

Dementia Strategy Refresh 2022-2026

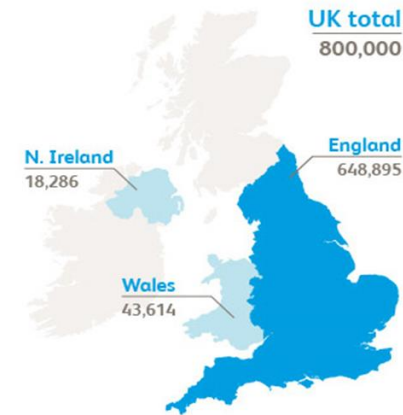


Dementia

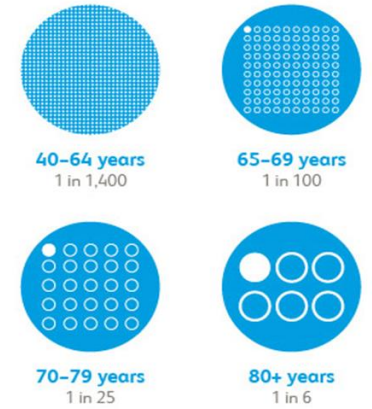
- Dementia is an umbrella term for a number of different diseases that affect the brain in different ways.
- Dementia is defined as a disease that is progressive, affects more than one aspect of thinking and affects daily life.
- Over 200 types) in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities for example, Alzheimers and Vascular...
- Dementia is not a natural part of ageing and it does not just affect older people. It is estimated that
 - NHS Digital (March 2022) states there are 15,280 diagnosed people living with dementia in Greater Essex. However, it is estimated that there are another 9,000 undiagnosed people living with dementia. This means there are approximately 25,000 people in total living with dementia in Greater Essex.
 - 24,578 people (over 65) in Greater Essex are living with dementia, with a 33% increase predicted, resulting in 34,560 people by 2030
- Dementia has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their unpaid carers, families and our communities.
 - Dementia is one of the major causes of disability and dependency among older people.
 - It is estimated that a person is formally diagnosed with dementia every 3 minutes in the UK.
 - 1 in 3 people born this year will develop dementia in their life.
- Dementia caused more deaths in England March 2021 than COVID19
 - A quarter of all those who died of COVID-19 had dementia.

The size of the challenge

The breakdown of the population with dementia across the UK.



Dementia is most common in older people but younger people (under 65) can get it too.



Two thirds of people with dementia are women



One in three people over 65 will develop dementia

Case For Change

The UK population is ageing; people are living longer and being diagnosed with long term health conditions, such as dementia, is growing, with further growth predicted.

In Essex, the current old age dependency ratio is equivalent to 335.6 people aged 65+ to every 1,000 working age people. In Southend, this is 310.

These are both higher than the national average and whilst Thurrock is lower these are all predicted to increase

If the prevalence remains constant, for Greater Essex as a whole, there will be an additional 10,554 people aged 65+ with Dementia in 2030.

In 2019/20 the cost to ASC in Essex alone for supporting people living with Dementia was **£32.6m** - by 2030 this will increase by 30%

- We know that 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.
- Approx. 40% of people living with Dementia over the age of 65 are living in Care Homes ... In Essex, by 2030 this will equate to approx. 13,824 people.
- We know that People living with dementia who are over 65 have on average four comorbidities, while people without dementia have two on average. 91.8% of people living with dementia have another health condition.
- **Dementia diagnosis rate remains below national average.** In Essex there are 15,280 diagnosed (over 65) with dementia, estimated population 24,578 (March 2022)
- It is safe to assume that people living with Dementia will be supported by higher-cost packages (whether they are at home or in residential care) **Projected cost of Dementia to Southend, Essex and Thurrock in 2020 £1,110 Million (the Alzheimers Society)**

But more importantly...

All people living with Dementia should be supported to Live Well and Partners roles in making that happen is more important than ever!

An ongoing Change Journey

A diagram illustrating an ongoing change journey. It features two main sections, 'Challenges' and 'Opportunities', each enclosed in a light blue rounded rectangle. These rectangles are positioned side-by-side and connected by two large, curved blue arrows. One arrow starts at the top of the 'Challenges' box and points to the top of the 'Opportunities' box. The other arrow starts at the bottom of the 'Opportunities' box and points back to the bottom of the 'Challenges' box, creating a continuous loop that signifies an ongoing process.

