthy lifestyles • Children and young people will have an increased knowledge and understanding of dementia to support improved awareness • Children and young people will undertake action in support of a dementia friendly generation to actively promote and support dementia enabled communities • To increase the reach and volume of Essex schools engaged in dementia intergenerational activity from the 2021 baseline by a further 50% in 2022/23 • Links to 'starting well' and 'risk reduction' 	<ul style="list-style-type: none"> • ECC key service areas – Adult Social Care, Public Health, education and CCG/ICS • Voluntary and community sector (VCS) partners • LA commissioned dementia support services 	<ul style="list-style-type: none"> • Ongoing monitoring • Annual EDIP oversight report

Develop and align to Healthy Living activities and opportunities	<ul style="list-style-type: none"> • People living with dementia and their unpaid carers can access activities and maintain their independence, and physical, emotional and mental health 	<ul style="list-style-type: none"> • Joint Health and Wellbeing Strategy • Find your active PEM and Essex Wellbeing Service • Social Prescribing outcome/performance measures 	Timescales to be aligned to respective strategies action plans and service areas.
Develop and monitor routine inclusion of best practice advice on Dementia during NHS Health checks delivered to those age 65 and above.	<ul style="list-style-type: none"> • People receiving and delivering NHS Health Checks will have increased awareness of the link between cardiovascular disease and Dementia and information around prevention of cardiovascular disease through risk behaviour modification information and advice. 	<ul style="list-style-type: none"> • NHS Health checks Providers 	Ongoing
Continue to develop and expand the hypertension case finding and quality improvement project with PCNs in Thurrock to increase the proportion of people with undiagnosed hypertension that are well managed and whose BP is controlled safely to prevent development of vascular dementia.	<ul style="list-style-type: none"> • Decrease the proportion of people that have undiagnosed and therefore unmanaged hypertension • Increase the proportion of people that have BP within a safe range to prevent the development of conditions that impact on their health and wellbeing including vascular dementia. 	<ul style="list-style-type: none"> • Thurrock Council Healthcare Public Health Team • Thurrock PCNs • Community Pharmacists 	<p>Timescale to be aligned to respective Public Health plans in localities.</p> <ul style="list-style-type: none"> • Public Health Service Plan & Better Care Together Thurrock; A case for further change strategy delivery timeline.

Priority 2 – Supporting unpaid carers: Carers are supported to enable people living with dementia to remain as independent as possible

Commitment 2 – We will involve and seek the views of people living with dementia and their unpaid carers, recognising their role as valued experts and equal partners to ensure carers have increased opportunity to access good quality support

Improve pathways to formal assessment where needed	<ul style="list-style-type: none"> • Offer a carer's assessment and contingency plan to every unpaid carer of someone with dementia to identify so that they get the benefit of the support they are entitled to 	<ul style="list-style-type: none"> • All Age Carers Strategy • Adult Social Care data • Commissioned Carer and Dementia Support Services monitoring • Unpaid carers voice and dementia voices • Carers Survey 	Timescales to align with commissioned services reporting and other strategies action plans
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<p>Support and training for unpaid carers of people with dementia</p>	<ul style="list-style-type: none"> • Unpaid carers are supported to be able to continue working and to access health and support services to maintain their own health and wellbeing • Work with system partners including health, education, voluntary and community sector organisations to build on and develop support in local communities • Number of unpaid carers supported to understand impact of dementia 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services including Primary Care Essex Wellbeing Service • LA commissioned carer and dementia support services • Health outcomes and service data 	<p>Timescales to align with commissioned services reporting</p>
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Priority 3 – Reducing the risk of crisis: All people with dementia receive support to reduce the risk and manage crisis

Commitment 3 – We will work across our systems in to develop an integrated approach within communities to improve timely support following diagnosis to promote independence, optimise strength, build resilience and prevent unnecessary crises

<p>Develop health and care services that work for people living with dementia to reduce the risk of crisis, reduce avoidable admissions and delayed discharge</p>	<ul style="list-style-type: none"> • Flexible alternatives to hospital admission and to support early discharge wherever possible, including access to urgent community response/virtual wards and intermediate care • Reduction in number of emergency admissions and delayed discharges 	<ul style="list-style-type: none"> • Local Alliances, ICB delivery of urgent care response teams and discharge to assess models • NHS England dementia diagnosis rates 	<p>Timescales align to local system surveillance and reporting arrangements</p>
<p>Build services, support and communities in Essex that will enable people living with dementia and their carers to have improved confidence in navigating the health and social care system to ensure their needs are met</p>	<ul style="list-style-type: none"> • People living with dementia and their carers are provided with good post diagnostic support and information about the options available to them as their dementia progresses • Increase number of primary care navigators that have achieved Dementia Friendly accreditation • Number of people supported to make contingency and advance care plans • Number of advance care plans completed 	<ul style="list-style-type: none"> • NHS England dementia diagnosis rates • CCG, Alliance and ICB commissioned • NHS England dementia diagnosis rate • Primary care data 	<p>Timescales align to local system surveillance and reporting arrangements incl. NHS digital Dementia Diagnosis Rates</p>

Priority 4 – **A knowledgeable & skilled workforce:** All people with dementia receive support from knowledgeable and skilled professionals where needed

Commitment 4 – We will develop and build on activities and training that improve professional practice and process

<p>Map the current training and development offer for those working to provide advice and support to people living with dementia</p>	<ul style="list-style-type: none"> • Training and education activities are aligned to the HEE dementia training standards framework • People living with dementia can lead fulfilling lives and live independently for longer • People living with dementia are enabled, with their carers, to access assessments, care and support services that help maintain their physical and mental health and wellbeing • People living with dementia receive care and support from an appropriately trained workforce 	<ul style="list-style-type: none"> • Employers • Health and social care commissioners • Health Education England (HEE) 	<p>Review and refresh of mapping to commence Jan' 2023</p>
<p>Develop and build on activities that improve professional practice and processes</p>	<ul style="list-style-type: none"> • Numbers of care and support workforce who participate in standards of training and professional development as appropriate to the levels and requirements of their role • Prosper programme measures • Training and education programmes are aligned/accredited to HEE dementia training standards framework 	<ul style="list-style-type: none"> • Market shaping programme • HEE/workforce development programmes • ESCA programmes 	<p>Review and refresh of mapping to commence Jan' 2023</p>
<p>Engagement work with workforce/care market to understand levels of confidence when working with people with dementia</p>	<ul style="list-style-type: none"> • The workforce feels confident and empowered in their competences • Engagement and surveys • Prosper programme measures • Annual workforce and staff surveys 	<ul style="list-style-type: none"> • Health and social care employers 	<p>Annual workforce & staff surveys. Prosper programme outcomes/data.</p>

Priority 5 – **Finding information and advice:** Everyone with dementia will have access to the right information at the right time

Commitment 5 – We will work collaboratively with system partners to engage people living with dementia, their families, unpaid carers and wider support networks to better

