Title of paper	**Suffolk Dementia Strategy**
Presented by	Eugene Staunton, Deputy Director of Mental Health Transformation, NHS Suffolk and North East Essex ICB
On behalf of	NHS Suffolk and North East Essex ICB Suffolk County Council
Brief Summary *(a clear, brief overview of the paper)*	Provide the background to the dementia strategy, the importance of co-production of the strategy and priorities, based on the NHSE dementia well pathway dementia-well-pathway.pdf (england.nhs.uk) • **Preventing Well:** Raising awareness, understanding and information • **Diagnosing Well:** Improve assessment and diagnosis • **Supporting Well:** Increased need as symptoms develop • **Living Well:** Providing support for people with dementia and their families • **Dying Well:** Having the opportunity to prepare for end of life The vision is that to create a society without stigma where people with dementia feel safe and empowered in the knowledge that responsive services are based on an understanding of their needs and access to information, advice, guidance, and support is readily available whenever they or their families need it.
What is being asked of the ICP Committee?	**Approval:** Suffolk Dementia Strategy and priorities **Action:** Support the oversight and delivery of the co-produced action and implementation plan
Who will be responsible for any actions from the meeting?	Gail Cardy, Contracts and Service Development Manager – Dementia Strategy Development & Implementation Lead gail.cardy@suffolk.gov.uk
Does the paper propose Strategy to be adopted by the ICS?	Yes
What sources of evidence underpin the paper?	**Data** (public health) **Live experience** (the strategy was co-produced with extensive engagement across the system and those with dementia, carers and families) **Published evidence** (referenced throughout the strategy) The deadline for the completion of the strategy, implementation and action plan has always been ambitious, with further challenges in trying to achieve this in the spirit of true co-production, with wide engagement and consultation. Further co-production will also be required to develop a meaningful action plan and outcomes between January and the end of October 2024.

Who will be impacted and how?	Those with memory concerns and dementia (all age) including their carers and families Suffolk and Waveney. Within the strategy there is a focus on the dementia well pathway dementia-well-pathway.pdf (england.nhs.uk) which includes prevention, so this would cover more than just those with a diagnosis of dementia.
Has the impact on health inequalities been assessed?	Yes
How will this paper progress partnerships and integration?	The strategy has been discussed and shaped in detail across both health and social care ensuring that as the strategy emerged it received sufficient attention, priority, and ownership across the system. The strategy will influence decision, policy making and strategic commissioning by the Integrated Care Systems (ICS), Suffolk County Council (SCC), and other stakeholders who commission and provide services for those living with dementia, their carers and families. The ethos of the Suffolk Dementia Strategy and for the action plan going forward is to be co-produced and co-owned by people of Suffolk.
Impact for Specific ICS Partners • NHS Providers • NHS Commissioners • Social Care Commissioners • Social Care Providers • Public Health • VCSE Sector • Primary Care • Local Government • Clinicians	We have developed the dementia strategy to be ambitious and reflect the feedback from service users and those involved with care. To implement this well it is likely to require additional resource. Considering the resource constraints across the health and care system, the action plan will reflect this with short-, medium- and long-term actions, that will allow the most suitable options and governance to progress this. Furthermore, there will be an action plan for East Suffolk, West Suffolk and Waveney Alliances linked with the Age Well Domains which will include all partners.