Challenges

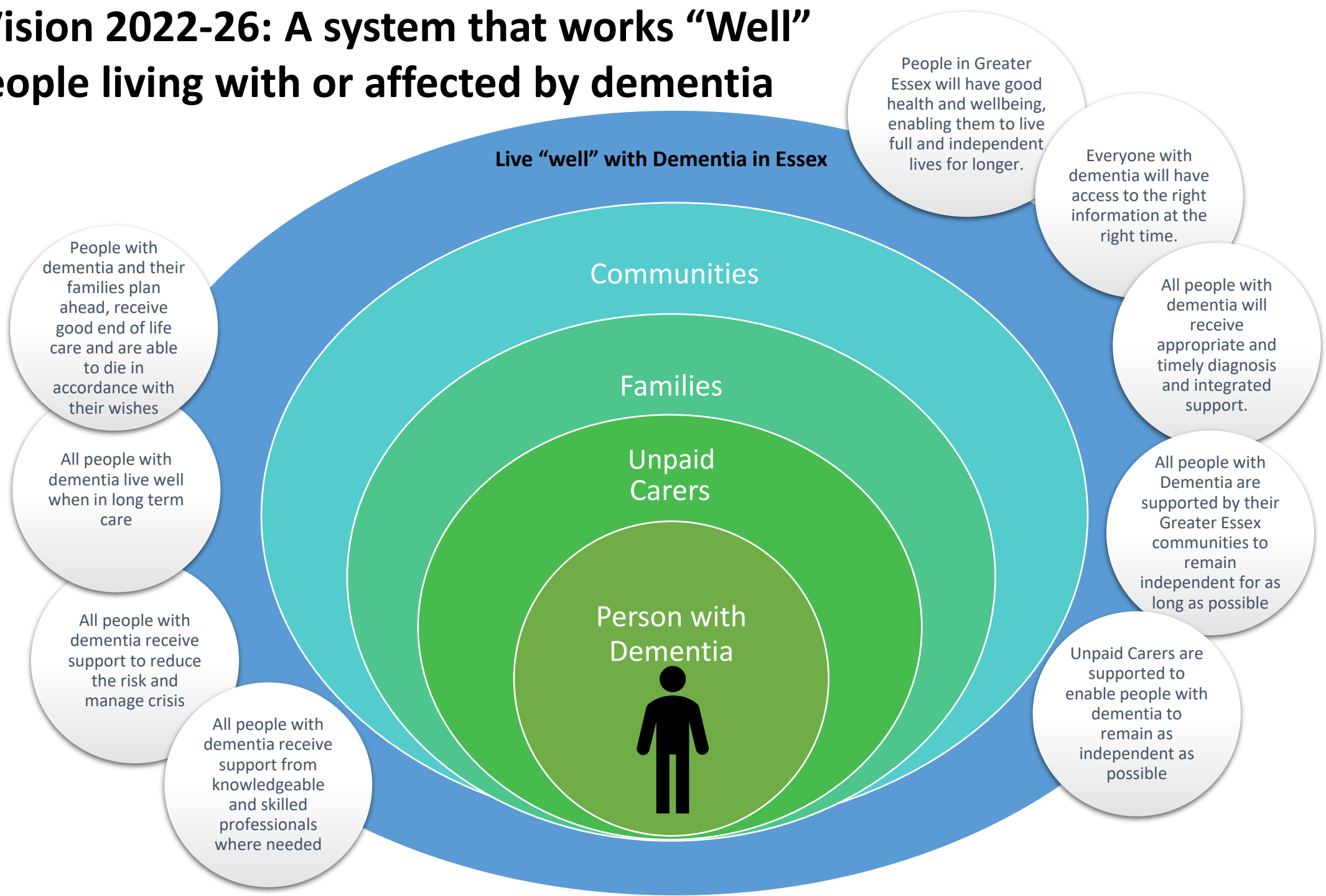
- There is an ageing population with more people with long term conditions
- Dementia diagnosis is not as good as we want it to be
- Driving system change is complex
- Aligning priorities among multiple stakeholders
- Fulfilling expectations across the system
- Stigma of Dementia
- Financial resources
- Understanding the cost of care - Health & Social Care systems not set up to identify the cost of care for adults living with dementia
- Population needs analysis (Dementia JSNA?)
- COVID-19 Pandemic
- Integrated Care Systems
- Data & Insight
- Data-sharing

Opportunities

- Increasing focus on early help and the wider determinants of health through promotion of risk reduction to support starting well and ageing well
- Mobilising place and communities – opportunities for synergy
- Emphasis on results-based accountability through outcomes-based activity
- Increased application of digital technologies and innovation
- A new duty to collaborate
- Enabling dementia-friendly environments
- Collaborative Commissioning
- Covid-19 has accelerated new and better ways of working, ways to harness and sustain the collaboration and integration.
- Greater integration of partners to widen the offer to meet need through the ambitions and opportunities in the White Paper.
- Population Needs Assessment (Dementia JSNA?)
- My Care Record

Our Strategy

Our Vision 2022-26: A system that works “Well” for People living with or affected by dementia



Our 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 or enhance the conditions which will contribute to a reduction in prevalence in the long-term

Priorities to enable delivery of the mission:

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

Supporting unpaid carers: Unpaid carers are supported to enable people with dementia to remain as independent as possible

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

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

Finding information and advice: Everyone with dementia will have access to the right information at the right time.

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

Living well with dementia in the community: All people with Dementia are supported by their Greater Essex communities to remain independent for as long as possible

Living well in long term care: All people with dementia live well when in long term care

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

Commitments


1. We will work collaboratively across voluntary, health and statutory services to develop and deliver information to improve awareness of dementia and the support available.
2. We will involve and seek the views of people living with dementia and their carers, recognising their role as valued experts and equal partners.
3. We will work across our systems to improve 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 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
6. We will improve access to dementia diagnosis at the earliest possible stage for the people of Essex
7. We will 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.
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 market to encourage long term care settings to promote activities and solutions that increase community connections for people living with dementia.
10. We will improve information that enables families to plan ahead to make informed decisions that support individuals to remain cared for in their preferred care setting.

How we will know we have
delivered our ambitions


Local dementia systems that respond to their communities needs & support every person to “live well” with dementia at all stages of the disease progression.

How do we get there?

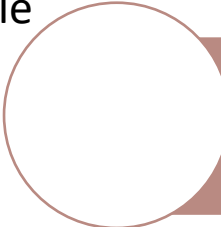
- ✓ embed dementia priorities in “LiveWell” programmes
- ✓ create implementation & delivery plans with measurable outcomes defined & owned by local systems
- ✓ improve use of population health management data & insight to enable development of an earlier offer, reducing health inequalities for people affected by dementia & their carers.
- ✓ use language that the people of Essex understand & feel is relevant to them, as well as to local systems.