<p>Work with residents to understand what good quality information and advice, for both pre and post diagnosis of dementia is and how it is accessed</p>	<ul style="list-style-type: none"> • People are able to say they can access appropriate information, advice and guidance in a timely fashion that supports them to achieve their desired outcomes • Co-production work with people living with dementia to inform what ‘good’ information is. 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services, including primary care 	<p>NHS patient experience Surveys. Carer annual survey. Dementia strategy Annual and report. commissioned services reporting (quarterly)</p>
<p>Work to maximise access to information, advice and guidance so that people have clear access to the right support, at the right time in the right place</p>	<ul style="list-style-type: none"> • People are able to say they have confidence and feel empowered to access care and support through a variety of mechanisms, including but not limited to digital and technological interventions • Engagement and surveys • Virtual/social media engagement levels • Numbers of people of accessing digital technologies through commissioned technology services 	<ul style="list-style-type: none"> • Technologies programme and commissioned technology services 	<p>NHS patient experience Surveys. Carer annual survey. Dementia strategy Annual and report. commissioned services reporting (quarterly)</p>
<p>Publicise information, advice and guidance in effective ways and in clear and accessible language</p>	<ul style="list-style-type: none"> • People can access information, advice and guidance through a range of mediums including social media and in community spaces (i.e. libraries, GPs and local councils) • “Making every contact count” survey • Virtual/social media engagement levels • Organisations/communities achieving Dementia Friendly Communities accreditation 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services, including primary care 	<p>NHS patient experience Surveys. Carer annual survey. Dementia strategy Annual and report. commissioned services reporting (quarterly)</p>

Priority 6 – Diagnosis and support: All people with dementia will receive appropriate and timely diagnosis and integrated support

Commitment 6 – We will improve access to and opportunities for dementia diagnosis at the earliest possible stage for the people of Southend, Essex and Thurrock

Design, promote and support activities that enable people to understand how to seek a diagnosis	<ul style="list-style-type: none"> • Number of people able to find the right information, at the right time to gain a timely diagnosis enabling them to plan to live well with dementia • Surveys and engagement • Community Dementia Support Service/primary care data 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services, including primary care 	NHS patient experience Surveys. Carer annual survey. Dementia strategy Annual and report. commissioned services reporting (quarterly)
Good quality support and information available from pre diagnosis and throughout the diagnosis journey and people know where to access this	<ul style="list-style-type: none"> • Development of engagement programme/residents' panel • Annual surveys and engagement • Community Dementia Support Service data • Primary care data • NHS England dementia diagnosis rates 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services, including primary care 	Timescales to align with commissioned services reporting and other strategies action plans
Clear dementia diagnosis pathways to enable people to receive timely diagnosis	<ul style="list-style-type: none"> • People are supported to understand their conditions and plan accordingly • Improve dementia diagnosis rate to NHS national aspiration of 66.7% 	<ul style="list-style-type: none"> • NHS England recorded data 	<ul style="list-style-type: none"> • Monthly NHS digital Surveillance and diagnosis data

Priority 7 – Living well with dementia in the community: All people with dementia are supported by their Southend, Essex and Thurrock communities to remain independent for as long as possible

Commitment 7 – We will work with people living with dementia, their families, unpaid carers and wider support networks to build more dementia-friendly and dementia-enabled communities and work to understand what timely support they need in relation to access to housing, transport, employment and technology

Development and delivery of a co-produced dementia awareness programme to improve awareness, challenge stigma, enable, inspire and facilitate dementia inclusive communities	<ul style="list-style-type: none"> • People living with dementia and their carers are enabled to live independently, to take part in activities (including commissioned day opportunities and domiciliary care) based on individual interest and choice, feel valued and included, reducing loneliness and contributing to their community • People with young onset dementia, from ethnic minority and LGBTQ+ communities receive support appropriate to their specific needs 	<ul style="list-style-type: none"> • LA dementia programmes working with/across relevant LA and health partners and commissioned services, including primary care • Local district/borough/city councils 	Developing programme of activity over the course of the strategy, progress to be measured annually incl. <ul style="list-style-type: none"> • Quarterly through commissioned services reporting/monitoring
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	<ul style="list-style-type: none"> • Increase in the number of Dementia Friendly and enabled community places and spaces <ul style="list-style-type: none"> ○ Number of organisations and communities achieving Dementia Friendly Communities accreditation ○ Number of Local, District & Borough Councils achieving Dementia Friendly Communities Accreditation • Number of District/Borough “Local Plans” adopting Dementia friendly principles and shared with District Dementia Action Alliances • People living with dementia, communities and carers are equipped with a better understanding of dementia and how to manage it and consequences of progression and support carers in their caring role. 		<ul style="list-style-type: none"> • Annual review • Action plan activities within other strategies - Timescales to align • NHS Patient Experience & Primary Care Surveys.
Commitment 8 – We will continue to promote access to care technology to promote health, prevent deterioration and promote independence			
Ensure access to Improving Access to Psychological Therapies (IAPT) programme and psychological interventions for people living with dementia	<ul style="list-style-type: none"> • People living with dementia, or a non-dementia diagnosis mild cognitive impairment (MCI), depression, anxiety) and their carers are aware of the possibility of psychological support from IAPT services, and are routinely considered for and offered support • Number of people living with dementia accessing IAPT and psychological support 	<ul style="list-style-type: none"> • Health and social care commissioners • IAPT and Essex Wellbeing Service 	<ul style="list-style-type: none"> • Frequency aligned to services monitoring/ reporting
Priority 8 – Living well in long-term care: all people with dementia live well when in long-term care			
Commitment 9 – We will work with the care markets to encourage long-term care settings to promote the knowledge, understanding and skills actively empowering activities and solutions that increase and retain their connections within their communities'			
Long-term care settings are Dementia Friendly, supporting residents with dementia to live well and being engaged with their local communities	<ul style="list-style-type: none"> • Increase social connectedness including enabling access to digital technology, links to local communities and the dementia intergenerational programme • The number of people in care homes with access to social contact through digital technology 	<ul style="list-style-type: none"> • Essex Dementia Intergenerational programme • Market shaping/procurement • LA commissioned Dementia Friendly 	<ul style="list-style-type: none"> • Timescales to align with commissioned services reporting and other strategies action plans incl. • EDIP Tracker (Quarterly)