Priorities from the Dementia Strategy

1.Preventing Well **Raising awareness, understanding and information**		
Themes	**Priorities**	**Outcome**
1a. Improve awareness of dementia	**Priority:** ensure that risk reduction messages are included in relevant public health campaigns, policies, and programmes.	**Outcome:** people will understand how to make changes to their own lifestyle where possible, limit the risk or delay the onset of certain types of dementia
1b. Improve training and education	**Priority:** ensure that people have the right skills to identify and support people earlier to ensure that a timely diagnosis is offered, reducing stigma through raising awareness of dementia.	**Outcome:** people will have increased awareness and understanding of dementia and the challenges it brings and know how to address them, including reducing stigma.
1c. Improve pre-diagnosis information, advice, and support	**Priority:** ensure that people (with memory concerns, pre diagnosis, diagnosis, and post diagnosis) can access the right information and advice, when it is right for them, so they are able to make informed decisions about their own health and wellbeing	**Outcome:** everyone in Suffolk will have the same opportunities for early intervention and support
2. Diagnosing Well **Improve assessment and diagnosis**		
Themes	**Priorities**	**Outcome**
2a. Improve timely diagnosis	**Priority:** ensure that services work together to increasing the number of people diagnosis with dementia	**Outcome:** people will be diagnosed earlier, enabling them to plan for their future and to access early support and care if needed.
2b. Improve accessibility and diagnosis for everyone:	**Priority:** ensure that the memory assessment services continue to develop access and provision to those with learning disabilities and young onset dementia	**Outcome:** people will be identified earlier and offered bespoke support, including their carers and families.
2c. Improve communication of assessment and diagnosis	**Priority:** ensure that services listen and don't ask people with dementia, carers, and their families to tell their story more than once.	**Outcome:** people will receive a compassionate assessment and diagnosis, including the benefits of assistive technology to help them live well.
3. Supporting Well **Increased need as symptoms develop**		
Themes	**Priorities**	**Outcome**
3a. Support for families and carers including home care, extra care, and personalised break	**Priority:** ensure that people have the right information and advice, provided when they want it, so they can make informed decisions about their own health and wellbeing as well as the person they care for.	**Outcome:** families will be supported by professionals in health and adult social care to ensure that the care given to the person with dementia in a place of their choice
3b. When there is a need for a care home placement	**Priority:** ensure the right level of personalised care and support is consistently offered once a person with dementia has been placed in a care home setting.	**Outcome:** care home staff will know who to contact in health and adult social care to ensure that any concerns they have are supported in a timely manner.

3c. When there is a need for a hospital admission	**Priority:** ensure that our acute settings are dementia friendly and that the right levels of training and education is provided to help communicate well with and support people with dementia and their families.	**Outcome:** carers, families, and the person with dementia will be involved in decisions around admission and discharge, as well as future care planning
3d. When there is a need for inpatient care for older people with mental health services	**Priority:** ensure there a jointly agreed clear pathway and way of working across health and social care with shared multi-disciplinary meetings, responsibility and shared care agreements which offer consistency of care for people with dementia and their families	**Outcome:** services will work together to jointly assess a person with dementia's needs holistically to ensure that they are supported in a safe and personalised way, alongside the needs of their families.
4. Living Well **Providing support for people with dementia and their families**		
Themes	**Priorities**	**Outcome**
4a. Improve lifestyles	**Priority:** ensure that people are provided with person centred, holistic support that empowers independence and healthy behaviours	**Outcome:** people with dementia, carers and families will know where to get support which will enable them to remain part of their community for longer by accessing inclusive groups and activities
4b. Support to stay well: with dementia	**Priority:** ensure that people with dementia can receive person centred care and support which is flexible	**Outcome:** people with dementia will be seen independent of their carer and provided with support within their community
4c. Support to stay well: as a carer	**Priority:** ensure that carers and families can receive person centred care and support which is flexible	**Outcome:** carers and families will be seen independent of the person with dementia that they care for and provided with support within their community
5. Dying Well **Having the opportunity to prepare for end of life**		
Themes	**Priorities**	**Outcome**
5a. Improve understanding of end-of-life care for the carer	**Priority:** ensure that carers and families are aware if the process of dying	**Outcome:** families will be more prepared at end of life and what options are available
5b. Improve the needs at end of life for the person with dementia	**Priority:** ensure that the people are aware of the options they have at end of life	**Outcome:** people will be aware of what the end-of-life options are earlier, which supports how they wishes and can be communicated to families and professionals
5c. Improve palliative and end of life care	**Priority:** ensure that people with dementia, and their families, receive person centred care and support that adapts as the needs of an individual increases	**Outcome:** systems will work together in a person-centred holistic way that is supportive to people with a diagnosis of dementia and their families

Suffolk Dementia Partnership

Suffolk Dementia Strategy

2024 - 2029

Contents

Foreword pg3

Introduction *pg6*

Context *pg7*

Engagement and Co-production *pg9*

Co-produced priorities and outcomes *pg11*

01.Preventing Well *pg14*
Raising awareness, understanding and information

02. Diagnosing Well *pg17*
Improve assessment and diagnosis

03. Supporting Well *pg19*
Increased need as symptoms develop

04. Living Well *pg25*
Providing support for people with dementia and their families

05. Dying Well *pg30*
Having the opportunity to prepare for end of life

How we will achieve this *pg32*

Appendix 1 *pg33*
Protected characteristics and dementia

Foreword

Dementia is often hidden within our local communities. Yet so many of us know of a person whose life has been profoundly altered in some way by dementia. Dementia has the potential to touch every one of our lives, which is why listening and responding to the experiences of those living with dementia is so vital. It is the only path to enable health, social care services and our communities to support us to live and age well.