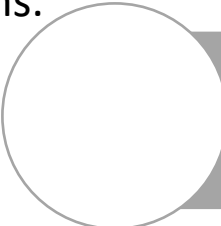
Responsive to dementia, shaped by the voice of lived experiences, promoting health & social care integration and working across established local dementia partnerships in Greater Essex, raising the profile of dementia & embedding principles that transform the lives of people living with dementia & their carers.



Communities across Greater Essex taking practical actions to enable people to live well with dementia & reduce the risk of costly crisis or long-term interventions



Best practice solutions used to embed dementia-enabled & aware networks locally and across Greater Essex



Opportunities are created to develop dementia enabled environments & activities, working with public health to create early offers of support across Greater Essex.

Early thinking - Focus, Actions and Outcomes

Commitments	Action	Outcome	Measures	Timeframe
Prevention: People in Greater Essex will have good health and wellbeing, enabling them to live full and independent lives for longer.			Sponsor: Essex Health & Wellbeing Board	
1. We will work collaboratively across voluntary, health and statutory services to develop and deliver information to improve awareness of dementia and the support available.	Development and delivery of a Dementia awareness activities. The system will work to build services, support and communities in Essex that, through the use of information, education and social media will help people to keep healthy in order to reduce the risk of dementia developing. (Current UK data says that only 34% of adults think it is possible to reduce their risk of dementia)	People will have better understanding of the effectiveness and impact of healthy lifestyle on modifiable risk factors such as: • Stop smoking • Be more active • Reduce alcohol consumption (only drink within NHS recommended limits) • Improve 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	2022 -26
	Intergenerational programme activities to increase awareness of dementia/Starting well	Young people will have better understanding of healthy lifestyles and improved understanding of dementia Young people will be active champions to support dementia enabled communities	increase reach and volume of schools engaged in intergenerational activity from 2021 baseline by a further 50% in 2022-23.	2022-23
	Develop and align to Healthy Living activities and opportunities	People living with dementia and their unpaid carers are able to access activities and maintain their independence, and physical, emotional and mental health	Measures from Joint Health and Wellbeing strategy	2022-26
Supporting unpaid carers: Carers are supported to enable people with dementia to remain as independent as possible			Sponsor: Local Authorities/Carers sponsor	
2. We will involve and seek the views of people living with dementia and their carers, recognising their role as valued experts and equal partners.	Improve pathways to formal assessment where needed	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	All Age Carers Strategy outcome measures incl. ASC Data and Unpaid Carers voice	2022-23
	Support and training for unpaid carers of people with dementia. Work with system partners incl. health, education and voluntary and community sector organisations to build on existing, and develop more support for you in your local communities	Unpaid Carers report that they can attend training, or take a break, knowing that the person they care for will be safe and well looked after. Unpaid Carers are supported to be able to continue working and to access health and support services to maintain their own physical, emotional and mental health/ wellbeing	<ul style="list-style-type: none"> All Age Carer Strategy and Early Help Offer outcomes Number of unpaid carers supported to understand impact of dementia ECC commissioned Dementia service Health outcomes & service data 	2022-23

Early thinking - Focus, Actions and Outcomes

Commitments	Action	Outcome	Measures	Timeframe
Reducing the risk of crisis: All people with dementia receive support to reduce the risk and manage crisis			Sponsor: ICS/Local Alliances	
3. We will work across our systems to improve support following diagnosis to promote independence, optimise strength, build resilience and prevent unnecessary crises	Develop Health & care services that work for people living with dementia to reduce risk of crisis, reduce avoidable admissions & delayed discharge.	Flexible alternatives to hospital admission and to support early discharge wherever possible. Incl. access to UCRT/virtual wards and intermediate care.	Reduction in number of emergency admissions and delayed discharges – developing measure	2022-26
	Work to 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 & social care system to care and options to meet their needs.	People living with dementia and their carers provided with good post diagnostic support and information about the options available to them as their dementia progresses.	<ul style="list-style-type: none"> • Increase number of PCNs that have achieved Dementia Friendly accreditation • Number of people supported to make contingency and advance care plans. • Number of advance care plans completed 	2022-26
A knowledgeable & skilled workforce: All people with dementia receive support from knowledgeable and skilled professionals where needed.			Sponsor: ICS/Local Alliances	
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> <p>Develop and build on activities that improve professional practice and processes.</p>	<p>People living with dementia are able to lead fulfilling lives and live independently for longer.</p> <p>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.</p> <p>People living with dementia receive care and support from an appropriately trained workforce</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 	2022-26
	Engagement work with workforce/care market to understand levels of confidence when working with people with dementia.	Workforce feel confident and empowered in their competences	<ul style="list-style-type: none"> • Engagement and surveys. • Prosper programme measures 	2022-26

Early thinking - Focus, Actions and Outcomes

Commitments	Action	Outcome	measures	Timeframe
Finding information and advice: Everyone with dementia will have access to the right information at the right time.			Sponsor: Local Authorities: Adult Social Care	
5. We will 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	Work with citizens to understand what good quality information and advice, for both pre and post diagnosis of dementia is and how it is accessed.	People are able to say they are able to 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 and affected by dementia to inform what 'good ' information is.	2022-23
	Work to maximise access to Information, advice and guidance so that citizens have clear access to the right support, at the right time in the right place.	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 & technological interventions	<ul style="list-style-type: none"> Engagement and surveys. Virtual/Social media engagement levels. Numbers of people of accessing digital technologies through commissioned technology services. 	2022-26
	Publicise information, advice and guidance in effective ways and in clear and accessible language.	People are able to say they can access information, advice and guidance through a range of mediums including social media and in community spaces (for example through libraries, GPs and local councils).	<ul style="list-style-type: none"> "making every contact count" survey Virtual/Social media engagement levels. organisations/communities achieving Dementia Friendly Communities accreditation. 	2022-26
Diagnosis & support: All people with dementia will receive appropriate and timely diagnosis and integrated support.			Sponsor: Local Alliances	
6. We will improve access to dementia diagnosis at the earliest possible stage for the people of Essex	Design, promote and support activities that enable people to understand how to seek a diagnosis. Good quality support and information available from pre diagnosis and throughout the diagnosis journey and people know where to access this.	Number of people able to say they could find the right information, at the right time to gain a timely diagnosis enabling them to plan to live well with dementia	<ul style="list-style-type: none"> Surveys and engagement Community Dementia Support Service data 	2022-26
	Clear dementia diagnosis pathways to enable people to receive timely diagnosis.	People are supported to understand their conditions and plan accordingly. Improve DDR to NHS National aspiration 66.7%	NHSE recorded data	2022-26