	<ul style="list-style-type: none"> • Participation in the prosper and intergenerational programmes • Number of care home achieving Dementia Friendly Communities accreditation 	Communities programmes	<ul style="list-style-type: none"> • Frequency aligned to services monitoring/reporting
Work with the care markets to understand capacity and demand for long-term care for people living with dementia	<ul style="list-style-type: none"> • Market shaping strategy reflects the demand and capacity required to support people living with dementia • Care markets and commissioners have a shared understanding of “complex” needs for people living with dementia • Individual care and support plans are based on a shared understanding across the domains of complexity 	<ul style="list-style-type: none"> • LA procurement/ commissioning teams • Market shaping programme 	ECC Bed tracker Align to market shaping strategy action plans (timescales to be confirmed)
Work with the care markets to understand the scale of ‘complex’ needs for people living with dementia and whether separate commissioning is required	<ul style="list-style-type: none"> • LA market shaping strategy deliverables • Number of people supported to access appropriate care • Reduction in the number of “hand-backs” • Care markets and commissioner's agree domains of complexity and impact on commissioned services 	<ul style="list-style-type: none"> • LA procurement/ commissioning teams • Market shaping programme 	Align to market shaping strategy action plans (timescales to be confirmed)
Priority 9 – End of life: People with dementia and their families plan ahead, receive good end of life care and are able to die in accordance with their wishes			
Commitment 10 – We will work with families, communities and palliative specialists to improve information that enables families to plan ahead to make informed decisions that support individuals to remain cared for in their preferred care setting			
Work with health partners to enhance choice, aid delivery of person-centred end of life care, help to guide care when mental capacity is lost and provide support for families and carers	<ul style="list-style-type: none"> • People are given opportunities and supported to have early conversations about advanced care and treatment options, including but not limited to faith and culture, to allow for informed decision-making, and providing a person-centred approach to allow for individuals to remain cared for in their preferred care setting • Number of organisations working towards/achieving gold standard frameworks • Increase the number of people with advance care plans (ACPs) 	<ul style="list-style-type: none"> • LAs incl, Adult Social Care • CCGs/ICS • District/Borough & Local Councils • Voluntary and community sector (VCS) partners • LA/CCG/ICS Commissioned services 	Annual report incl. NHS Patient Experience Survey Healthwatch surveys Commissioned services monitoring and performance reporting (as per contracted performance requirements)

Annex B: Wider Initiatives Linked to Dementia Strategy Priorities

Priority Area	Initiative	Organisation/s involved
Prevention	Dementia Friendly Schools / Essex Healthy Schools Programme – aimed at primary and secondary school children to learn more about dementia and take part in dementia related activities	Essex Child and Family Wellbeing Service and Essex Child and Family Wellbeing Service
	Local Cycling and Walking Infrastructure Plans (LCWIPs) – with overall aims to improve health and wellbeing of all Essex residents	Essex county/district/city councils
	Find Your Active – taking regular physical exercise is one of the best things to reduce the risk of getting dementia	Active Essex, Sport England, Essex County Council and Thurrock council.
	Community Dementia Support Service – Dementia Friendly Communities Programme & Dementia Action Alliance Network leading dementia awareness and enabling a better understanding of Dementia, prevention and enabling people to live well with dementia in their communities.	Essex County Council commissioned and delivered through The Alzheimer's Society Southend City Council delivers through the Dementia Community Support Team
	Essex Wellbeing Service – help and support to make lifestyle changes, find support and access community groups and activities	Essex County Council and collaboration of local organisations and services
	The Prevention and Enablement Model (PEM) – 12-month 'test and learn' pilot, to see how the health and social care system in Essex can use physical activity to enable independence, improve population health and develop communities that are inclusive	Active Essex, Sport England and Essex County Council
	Thurrock Health Lifestyle Service – help and support to make lifestyle changes and to access community groups supporting weight management and Exercise on Referral (for eligible groups (BMI 27.5-39.9 or some Long-Term Conditions))	Thurrock Council
	Thurrock Cycling Opportunities – cycle routes and hire schemes that aim to provide physical activity opportunities to residents	Thurrock Council and local scheme providers
	Hypertension Case Finding - Taking a Population Health Management approach to preventing cardiovascular disease through detecting and managing hypertension.	Thurrock Council, Thurrock PCNs, Community Pharmacy
Supporting unpaid carers	Superfast Essex – ECCs subsidised broadband programme to improve connectivity throughout the county	Essex County Council
	Dementia Interpreters – offers an understanding dementia specific communication and understanding how to translate the 'language of dementia'.	West Essex CCG and North East Essex CCG
	Carers First – offers online help and advice as well as practical and emotional support, local support groups and wellbeing activities	Essex County Council and Carers First
	Community Dementia Support Service, Dementia Connects – online, telephone and 1:1 practical and emotional help and advice, information hubs, peer support groups, and community/online activities, providing local support to carers of people affected by dementia	Essex County Council commissioned, delivered through The Alzheimer's Society

	Other Halves – project covering mid-Essex with local people organising activities and supporting one another	Other Halves
	Time for you – fund to enable carers to have time away from direct caring responsibilities	Colchester and Tendring CVSS
	Dementia Support Workers – Essex Community Dementia Support Service, Telephone and 1:1 practical/emotional help and advice, peer support groups, providing local support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Essex.	Essex County Council commissioned Community Dementia Support Service delivered through the Alzheimer’s Society
	Dementia Support Workers – South East Community Dementia Support Team, Telephone and 1:1 practical/emotional help and advice, providing support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Southend, castle Point and Rochford	Castle Point & Rochford BCF Board and Southend City Council commissioned service delivered by Southend City Council
	Information Hubs/Dementia Cafes/Library hubs – several available across Southend, Essex and Thurrock enabling people live well in their homes and continue to actively engage in their local communities.	Local Groups, Dementia Action Alliances, Essex County Council (ECC), Essex Library service and The Alzheimer’s Society through the ECC commissioned Community Dementia Support service.
	Robotic Companion Pets – offer an alternative to traditional pet therapy to support management of distressed behaviours providing comfort, stimulation, and interaction for people in their own homes	North East Essex CCG and Age Well East. Mid & South Integrated Care Partnership, Essex County Council – Prosper programme
	Guardian Angel initiative – to help people with dementia stay safe while maintain their independence through use of wristbands, badges, hand tags and keyrings with the individuals first name and emergency contact information	Dementia Buddy, backed by Essex County Council, Thurrock Council, Southend City Council and wider systems
A knowledgeable and skilled workforce	Sector Development Strategy – identifying 5 county-wide economic growth sectors to provide 13,000 jobs	Essex County Council and key system partners
	North East Essex CCG Health and Care Academy Programme – aimed at 14–18-year-olds	North East Essex CCG
	Pathways to Diagnostics Trailblazer – offering jobseekers support to gaining a career with the NHS	East Suffolk and North Essex NHS Foundation Trust (ESNEFT) and the Colchester Institute
	The Advanced Dementia Mobility Experience Essex (TADMEE) Experiential training suite adult social care, advanced HEE L3	Essex Social Care Academy (ESCA) and Essex County Council
	Essex Community Dementia Support Service – bespoke Dementia awareness sessions targeted to the workforce, sharing information and situational experiences which relate to the roles of the teams. Information sharing in relation to care and support available and opportunities within communities throughout Essex incl. Dementia Support Workers, Telephone and 1:1 practical/emotional help and advice, peer support	Essex County Council commissioned Community Dementia Support service delivered through the Alzheimer’s Society. Southend City council provide through the Dementia Community Support Team