The development of this strategy is now an ideal opportunity for our integrated care system to meet the challenge of tackling dementia in new ways. Doing this will require an enduring commitment to change from partners across our systems, driven by leaders inspired to make a difference. This is a strategy rooted in co-production and lived experience, with the potential for real change that could mean Suffolk is at the forefront of tackling the huge impact of dementia on people's lives.

We have valued the opportunity to contribute to the development of this strategy and to champion the voice of those with lived experience, at every stage of the process. In our research, people have been clear with us about the help they need. They need compassion, empathy and understanding from health and care staff, and the wider community. They need timely, proactive support in the form of a guiding hand, (a service or person) to turn to in the most difficult and challenging moments. Above all, they need not to feel left to manage alone.

Families affected by dementia spoke of being embroiled in stigma, crisis, and emotional distress, struggling to find support and information at the hardest time. People asked why dementia is treated differently to other terminal illnesses and why there was not the parity of support for them as there was for other serious life-limiting illnesses.

The development of this strategy is an important step towards addressing the issues and concerns raised by those affected by dementia, however it is only through action that we will start to see the changes needed. We urge our local leaders (not just within health and social care but across the wider statutory, voluntary and faith sector) to take meaningful steps, as quickly as possible, to align and improve support for people with dementia, their families, and carers and to make an enduring commitment to change.

We would like to thank each and every person who took part in our research for sharing their experiences and helping to shape this strategy. Getting local support right matters to so many people, for so many reasons. And in the words of one of our participants in the research, if we do not do something now to address the needs of those living with dementia, and their carers, 'people will need care before they have had support, and let's face it, care has to be more expensive than support – so let's support people the best we can'.

Andy Yacoub (Chief Executive) and Wendy Herber (Independent Chair)

Acknowledgement

This strategy could not have been produced without the support of so many people, networks and organisations working across Suffolk who strive to improve dementia support. That includes members of the Suffolk Dementia Action Partnership, Dementia Forum, and professionals working within Suffolk and Norfolk County Councils, the Suffolk and North East Essex and Norfolk and Waveney Integrated Care Boards. We would particularly like to thank Healthwatch Suffolk for their extensive research and capturing the voice of the personal experiences of living, or supporting someone, with dementia in Suffolk.

"Dementia has taken so much from me" "my income, my self-esteem, my future," "But here's a thing: I have taken so much from dementia. I live every day; I enjoy every day. I might forget it moments later, but I have learned to live in the moment and that's a wonderful, precious thing to do. How lucky am I? They say you only live once, but that's rubbish: you only die once. You live every day. And that's what I fully intend to do."

Quote taken from Peter, Slow Puncture Living Well with Dementia Peter Berry, and Deb Bunt

Introduction

This is the first dementia strategy across Suffolk that has been truly co-produced and responds to shared experiences through extensive engagement. It re-enforces the commitment across the Suffolk system to provide high quality information, advice, and support, at the right time, in the right place for people with dementia, their carers and families.

We recognise that dementia is a significant health and social care issue which impacts not only those living with dementia, but also their carers, families, and friends. 2021/22 GP data indicates there are around 7,500 people living in Suffolk with a diagnosis of dementia[1]. However, this is likely to be an underestimate, as it does not include those without a formal diagnosis. Using research data, we can estimate that there are likely to be14,200 people aged 65 and overliving with dementia in 2023, which is expected to increase to 19,200 by 2035 (a 35% increase)[2].

The strategy highlights the need for more joined up working across the system to reduce gaps and improve the experiences of people with dementia, their carers, families, and friends. This means reflecting on the systems strengths, as well as our weaknesses across the dementia pathway and services, and by raising the profile of dementia to help reduce the stigma that is associated with dementia. We need to embed the importance of prevention and early support to reduce potential crisis and ensure that the person with dementia, carer and family is supported throughout their journey so they can continue to live well within the wider community.