Commitments	Action	Outcome	measures	Timeframe
Living well with dementia in the community: All people with Dementia are supported by their Greater Essex communities to remain independent for as long as possible			Sponsor: Essex Health & Wellbeing Board	
7. We will 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. 8. We will continue to promote access to care technology to promote health, prevent deterioration and promote independence.	Development and delivery of a co-produced Dementia awareness programme to improve awareness, challenge stigma, enable, inspire and facilitate dementia inclusive communities that enable people living with dementia and their carers to live a meaningful life, doing the things that are important to them pre and post diagnosis.	People living with dementia and their carers are enabled to live independently, to take part in activities (incl. commissioned Day opportunities & domiciliary care) based on individual interest and choice, feel valued and included, reducing loneliness and making contribution to their community. People with young onset dementia, from BAME & LGBTQ+ communities receive support appropriate to their specific needs.	<ul style="list-style-type: none">• Increase number of Dementia Friendly and enabled community places and spaces.• Number of organisations & communities achieving dementia friendly communities accreditation.	2022-26
	Improving access to housing, transport, employment.			
	Ensure access to IAPT and Psychological interventions for people living with dementia.	People living with dementia, or a non-dementia diagnosis (MCI, depression, anxiety) and their carers are aware of the possibility of psychological support from IAPT services, and are routinely considered for and offered this support,	<ul style="list-style-type: none">• Number of people living with dementia accessing IAPT and psychological support.	2022-26
Living well in long term care: All people with dementia live well when in long term care			Sponsor: Local Authorities: Adult Social Care	
9. We will work with the care market to encourage long term care settings to promote activities and solutions that increase community connections for people living with dementia.	Long term care settings are Dementia Friendly, supporting residents with dementia to live well and being engaged with their local communities.	Increase social connectedness incl. enabling access to digital technology, links to local communities and the dementia intergenerational programme.	<ul style="list-style-type: none">• Number of people in care homes with access to social contact through digital technology.• Participation in the prosper and intergenerational programmes• Number of care home achieving Dementia Friendly Communities accreditation.	2022-26
	Work with the care market to understand capacity and demand for long term care for people living with dementia. Work with the care market to understand the scale of ‘complex’ needs for people living with dementia and whether separate commissioning is required.	Market shaping strategy reflects the demand and capacity required to support people living with dementia. Care market 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">• Essex Market Shaping strategy deliverables.• Number of people supported to access appropriate care.• Reduction in the number of “hand-backs”• Care market and commissioner's agree domains of complexity and impact on commissioned services.	2022-26

Commitments	Action	Outcome	measures	Timeframe
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			Sponsor: Local Alliances	
10. We will improve information that enables families to plan ahead to make informed decisions that support individuals to remain cared for in their preferred care setting.	ACP (advance care plans) are seen an integral and essential part of the dementia post diagnosis pathway. Enhancing 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.	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	<ul style="list-style-type: none">• Number of organisations working towards/achieving Gold Standard frameworks.• Number of people with advance care plans	2022-26