	groups and local support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Essex.	
	Dementia Integrated Clinical Lead - closer integrated working practices between the MAS and Primary Care North East Essex to facilitate increased Dementia Diagnosis Rates	North East Essex CCG. Pilots underway across Mid & South Essex Integrated Care Partnership (ICP)
	Local Council elected Member Training Programme – Development of learning points and curriculum for elected members to enable members to undertake statutory duties with an understanding of the implications/potential impact for people living with dementia in their communities.	Essex County Council, Dementia Friendly Community Coordinator and the Essex Association of Local Councils, delivered by the Integrated Dementia Commissioners and the Essex County Council Commissioned Community Dementia Support Service
	EQUIP Audit – understanding the challenges in primary care and supporting practices to facilitate timelier diagnosis and knowledge to ensure the practice population living with dementia have access to appropriate care and support	North East Essex CCG, Mid & South Essex CCGs
Finding information and advice	Dementia Connect Essex – Community dementia support service for anyone affected by dementia. Providing online, telephone and 1:1 practical and emotional help and advice, information hubs, peer support groups, and community/online activities, providing local support to anyone affected by dementia working, Living or with family in Essex	Essex County Council Commissioned Community Dementia Support Service delivered by the Alzheimer’s Society
	Dementia Support Workers – South East Community Dementia Support Team, Telephone and 1:1 practical/emotional help and advice, providing support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Southend, castle Point and Rochford	Castle Point & Rochford BCF Board and Southend City council commissioned service delivered by Southend City Council
	Essex Community Dementia Support Service - Dementia Support Workers, Telephone and 1:1 practical/emotional help and advice, peer support groups, providing local support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Essex.	Essex County Council Commissioned Community Dementia Support service delivered through the Alzheimer’s Society
	Dementia Adventure – training and information for families and friends providing practical hints, tips and connections	Essex County Council
	Dementia Directory – to find a range of support available in local areas	Alzheimer’s Society
	Essex Map – local activities, group and opportunities for people to be active and engaged in their local communities	Essex County Council
	Mid Essex Community Specialist Nurses – including their role in facilitating diagnosis within the community/people’s homes	Mid Essex CCG, Dengie Neighbourhood team
Diagnosis and support	Dementia Intensive Support Models – various models of intensive support	Essex Partnership University Trust (EPUT), North East London Foundation Trust (NELFT)

	Dementia Diagnostic Review – to understand priority areas for improving dementia diagnosis rates and pathways in North East Essex	North East Essex CCG
	Memory Service National Accreditation Programme (MSNAP) – to improve assessment, diagnostic and care for people with dementia and their carers	EPUT
Living well with dementia in the community	Essex Year of Reading – part of a countywide campaign to improve educational attainment of children and young people and enabling older generations to remain connected to communities through the Essex Dementia Intergenerational programme	Essex Education Taskforce at Essex County Council and respective district/borough/city councils
	Dementia Friendly GPs – providing information and signposting needed to access support, holding responsibility for care plans and reviews for ongoing management	Essex County Council, CCGs, Southend City Council, Thurrock Council and North, Mid and South Essex
	Essex Community Dementia Support Service - Dementia Support Workers, Telephone and 1:1 practical/emotional help and advice, peer support groups, providing local support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Essex.	Essex County Council commissioned Community Dementia Support service delivered through the Alzheimer's Society
	Dementia Friendly Communities – to enhance understanding, respect and support for those affected by dementia (with best practice examples to learn from as demonstrated by Ingatestone and Fryerning Parish Council Dementia Action Plan). Communities are supported through a range of activities, information and awareness sessions through the Dementia Friendly communities' programmes commissioned by Essex County Council (community Dementia Support service), Thurrock council, Southend Council and the CPR BCF Board..	Programme delivered through a range of programmes commissioned by Essex County council, BCF Board in Castle Point & Rochford (CPR, Southend City and Thurrock councils. delivered locally by the Alzheimer's Society and Southend City Council.
	The WayBack VR – a virtual reality film series designed for those living with dementia and their carers used to trigger intact memories and stimulate conversations	Essex County Council - Challenge Prize, piloting/evaluation in day care settings and the intergenerational programme linking care homes and schools across Essex
	Memory Café – Essex County Council marked Dementia Action Week 2022 with the opening of the first Memory Café in Harwich Library to support people living with dementia, their family, friends and carers	Essex County Council and Harwich Library
	Admiral Nurses – registered nurses who specialise in dementia, helping family carers gain the necessary skills to assist with dementia care, promoting positive approaches in living well with dementia and improving quality of life	North East Essex CCG and EPUT
Living well in long-term care	Robotic pets in care homes – providing care home residents with comfort, interaction, and stimulation in the absence of visitors	Mid and South Essex Care Partnership
	Enhanced Care Home Liaison Nurses (EHLN) – to improve quality and access to primary care for residents in residential and nursing homes through a proactive and preventative approach to improved health outcomes	North East Essex and EPUT
	Interactive Tables & The light Project - to create a dementia friendly Care System with continuity of care at its heart, offering secure, safe and therapeutic environments	Mid and South Essex Care Partnership

	where patients with Dementia, LD, ABI and other such complex conditions are cared for with more than their physical needs being met.	
	Prosper Programme – improve safety and reduce harm for vulnerable care home residents, who are at particular risk of admission to hospital or significant deterioration in their health and quality of life	Essex County Council
End of life	Palliative Care Gold Standard Framework - evidence-based end of life care service improvement programme, identifying the right people, promoting the right care, in the right place, at the right time, every time. The training is for generalist front-line care providers.	St Helena Hospice
	My Care Choices/Single Point – a care coordination hub for out of hospital end of life care for people in the last year of life to increase support to maintain patients in their usual place of residence	St Helena Hospice, North East Essex.
	Namaste training – alternative therapies for people living with dementia in hospice and hospital settings	Princes Alexandra Hospital and various hospices across Essex
	My Care Choices – end of life planning tool to ensure individual choices and wishes are supported	CCGs across Southend, Essex and Thurrock
	Essex Community Dementia Support Service - Dementia Support Workers, Telephone and 1:1 practical/emotional help and advice, peer support groups, providing local support to carers of people affected by dementia and people affected by Dementia, living, working and with family throughout Essex.	Essex County Council commissioned Community Dementia Support service delivered through the Alzheimer’s Society
	Specialist dementia care and support – for those living with dementia and their families at end of life	Farleigh Hospice
Health and wellbeing	Neighbourhoods model – an integrated model of care to deliver outcomes and tackle inequality using neighbourhood teams, currently being rolled out in Colchester and South Tendring	North East Essex Health and Wellbeing Alliance
	Pedal Power – in partnership with Active Essex (with Clacton and Jaywick as Essex pilots) which allow residents to apply for a free bike	Active Essex and Pedal Power
	Dancing with Dementia – creative dance classes that focus on stimulation of the brain through movement, repetition, props and musical timelines	Dance Network Association and Active Essex

Annex C: The Impact of Dementia; Data and Insights

The impact of dementia

It is estimated that the dementia diagnosis rate in England for people aged 65 and over in 2021 was 61.6% or 415,778 people¹⁵. Only 34% of adults believe it's possible to reduce their risk of dementia, with smoking given as one of the greatest risk factors due to its narrowing of the blood vessels in the heart and brain, and oxidative stress, which damages the brain¹⁶.