This strategy will inform the planning, development, and commissioning of current dementia related services across Suffolk as well as informing thinking about how the health and care systems in Suffolk respond to the challenges presented by dementia and the need for future provision for dementia support and services. An action plan for implementation of this strategy will be co-produced by those who helped to write and shape the strategy, reflecting the needs of those affected by dementia and work already being undertaken across Suffolk.

Vision

We want to create a society without stigma where people with dementia feel safe and empowered in the knowledge that responsive services are based on an understanding of their needs and access to information, advice, guidance, and support is readily available whenever they or their families need it.

To ensure that this vision is achieved an action plan will be co-produced based on the priorities and outcomes from the strategy with commitment to deliver change from, lead health and social care sectors across Suffolk, including Suffolk & Northeast Essex Integrated Care Board, Norfolk & Waveney Integrated Care Board, Suffolk County Council, local District and Boroughs Councils, Alliances, third sector and other key organisations, including the voluntary and private care market that support people with dementia and characteristics protected under Equalities legislation[3].

---

[1] https://digital.nhs.uk/data-and-information/publications/statistical/quality-and-outcomes-framework-achievement-prevalence-and-exceptions-data/2022-23/main-findings

[2] https://www.poppi.org.uk/

[3] https://www.local.gov.uk/our-support/workforce-and-hr-support/equality-diversity-and-inclusion-workforce/equality-act-and#:~:text=The%20Equality%20Act%20of%202010,this%20area%20of%20employment%20law.

Context

Dementia: The reality

The word 'dementia' describes a set of symptoms caused by different diseases that damage the nerve cells in the brain. Over time these can affect the memory, impacting on the way a person is able to communicate, solve problems and complete tasks.

Dementia is progressive. This means signs and symptoms may be relatively mild at first, but they progress over time, impacting on how a person is able to undertake and complete daily task, which may result in changes in mood including becoming more anxious, depressed, and distressed. In its final stages dementia significantly and detrimentally impacts on people's ability to cope with life.

There are many forms of dementia but around 19 out of 20 people with dementia have one of four main types:[4],[5]:

- Alzheimer's disease (50–75%), often co-exists with other forms of dementia such as vascular dementia.
- Vascular dementia (up to 20%).
- Dementia with Lewy bodies (10–15%).
- Frontotemporal dementia (2%).
- Some people develop multiple types of dementia; this is known as mixed dementia[6].

National context

According to the Alzheimer's Society[7] in 2023 there are currently around 900,000 people with dementia in the UK, although this is projected to rise to 1.6 million people by 2050.The prevalence of dementia in older people (age 65 and over) in the UK is estimated to be 7.1% -or around 1 in 14 older people[8]. Despite this, dementia diagnosis rates are too low for those aged 65 and above (and declined both nationally and locally during the pandemic).

Whilst dementia is more common in older populations, it is not a natural part of ageing. Additionally, new figures show a 'hidden population'[9] of 70,800 people in the UK who are currently living with young onset dementia. It is important to consider dementia across all ages, to give a more robust reflection of impact of dementia in the population.

The strategy supports the vision and outcomes within the National Dementia Strategy 2009[10]. In May 2022, the Health Secretary announced that there would be a 10-year plan for dementia. This was replaced in 2023 by the Major Condition's Strategy: case for change and our strategic framework[11]. The strategy also considers the legislation and guidance included in the Care Act 2014[12], the NHS Long Term Plan and National Institute for Health and Care Excellence (NICE)

---

4 https://cks.nice.org.uk/topics/dementia/

5 https://www.alzheimers.org.uk/about-dementia/types-dementia/what-is-dementia

6 https://www.alzheimers.org.uk/blog/what-is-mixed-dementia

7 https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

8 https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf

9 https://www.dementiauk.org/news/new-figures-show-70800-uk-adults-are-affected-by-young-onset-dementia/

10 https://www.gov.uk/government/publications/living-well-with-dementia-a-national-dementia-strategy

11 https://www.gov.uk/government/publications/major-conditions-strategy-case-for-change-and-our-strategic-framework

12 https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

guidance, Dementia: assessment, management and support for people living with dementia and their carers 2018[13].