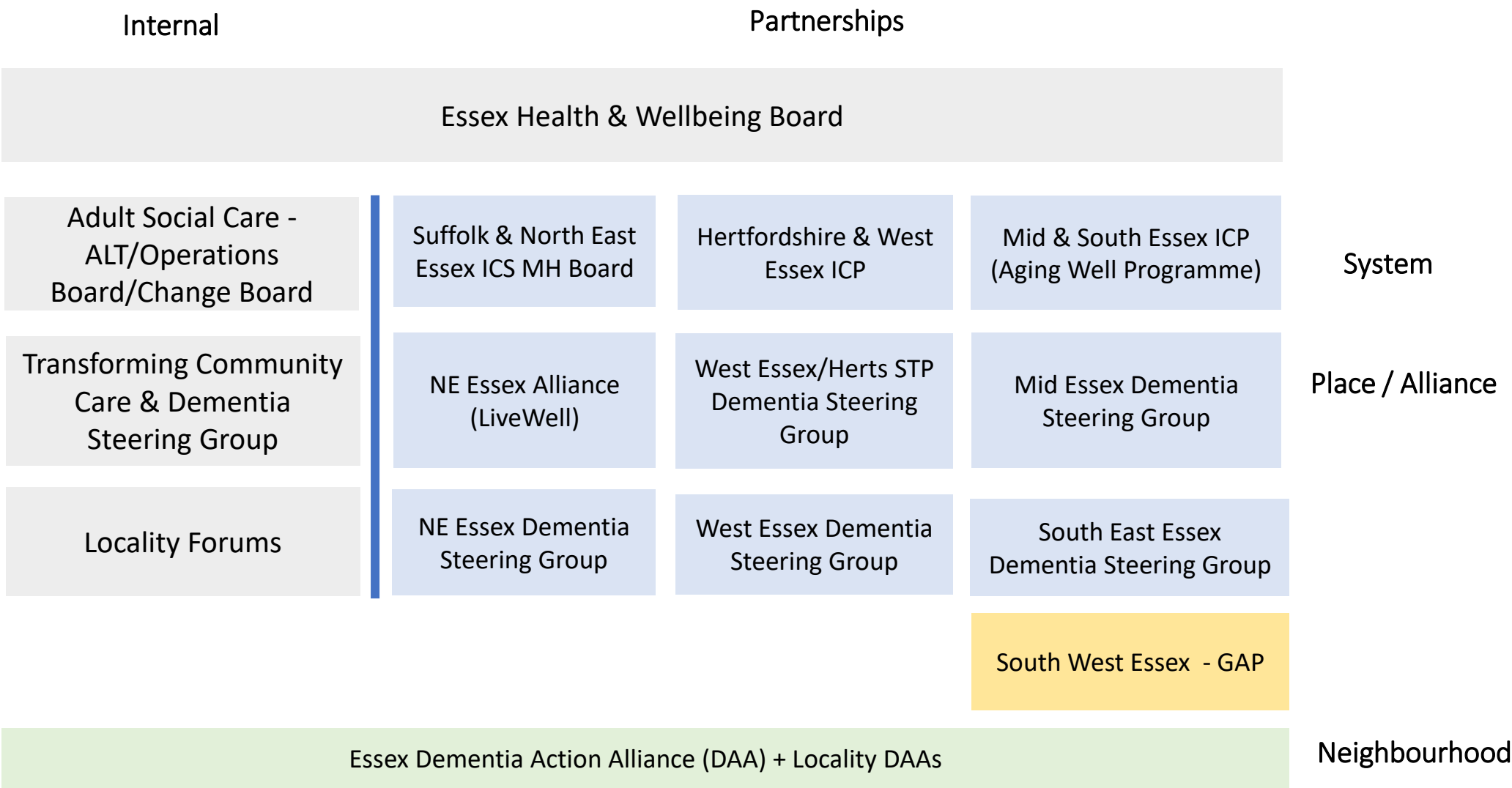
Current activities supporting
delivery against the priorities.

Priorities	Activities	Owner/Lead organisation	Delivery timeline
Prevention: People in Greater Essex will have good health and wellbeing, enabling them to live full and independent lives for longer.	Early Help offer development	ECC	Ongoing
	Dementia diagnosis rate improvement	NHS	Ongoing
	Dementia Action Alliance programme/Dementia Awareness social media campaigns/Dementia friendly & enabled communities	LAs, districts/borough, local councils & communities	Ongoing
	Dementia Diagnosis Rates – Memory Assessment services supporting timelier diagnosis	Health	Ongoing
	Intergenerational Dementia programme as part of earlier intervention and starting well - wider determinants health approaches	ECC	Ongoing
	Review of Dementia Pathways	ECC/Health/LAs	2022/23
Supporting unpaid carers: Unpaid Carers are supported to enable people with dementia to remain as independent as possible	Community Dementia Support Service – commissioned service with specific Unpaid Carer support as part of core offer and dedicated Carer Information and Support Programme	ECC	2020-2023 (procurement review underway – possible +1 extension)
	All Age Carer strategy	ECC	Launch date April 2022
	Carers Support Service– commissioned service Carer Support interventions/IAPT	ECC Health	Ends March 2023 (possible 6 month extension)
Reducing the risk of crisis: All people with dementia receive support to reduce the risk and manage crisis	Post diagnostic support (variation of services across localities) EPUT/NELFT, voluntary and community sector providers	Health	tbc
	Community Dementia Support Team (South East) Community Dementia Crisis Team (South West) Dementia Intensive Support Service (Mid) Dementia Intensive Support Team (North)	Health	Ongoing (health contract agreements)
A knowledgeable & skilled workforce: All people with dementia receive support from knowledgeable and skilled professionals where needed	Health Education England/equivalent Dementia Standards of Training Advanced Dementia Training – Development of ESCA workforce programme	ECC - ESCA	Ongoing
	Information exchange sessions with ASC operational teams to inform understanding of ECC commissioned offer.	ECC/ESCA	Quarterly
	Prosper Programme	ECC	Ongoing

Priorities	Activities	Owner/Lead organisations	Delivery timeline
Finding information and advice: Everyone with dementia will have access to the right information at the right time.	Community Dementia Support Service -Single point of contact /IAG– commissioned service	ECC	2020-2023
	Memory Assessment Services/ Information meetings at point of diagnosis	Health	Ongoing (health contract agreements)
	Social media - Dementia Awareness and information campaigns	ECC	Ongoing
	Early Help offer development	ECC	Ongoing
	All Age Carer Offer	ECC	In Review
Diagnosis & support: All people with dementia will receive appropriate and timely diagnosis and integrated support.	Memory Assessment services /primary care/ Advanced Care Planning/IAPT service/CST & Therapy	Health	Ongoing (health contract agreements)
	Community Dementia Support Service Single point of contact triage/IAG	ECC	2020-23 (commissioned service)
	Various Dementia Identification workforce roles across all system spaces	Health	Ongoing (health contract agreements)
Living well with dementia in the community: All people with Dementia are supported by their Greater Essex communities to remain independent for as long as possible	Community Dementia Support Service - Dementia Enabled communities/ Awareness raising	ECC	2020-23 (commissioned service)
	Young onset service (early stage development in Mid Essex)	Health	In planning stage
	Dementia Action Alliances	LAs/ECC/Local communities	Ongoing
	EALC dementia awareness programme for elected member and officers. Local Councils supported to achieve Dementia Friendly Communities accreditation	ECC	Ongoing
Living well in long term care: All people with dementia live well when in long term care	Prosper Programme	ECC	Ongoing
	Dementia Care home Nurses/Enhanced Care Home Liaison services	Health	Ongoing
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	Gold Standard Frameworks	Health	Ongoing
	Essex Multi Faith, Beliefs & Dementia Inclusion Group	LAs/ECC/Local Communities	Ongoing
	Community Dementia Support Service - Dementia Family Navigator support	ECC	2020-23 (commissioned service)