The impact of Dementia on the population is... 1 in 3 people born in the UK will develop dementia

Whilst dementia is commonly associated with older people, there are more than 40,000 people under the age of 65 in the UK affected by dementia.

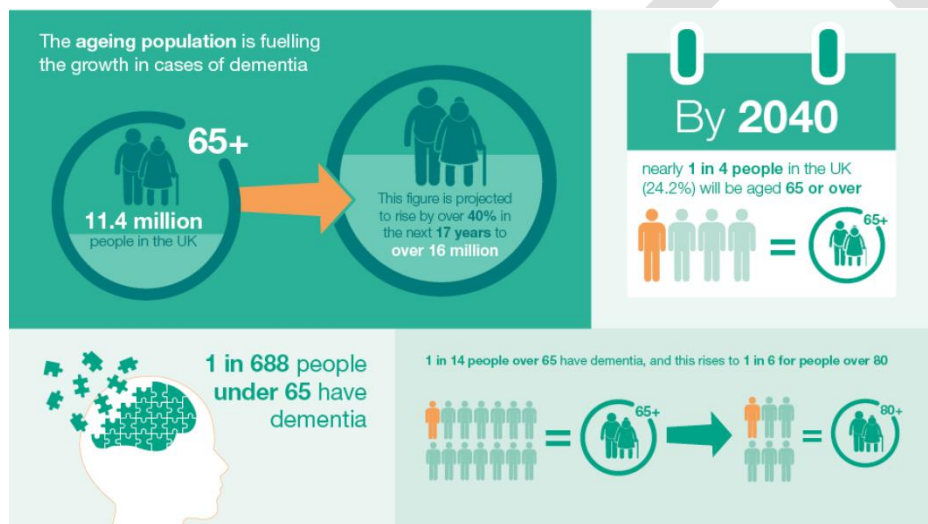


Image 3, source – Public Health England¹⁷

Impact on Carers:

An estimated 540,000 people in England act as primary carers for people with dementia; half of these are employed, 112,540 have needed to leave employment to meet their caring roles and 66,000 carers have cut their working hours. This results in a lower standard of living for those carers and significant costs to society in general, including a £3.2 billion cost of working time lost to caring¹⁸.

Impact on Emergency Care Services

The number of people with dementia admitted to hospital in an emergency rose by 70% between 2012 and 2018. Around a fifth of these admissions related to potentially preventable acute conditions such as urinary tract infections, pneumonia and other respiratory infections¹⁹.

¹⁵ Fingertips, Public Health data: dementia profile <https://fingertips.phe.org.uk/profile-group/mental-health/profile/dementia/data#page/1>

¹⁶ Government guidance, *Dementia: applying All Our Health*, <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

¹⁷ Public Health England: *health matters: midlife approaches to reduce dementia risk* <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

¹⁸ Government guidance, *Dementia: applying All Our Health*, <https://www.gov.uk/government/publications/dementia-applying-all-our-health/dementia-applying-all-our-health>

¹⁹ Ibid

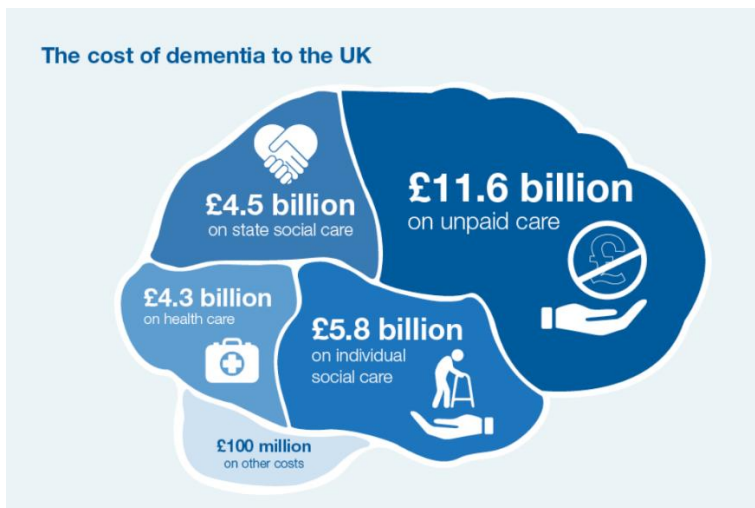


Image 4, source – Public Health England²⁰

Impact on an individual’s quality of life:

Public Health England suggests that 60% of people with dementia are more likely to be lonely. Approximately 60% of people with dementia go out of their houses less than once a week and in sparsely-populated rural areas, it is harder for older people living alone to find the opportunity to mix with others.

We know that Essex has an increasing older population and nationally up to 14% of older people (for Essex that's over 33,000 people) report feeling lonely all the time. With loneliness increasing the risk of dementia by up to 50% and those who are socially isolated more likely to enter residential or nursing care early, this is a pressing issue for Essex.

Some studies suggest that people from Black African, Black Caribbean and South Asian ethnic groups are more likely to get dementia than people from White ethnic groups, with a recent study identifying Black ethnic groups in London as having the highest risk, with links to diabetes and cardiovascular disease prevalence in such groups given as a possible cause²¹. Although, it is argued that more evidence is needed to determine ethnicity as a significant risk factor for dementia.

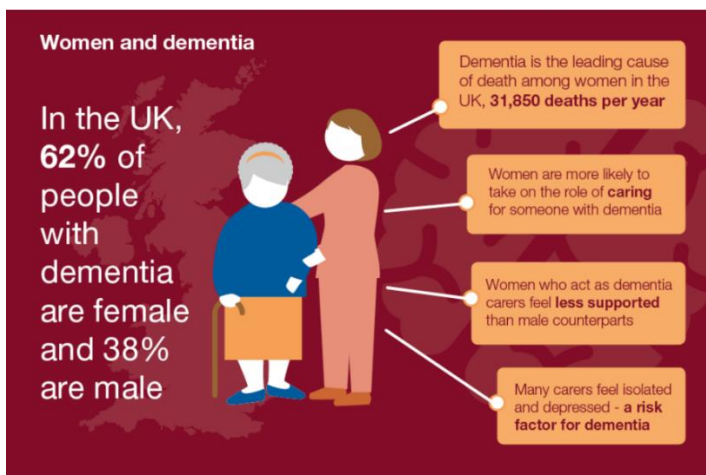


Image 5, source – Public Health England²²

²⁰ Public Health England: *health matters: midlife approaches to reduce dementia risk*
<https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

²¹ Alzheimer’s Society factsheet: *risk factors for dementia 2021 factsheet risk factors for dementia.pdf*
<https://www.alzheimers.org.uk>

²² Public Health England: *health matters: midlife approaches to reduce dementia risk*
<https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

Impact on Women:

Dementia has been the leading cause of death for women in the UK since 2011 and, while women have a longer life expectancy than men, not only are they at greater risk of dementia, but they are also more likely to be impacted in other areas of their lives such as through caregiving to a family member with dementia, financial stability, mental wellbeing and career progression²³.

Impact on Adults with Learning Disabilities:

Adults with learning disabilities are at increased risk of developing dementia as they age, compared to those without a learning disability (about 13% in the 60- to 65-year-old age group compared to 1% in the general population²⁴), although the figures vary according to how the diagnosis is made.

Around 1 in 5 adults with a learning disability who are over the age of 65 will develop dementia. People with learning disabilities who develop dementia generally do so at a younger age, across all over 60 age groups the prevalence was estimated at 2 to 3 times greater for those with learning disabilities, with a third of adults with Down Syndrome developing dementia in their 50s.

The importance of dementia awareness:

Dementia does not just impact the person – everyone around them, from family members to friends, is affected in some way. The impact on those living with dementia, including their family and carers, cannot be underestimated and demonstrates the need for a whole system approach to awareness, care and support including diagnosis. 1 in 3 people born in the UK will develop dementia in their lifetime, the importance of increased awareness and understanding of dementia throughout our communities again, cannot be underestimated given the anticipated rise in the number of people living with dementia.

The potential to reduce the risk of dementia to our population:

Around 40% of dementia cases might be attributable to potentially modifiable risk factors. A 20% reduction in risk factors per decade could reduce the UK prevalence by 16.2% (300,000 cases) by 2050²⁵. The Lancet Commission²⁶ offer 12 modifiable risk factors for dementia as:

1. Hypertension (high blood pressure)
2. Obesity
3. Smoking
4. Physical inactivity
5. Diabetes
6. Depression
7. Lack of education in early life
8. Social isolation
9. Hearing loss
10. Alcohol consumption >21 units per week
11. Air pollution
12. Traumatic brain injury

²³ Alzheimer's Society: *The Impact of Dementia on Women* <https://www.alzheimersresearchuk.org/wp-content/uploads/2022/05/The-Impact-of-Dementia-on-Women-ARUK-report.pdf>

²⁴ Gov: *Dementia and people with learning disabilities: making reasonable adjustments guidance* <https://www.gov.uk/government/publications/people-with-dementia-and-learning-disabilities-reasonable-adjustments/dementia-and-people-with-learning-disabilities>

²⁵ Source – Gov guidance: *Health matters: midlife approaches to reduce dementia risk* available at <https://www.gov.uk/government/publications/health-matters-midlife-approaches-to-reduce-dementia-risk/health-matters-midlife-approaches-to-reduce-dementia-risk>

²⁶ The Lancet: *Dementia prevention, intervention, and care: 2020 report of Lancet Commission* [https://www.thelancet.com/article/S0140-6736\(20\)30367-6/fulltext](https://www.thelancet.com/article/S0140-6736(20)30367-6/fulltext)

Health and social care professionals are an integral part of a whole-system approach to promoting key messages to citizens to help reduce their risk of getting dementia. Key messages include

- Be more physically active
- Eat healthily and maintain a healthy weight
- Drink less alcohol
- Stop smoking
- Be socially active
- Control diabetes and high blood pressure

It is good practice for NHS Health Check providers to offer information to those aged 65+ receiving an NHS Health Check. In Thurrock, as part of the prevention agenda, this advice is extended beyond the guidance and is provided to younger age groups. The national programme invites those aged 40-74 to a check-up designed to spot early signs of stroke, kidney disease, heart disease, type 2 diabetes and dementia. In Thurrock during 2021/22 there were 1575 health checks completed in total. Of those complete in GP surgeries 42% offered advice on dementia (393/941) This was 83% in 2019/20 with a larger number of checks completed. Of those completed by the Thurrock Healthy Lifestyle Service 99% were offered this advice (630/635) in 2020/21 with a similar percentage in 2019/20. The volume of health checks completed since the Covid 19 pandemic has reduced as has the inclusion of dementia advice.

Hypertension and Cardiovascular Disease

Research has shown that Hypertension in middle age increases the risk for vascular dementia. Over time, uncontrolled high blood pressure can damage blood vessels, including the blood vessels in and leading to the brain. This can interrupt the flow of blood to the brain, leading to a type of dementia known as vascular dementia. According to the World Alzheimer Report 2014²⁷, multiple longitudinal studies have demonstrated that individuals who had high blood pressure in mid-life (usually characterised as people who are around 40-64 years of age) were more likely to develop vascular dementia in later life. Taking a preventative approach, keeping blood pressure levels normal along with exercise, diet, smoking, and alcohol consumption are important to minimise risk. As high blood pressure does not necessarily initially show any symptoms being proactive in maintaining a healthy lifestyle is important.

Dementia in Southend, Essex and Thurrock

Dementia is not a natural part of ageing and as noted, does not just affect older people. As of March 2022, NHS Digital²⁸ state there are 15,280 diagnosed people living with dementia in SET. However, it is estimated that there are another 9,000 undiagnosed people living with dementia.

Dementia prevalence is known to increase with age, the most recent figures from NHS Digital highlight that there are 24,578 people (over 65) in SET living with dementia, with a 33% increase predicted, resulting in 34,560 people by 2030. 64% of those diagnosed are female and 70% are aged 80+ (48% are both female and aged 80+) as illustrated below.

²⁷ Prince, M, Albanese, E, Guerchet, M & Prina, M 2014, *World Alzheimer Report 2014: Dementia and risk reduction: An analysis of protective and modifiable risk factors*. Alzheimer's Disease International, London.
<<http://www.alz.co.uk/research/world-report-2014>>

²⁸ NHS Digital, *recorded dementia diagnosis* <https://digital.nhs.uk/data-and-information/data-collections-and-data-sets/data-collections/quality-and-outcomes-framework-qof/quality-and-outcome-framework-qof-business-rules/recorded-dementia-diagnoses>

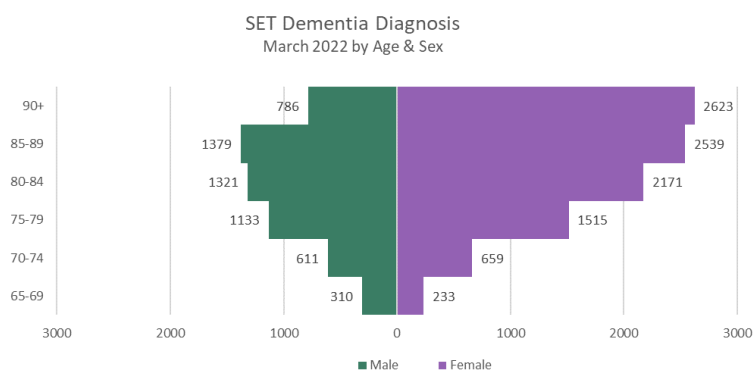


Image 6 NHS Digital March 2022, recorded dementia diagnosis

Dementia diagnosis rates in Essex remain below the national average (62%).