Governance, Oversight and Strategic Alignment






Governance & Oversight

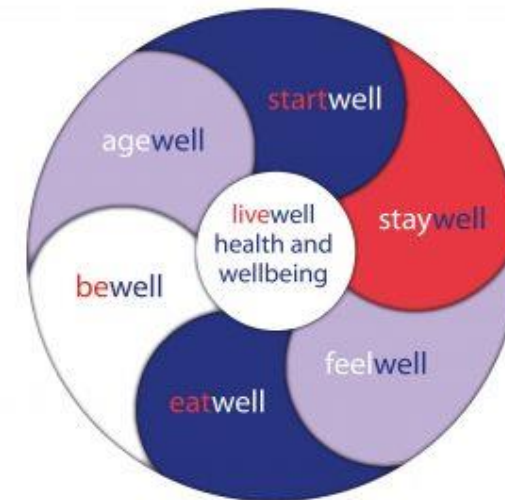


National Alignment

The Strategy will align to the NHS Well pathway for Dementia and to the Livewell themes

- SET Dementia strategy mirrors the NHS England Well Pathway for Dementia, and aims to provide the best care possible for people living with dementia, their unpaid carers and those important to them, and to the Livewell health and wellbeing themes.
- To ensure consistency, clarity and reduce fragmentation of services and support available at all stages of the condition, and will set out our vision and ambitions over the next three years in order to achieve further integration of good quality care and support, better outcomes and a system that is simpler to navigate for those in need of care and support.

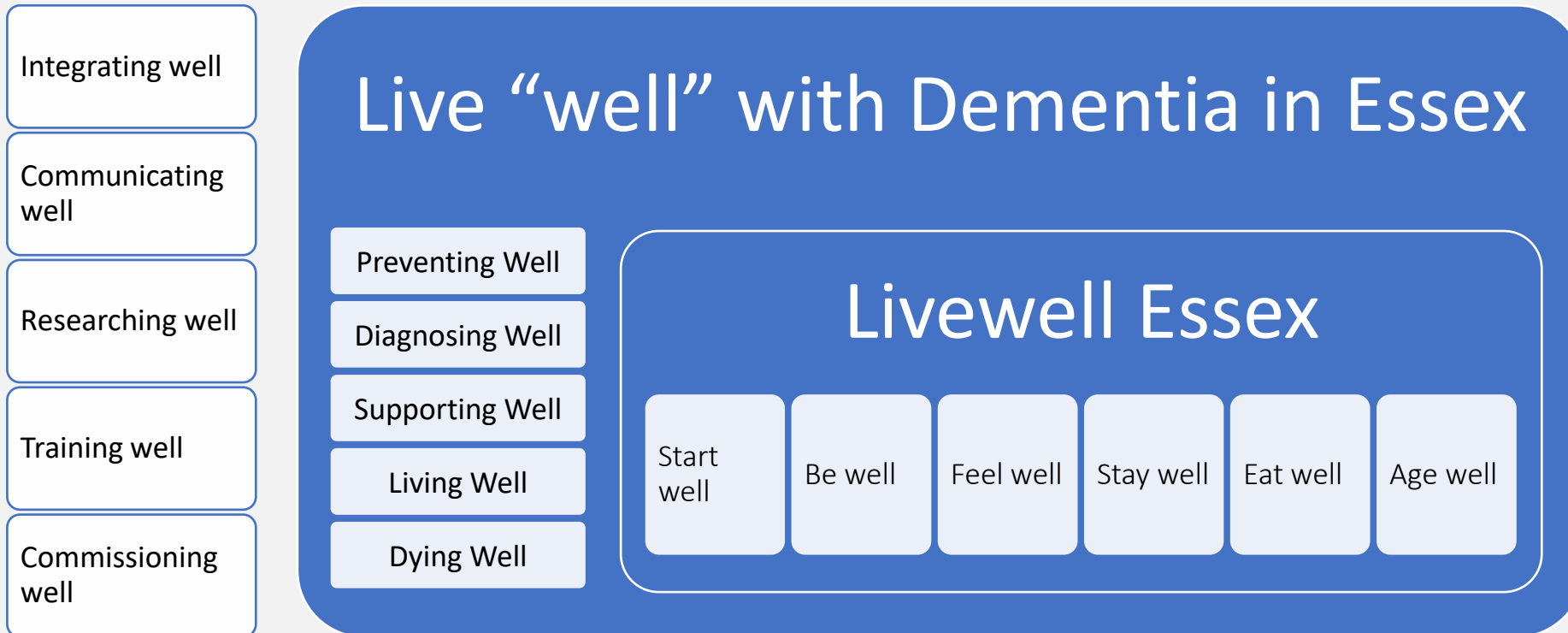
NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
 <p>Risk of people developing dementia is minimised</p> <p>"I was given information about reducing my personal risk of getting dementia"</p>	 <p>Timely accurate diagnosis, care plan, and review within first year</p> <p>"I was diagnosed in a timely way"</p> <p>"I am able to make decisions and know what to do to help myself and who else can help"</p>	 <p>Access to safe high quality health and social care for people with dementia and carers</p> <p>"I am treated with dignity & respect"</p> <p>"I get treatment and support which are best for my dementia and my life"</p>	 <p>People with dementia can live normally in safe and accepting communities</p> <p>"I know that those around me and looking after me are supported"</p> <p>"I feel included as part of society"</p>	 <p>People living with dementia die with dignity in the place of their choosing</p> <p>"I am confident my end of life wishes will be respected"</p> <p>"I can expect a good death"</p>
STANDARDS:	STANDARDS:	STANDARDS:	STANDARDS:	STANDARDS:
Prevention ⁽¹⁾ Risk Reduction ⁽²⁾ Health Information ⁽⁴⁾ Supporting research ⁽⁵⁾	Diagnosis ⁽¹⁾⁽⁵⁾ Memory Assessment ⁽¹⁾⁽²⁾ Concerns Discussed ⁽²⁾ Investigation ⁽¹⁾ Provide Information ⁽⁴⁾ Integrated & Advanced Care Planning ⁽¹⁾⁽²⁾⁽³⁾⁽⁵⁾	Choice ⁽²⁾⁽³⁾⁽⁴⁾ BPSD ⁽⁴⁾⁽⁵⁾ Liaison ⁽²⁾ Advocates ⁽³⁾ Housing ⁽²⁾ Hospital Treatments ⁽⁴⁾ Technology ⁽²⁾ Health & Social Services ⁽²⁾ Hard to Reach Groups ⁽³⁾⁽⁵⁾	Integrated Services ⁽¹⁾⁽³⁾⁽⁴⁾ Supporting Carers ⁽²⁾⁽⁴⁾⁽⁵⁾ Carers Respite ⁽²⁾ Co-ordinated Care ⁽¹⁾⁽⁵⁾ Promote independence ⁽¹⁾⁽⁴⁾ Relationships ⁽²⁾ Leisure ⁽²⁾ Safe Communities ⁽³⁾⁽⁵⁾	Palliative care and pain ⁽¹⁾⁽²⁾ End of Life ⁽⁴⁾ Preferred Place of Death ⁽²⁾
<small>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.</small>				
RESEARCHING WELL <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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 <ul style="list-style-type: none"> 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. 				