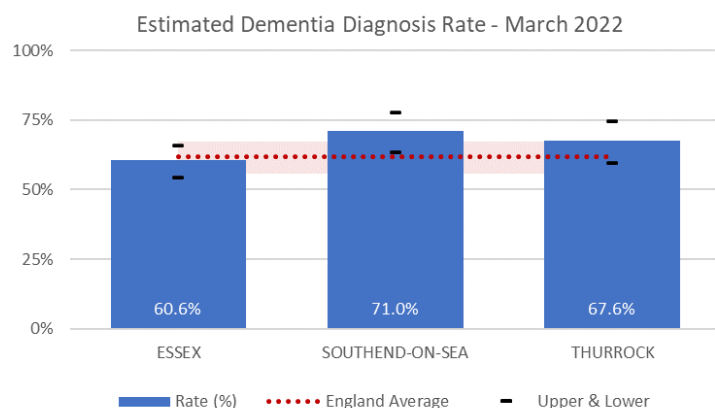


Image 7 NHS Digital March 2022, estimated dementia diagnosis

Additionally, **in Essex**

- Old age dependency ratio: currently equivalent to 335.6 people aged 65+ being economically inactive to every 1,000 working age people. In Southend, this is 310. These are both higher than the national average and whilst this is lower in Thurrock, these are all predicted to increase
- If the prevalence remains constant, for SET as a whole, there will be an additional 10,554 people aged 65+ with dementia in 2030
- In 2020/21 the cost to Adult Social Care in Essex for supporting people living with dementia was £42.3 million – by 2030 this is estimated to increase by 30% to £55 million
- A person's risk of developing dementia rises from one in 14 over the age of 65, to one in six over the age of 80
- Approximately 40% of people living with dementia over the age of 65 are living in care homes – in Essex, by 2030 this will equate to around 13,824 people
- People living with dementia who are over 65 have on average four comorbidities, while people without dementia have on average two and 91.8% of people living with dementia have another health condition
- People living with dementia will generally be supported by higher-cost care packages, whether they are at home or in residential care
- The Alzheimer's Society projected the cost of dementia to Southend, Essex and Thurrock for 2020 to be £1,110 million

Dementia in Thurrock

The graph below shows the estimated number of people aged 65+ with dementia could increase from just over 1,500 in 2020 to approaching 2,400 in 2040. It is worth bearing in mind that the figures below will include some people with dementia who have not received a formal diagnosis, and therefore not receiving care. Thurrock can expect to see a large increase in the number of older people with dementia, and that might not be uniform across the borough. Within Thurrock the prevalence of patients with a diagnosis of dementia ranges from Purfleet Care Centre and Dr Abela T Practice with 0.2% to Commonwealth Health Centre with 1.8%. This could be due to genuine differences in underlying prevalence of this condition between different practice populations and/or differences between GP practices' ability to identify and diagnose this condition in their patients.

The BCTT strategy identified that dementia was one of the four main causes of death amongst Thurrock residents in 2020.

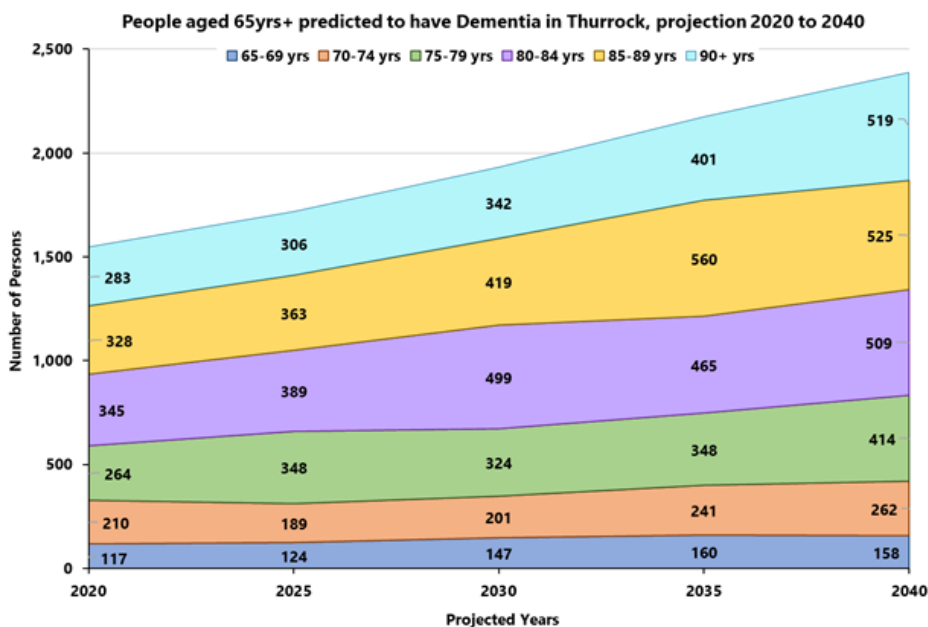


Image 8 POPPI 2022 Over 65yrs predicted to have Dementia

The impact of Covid-19

Covid-19 had a significant impact on the most vulnerable members of our communities, placing additional pressures on unpaid carers which in turn had an impact on people living dementia.

During this time, approaches used included an increased focus on the use of social media channels and digital technologies to facilitate one to one conversations with people, virtual dementia awareness sessions and increased opportunities for communities to come together virtually via the Dementia Action Alliances.

Lived experience research and insight undertaken in 2020 by Adult Social Care, local systems and Covid-19 recovery teams highlighted feedback from those living with dementia, to include:

- Disruption to normal routines
- Lack of cognitive stimulation
- Feeling loneliness, stress and anxiety
- Fear of being abandoned
- Physical and mental deterioration
- Risk of premature admission to residential care
- Risky behaviours
- Self-neglect
- Improved wellbeing when supported by carers, friends and neighbours
- Acts of kindness from the community

The same feedback highlighted the voice of carers, which echoed much of the above, as well as:

- Disruption of routines and loss of services
- An increase in caring responsibilities
- No respite, reduced respite pool – informal means of support not available
- Lack of awareness of support and entitlement to it
- No access to internet or not comfortable using it/digitally disenfranchised
- Not receiving timely/appropriate information
- Finding isolation difficult not just because of impact on the cared for but also on their own mental health and wellbeing

Annex D: Insight from Stakeholder Engagement

Stage One

Essex County Council carried out a public consultation to inform a refresh of the SET Dementia Strategy. The consultation asked questions to establish if people agreed with the nine priorities and their reasons for this. The consultation ran during a period of lockdown, from 15 February 2021 to 5 April 2021.

A total of 164 online responses were received, including people living with dementia, their family and carers, partner organisations and health and social care professionals. These provided valuable insight into people's thoughts about our dementia priorities.

On average, 90% of respondents agreed that the nine proposed priorities were the right priorities, with further findings highlighted below.

1. **83% agreed that prevention is a priority to support citizens across SET who are living with or affected by dementia**
2. **94% of respondents agreed that diagnosis and support is a priority to support citizens across SET who are living with or affected by dementia**
3. **93% of respondents agreed that supporting carers is a priority to support citizens across SET who are living with or affected by dementia**
4. **93% of respondents agreed that finding information and advice is a priority to support citizens across SET who are living with or affected by dementia**
5. **92%** of respondents agree that **reducing the risk of crisis is a priority** to support citizens across SET who are living with or affected by dementia
6. **91%** of respondents agree that **living well in long-term care is a priority** to support citizens across SET who are living with or affected by dementia
7. **89%** of respondents agree that **end of life is a priority** to support citizens across SET who are living with or affected by dementia
8. **96%** of respondents agree that a **knowledgeable and skilled workforce is a priority** to support citizens across SET who are living with or affected by dementia
9. **91%** of respondents agree that **living well with dementia in the community is a priority** to support citizens across SET who are living with or affected by dementia
10. Free-text comments provided further detail which indicated:
 - A need for earlier help in the context of prevention, a need for ways to increase knowledge, information, and support for a people with dementia, their carers, and ongoing training for the workforce
 - A need to ensure there is an increased focus on both those with younger onset of dementia, and older within a broadening range of support interventions, through a pathway of care that reflects all 'ages and stages' of dementia within a pathway that is focussed on prevention through the promotion of risk reduction and early help and support to enable a person to live well for longer
 - The need to be clearer in defining what we mean by the terms 'living-well' and 'prevention', due to a higher % of 'unsure' comments in the survey within these two priorities

Consultation findings enabled further insight of people's views and identify that the nine priorities remain the right priorities.

Stage Two

Essex County Council carried out a second stage of consultation on the strategy refresh, seeking further views on the proposed commitments to deliver against the agreed nine priorities. An online consultation ran from 13 May 2022 to 17 June 2022. A total of 78 online consultation responses were received from people living with dementia, their family and carers, partner organisations and health and social care professionals.

Workshops and focus groups were held alongside this during the same period to gather further insight across a range of partners and stakeholders with an approximate total of 160 participants.

Groups engaged include but are not limited to ECC Carers focus group, ECC Adult Social Care focus group, South Essex Housing Group, One Colchester Delivery Board, Adult Social Care Braintree Neighbourhood Team, Essex Health and Wellbeing Board, North East Essex CCG Dementia Steering Group, North Essex Provider Forum, Pan Essex Dementia Action Alliance and SET District Dementia Action Alliances, East of England Older Peoples Mental Health & Dementia Network, Essex Local Councils, South East Essex Alliance Members and via a range of social media channels.

Stage two consultation findings are summarised below.

Online:

1. **88% agreed that across SET our commitment to work collaboratively across voluntary, health and statutory services to develop and deliver information to improve awareness of dementia and the support available is right.**
2. **88% agreed that across SET our commitment to involve and seek the views of people living with dementia and their carers, recognising their role as valued experts and equal partners is right.**
3. **89% agreed that across SET our commitment to work across our systems to improve support following diagnosis to promote independence, optimise strength, build resilience and prevent unnecessary crises is right.**
4. **93% agreed that across SET our commitment to develop and build on activities and training that improve professional practice and process is right.**
5. **87% agreed that across SET our commitment to work collaboratively with system partners to engage people living with dementia, their families and unpaid carers to better understand how we can improve access to the right information, advice and guidance at the right time to ensure they are fully supported is right.**
6. **86% agreed that across SET our commitment to improve access to dementia diagnosis at the earliest possible stage for the people of Essex, Southend and Thurrock is right.**
7. **87% agreed that across SET our commitment to work with people living with dementia, their families and carers to build more dementia-friendly and dementia-enabled communities and work to understand what support they need in relation to access to housing, transport, employment and technology is right.**
8. **81% agreed that across SET our commitment to continue to promote access to care technology to promote health, prevent deterioration and promote independence is right.**
9. **87% agreed that across SET our commitment to work with the care markets to encourage long term care settings to promote activities and solutions that increase community connections for people living with dementia is right.**
10. **86% agreed that across SET our commitment to improve information that enables families to plan ahead to make informed decisions that support individuals to remain cared for in their preferred care setting is right.**

Workshops/focus groups key findings:

1. The need to coordinate timelier diagnosis and support in the key weeks after diagnosis, recognised as a critical window for early support and intervention that promotes a positive view of diagnosis, facilitating access to timely care and support thus enabling people to live well with dementia in their preferred place of residence
2. The role of communities and groups is seen as crucial to the wrap-around offer of support for families and carers.
3. The need to promote opportunities to share lived experience such as through peer networks is seen as a key aspect of feeling empowered and enabled following diagnosis to ensure access to appropriate and timely support, although caution was advised against information overload, so a balance is needed.
4. To ensure learning from other care pathways and models (for example Cancer & Admiral Nurses) to gather insight on best practice and areas for improvement in care and support for individuals and carers.
5. To improve and enable access to training and support for families and carers, alongside training opportunities for health and social care professionals and community organisations
6. To develop closer working with the care providers incl. reablement and care home providers to improve experiences of discharge from hospital and to promote opportunities for access to appropriate training to understand distressed behaviours and the cause of perceived complexity relating to dementia
7. To promote increased choice and control for those with dementia, their carers and family to enable people to live well with dementia.

Annex E: Additional Information & Useful Links

For further information on any of the content in this strategy, please contact the Dementia Team dementia.team@essex.gov.uk

Alternative format versions of the strategy are available upon request.

Useful links

- Essex County Council: Adult Social Care website, *Dementia: recognising the signs* <https://www.essex.gov.uk/dementia/recognising-the-signs-of-dementia>
- Southend-on-Sea City Council: *Dementia services in Southend* <https://www.southend.gov.uk/specialist-support/dementia>
- Thurrock Council: *Memory loss and dementia* <https://www.thurrock.gov.uk/memory-loss-and-dementia/dementia>
- Alzheimer's Society: *Dementia connect Essex – community dementia support service* <https://www.alzheimers.org.uk/support-services/Mid+Essex+Local+Services/Dementia+Connect+Essex+-+Community+Dementia+Support+Service/regional>
- Dementia Action Alliance: *Pan Essex Dementia Action Alliance* https://www.dementiaaction.org.uk/local_alliances/13290_pan_essex_dementia_action_alliance

Annex F: Glossary: Terms and Abbreviations