System Alignment

From the consultation and experience working within the system to date we know that we need to work harder to connect Dementia to existing plans. The below puts a framework around the conversation and outlines some of the key building blocks for change which will be taken to a newly developed Strategic Dementia Partnership Group.

What does “well” look like...



How we built this strategy

Learning from Successes from the past 5 years

Care and support

- Increased levels of access to early help, Information, Advice & Guidance (incl. unpaid carers, professionals)
 - Community Dementia Support Services, Welfare Calls, Care Navigator Plus, peer support & group activities
- Increased assessment & diagnosis rates for dementia
 - sustained levels of achievement throughout the COVID19 pandemic tracking above national & regional baselines
- Memory Assessment Services that support earlier identification & timelier diagnosis
- Admiral Nurses: testing the approach as part of the dementia pathway
- Dementia Intensive Support; to provide intensive enhanced support
- Carer respite: Range of support for unpaid carers incl. short breaks.
- Mid & South Health & Care Partnership Dementia Intensive Out of Hours Support Team (COVID19 Response, Advice, Assessment & Support)

UK firsts for Essex

- Development of Dementia Friendly programmes
- Essex Dental Practices achieve dementia Friendly status.
- A programme of Dementia Intergenerational activity in Essex schools and wider to create a dementia friendly generation
- Supporting Essex Challenge Prize Winners and runners up to rollout of their inventions

Enabling People to live full and independent lives for longer.

- Dementia embedded into Livewell development accreditation as part of planning approval.
- Work with developers to ensure dementia aware developments and open spaces
 - Chelmsford Community Garden Village
- Increase in place based social action
 - High levels of volunteering activities to support People living with dementia & carers incl. befriending
- APPG for housing & care of Older People inquiry into housing for people living with dementia
- Social prescribing: supporting unpaid carers & people affected by dementia to access wellbeing and lifestyle opportunities in the community.

Living well with dementia in the community

- ECC: awareness raising throughout the organisation
- Working with Local Councils ensuring the needs of people living with dementia are recognized in discharging of their statutory duties
 - Elected Member training, adoption of HEE standards, Dementia Fair & RiPFA Conference
- Increased use of assistive technologies and research/innovation activities with tech. sector & higher education.
- “The Happiness Project” Pilot of sensory tables within care homes and community settings across mid and south Essex

Whilst some challenges remain, the time has now come to learn from the last five years and grow out of these foundations the best possible dementia offer for the citizens of Essex. This Strategy Refresh will provide an overarching ambition for local delivery.

Consulting on the Strategy

Essex County Council on behalf of Southend, Essex and Thurrock carried out a 6 week public consultation (15th Feb. to 5th April 2021) to inform the planned refresh of the existing Strategy. The consultation asked questions to establish whether, or not people agreed or disagreed that the nine priorities previously identified continued to be important and their reasons for this.

We asked, You said...

Responses

In total, we received 164 online responses to the public engagement survey, providing valuable insight into people's thoughts about our dementia priorities. Whilst this was not as many responses as we would have liked, given the impact of Covid on our ability to engage we believe it gives us enough steer to continue to progress with this activity.

Engagement

We have taken feedback from various engagement activity over the last 12 months to triangulating the themes, in mitigation.

- Alzheimer's Society Dementia Voices Programme
- Essex ASC Covid-19 Lived Experience research and insight
- Dementia Voices: Living through Lockdown – North East Essex Commissioned Activity
- ECC Social Media engagement
- Work through the Local Dementia Action Alliances
- Essex Welfare Service, welfare Calls & Care Nav + pathway

Respondents

Responses were received from a range of stakeholders

- People living with dementia,
- Families & unpaid carers,
- Partner organisations
- Health & Social Care professionals

The priorities

Are our priorities the right ones?

- 92% of respondent were in broad agreement to the priorities.
- 3 % of respondents strongly disagreed to the priorities.
- 5% of respondents were unsure

COVID19...

Dementia Voices: Living in Lockdown

Approaches the team have used

- Increased focus on use of social media channels
- Use of digital technologies to facilitate 1:1 conversations with People
- Virtual dementia awareness sessions
- Increased opportunities for communities to come together via the Dementia Action Alliances virtually
- Lived Experience research and insight - ASC 2020, Local systems, COVID19 recovery

We expect to continue to
utilise these new
communication channels
through delivery of the
new strategy

The voice of people living with Dementia

- 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 friends and neighbours
- Acts of kindness from community

"Nothing seems to be
working at the moment.
You can't see anyone.
Everything is on the phone.
I don't always remember."

"Regular contact from
social worker
important' - Some with
less contact from social
workers'

'Reassurance that help
there when needed'
incl. Residential care

The voice of Carers

- Challenges linked to those experienced by PWD e.g. disruption of routines; 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 – can't join Zoom etc.
- Not receiving timely/appropriate information
- Finding isolation difficult not just because of impact on cared for but also on their own MH and wellbeing.

* Quotes from ASC
& local systems lived
experiences 2020

• We know that Covid-19 has had significant impact on the most vulnerable members of our communities, placed additional pressure on unpaid carers and created an environment which has impacted on people living Dementia.

• This information has been essential in helping us position our thinking – we are not starting in the same place

Consulting on the Strategy

High Level Themes

Much of this will be continuing activity from the 2017 Strategy. This shows that whilst progress has been made there is still a lot to do for people living with Dementia in Essex.

Specific support needed for parent/unpaid carers

Specific support needed for People affected with Dementia

Needs of unpaid carers to be considered

Needs of family to be considered

Needs of the person affected by dementia to be considered

Strategy outcomes need to be measured to show success

Increased access to support groups needed

Holistic approach to planning for people affected by dementia

Training opportunities for family/unpaid carers to understand dementia

Better Information for help signpost people to services

Make health/care professionals take dementia awareness training

Ethical way to understand and involve people who are living with dementia

The priorities must be able to evaluate the outcomes

More regular points of contact for parent/unpaid carers

More dementia friendly environments needed

Keep and improve established support networks

More open information on Dementia

Dementia specific activities important

Personal experience of support services has been positive

More dementia friendly environments needed

Lived Experiences...

My eyes do see, my ears do hear
I am still me, so let's be clear
My memory may fade, my walk may slow
I am still ME inside, don't let me go

Poem from Alzheimer Nederland

Learning through various engagement routes have given us key themes to consider. These are from the voices of people living with or affected by dementia in Essex and will also support delivery of the new strategy

A timelier diagnosis enables informed early decision making, and facilitates advance care planning

The importance of post diagnosis support and timely information on an ongoing basis

Unpaid carers don't feel supported practically, and they aren't prioritised for support or as experts

People under 65 living with dementia require targeted support

Health and Social Care need to integrate, to reduce fragmentation, improve communication and reduce repetition and confusion for unpaid carers and people living with dementia

Good training for staff is essential, sharing specialist skills and acknowledging that people with dementia may have complex physical health needs and people with complex physical health needs may have dementia




Promotion of prevention and risk reduction

People are individual – personalisation, one size does not fit all

Importance of dementia aware communities

The following 9 Priorities will continue as part of the 2022-26 Strategy – those areas that had greater emphasis in the consultation will be a key focus areas



The priority areas we consulted on.	Key themes from engagement activity. People have told us they want...
Prevention: People in Greater Essex will have good health and wellbeing, enabling them to live full and independent lives for longer.	<ul style="list-style-type: none"> • Earlier help with prevention (Promotion of risk reduction) • to understand what “Living well” and “Prevention” mean 
Finding information and advice: Everyone with dementia will have access to the right information at the right time.	<ul style="list-style-type: none"> • Increased knowledge, information & support for people living with dementia and their carers.
Diagnosis & support: All people with dementia will receive appropriate and timely diagnosis and integrated support.	<ul style="list-style-type: none"> • a need to ensure there is an increased focus on both those with younger onset dementia as well older.
Living well with dementia in the community: All people with Dementia are supported by their Greater Essex communities to remain independent for as long as possible	<ul style="list-style-type: none"> • a broader range of support interventions through a pathway of care that reflects “all ages and stages of dementia”, Living well for longer. • us to develop dementia aware communities including working more closely with underrepresented groups. • us to promote the inclusion of people living with dementia in everyday life. A “Dementia friendly Essex” • an improved offer and opportunities to access digital and assistive technologies.
Supporting unpaid carers: Unpaid carers are supported to enable people with dementia to remain as independent as possible	<ul style="list-style-type: none"> • Increased knowledge, information and support for unpaid carers, families & friends. • Be able to access support through an broader menu of support options i.e. social media channels, virtual technologies. 
Reducing the risk of crisis: All people with dementia receive support to reduce the risk and manage crisis	<ul style="list-style-type: none"> • Improved confidence in navigating the health & social care system to care and options to meet their needs. 
Living well in long term care: All people with dementia live well when in long term care	<ul style="list-style-type: none"> • To understand what “living well” means • us to ensure that all care & support services are designed to support independence and provided within dementia enabled environments.
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"> • Increased knowledge, information & support for people living with dementia and their carers.
A knowledgeable & skilled workforce: All people with dementia receive support from knowledgeable and skilled professionals where needed	<ul style="list-style-type: none"> • Ongoing training for the workforce related to understanding the lives of people living with or affected by dementia. • Professionals to have the opportunity for Multidisciplinary training • Us to put the voice of people living with dementia and their carers at the centre of everything we do. • To improve co-production of care & support services. 