These strategic government documents recognise the increase in prevalence and need to focus on dementia diagnosis for all ages, highlighting the importance of ensuring that people who have dementia, their carers, families, and friends receive the highest quality of care. This includes the importance of early identification, support, advice, and information. However, dementia remains a terminal condition with no current cure. Until there is a significant shift in the way that dementia is diagnosed, viewed, and resourced, it will continue to significantly impact services, people, carers, and families.

Local context

Suffolk is predominantly a rural county and has a population of 760,700, (reported at the time of the 2021 Census) with approximately 305,000 people living in areas classed as rural. People living in more rural areas often find transport options more limited (such as infrequent public transport, or having to rely on expensive private transport), meaning access to key services is more difficult.

Adult populations (aged between 16 and 64 years) account for 59.3%, lower than England estimates (63.2%). 23.6% of Suffolk residents are 65 years or over, higher than the England average (18.6%)[14].

In Suffolk:

- 2021/22 aggregated GP level data indicates 7,450 people of all ages and registered with a GP were recorded as having dementia: 0.9% of the population, statistically significantly higher than England (0.7%)[15].
- October 2023 data is available for dementia estimates in those aged 65 and over. This indicated that 7,427 people aged 65 and over were recorded as having dementia, but that 13,016 people were *estimated* to have dementia in this age group. This equates to a diagnosis gap of 5,589 people[16].
- 'Young' onset dementia data is currently only published at sub-ICB level, making it difficult to understand the true number of people with a diagnosis who are younger than65 as there continues to be a focus nationally on those with a dementia diagnosis over 65 and above.

Dementia diagnosis rates are calculated by comparing recorded diagnoses of those over 65 in general practice against the estimated practice prevalence. This will then give an estimated dementia diagnosis gap for that practice area. This diagnosis does not take into consideration anyone diagnosed under 65 or who has mild cognitive impairment, so the true picture of dementia in Suffolk now and in the future is unknown. The 2023 dementia diagnosis rate for people in Suffolk over 65 is 56.9% The diagnosis rate has been statistically significantly below the target rate since the pandemic. This suggests further work is needed to improve local pathways and processes to ensure access and opportunities are available to everyone for early diagnosis and support, including carers, families, and friends

[13] https://www.nice.org.uk/guidance/ng97

[14] https://www.suffolkobservatory.info/

[15] QOF data via Fingertips (17 Nov 23)

[16] https://digital.nhs.uk/data-and-information/publications/statistical/primary-care-dementia-data/october-2023

Engagement and Co-production

Between September 2022 and February 2023 Healthwatch Suffolk undertook extensive stakeholder engagement with people with dementia, their carers, and families across Suffolk,

In total Healthwatch Suffolk collected 156 people's experiences in three ways, including 19 in-depth interviews with carers, families, and the person with dementia, 100 feedback forms and 28 comments from the feedback centre.

People were asked to share:

- Their experiences of accessing health and care services, including getting a diagnosis, and care received in hospital, at home or in a care home
- What sources of information and support they had found useful and what was missing
- What they would like people to know about living with dementia or caring for someone with dementia
- Their understanding of 'dementia friendly communities' and what is needed to make a community dementia friendly
- Carers were asked about the support they had received in their role as a carer

Between November 2022 and June 2023 further engagement and co-production sessions were held across Suffolk involving people with dementia, their carers and families, health, social care professionals, stakeholders and the voluntary community and faith sector.

This included

- **Dementia Marketplace event:** co-produced with people with lived experiences and the voluntary, community and faith sector, providing resources, information, and advice for those with dementia and their families across Suffolk
- **8 Dementia roadshows across Suffolk:** to ensure that people in rural locations could access resources and information, as well as sharing their experiences of dementia.
- **16 Dementia groups and 8 awareness sessions across Suffolk:** to ensure that those living with dementia and their families who are currently accessing services and support were able to share their experiences.
- **Gathered feedback from over 152 people from 48 organisations either in person or virtually:** to ensure that people of Suffolk had the opportunity to share their experiences and have them included in the strategy

From these co-production sessions, consistent themes emerged around:

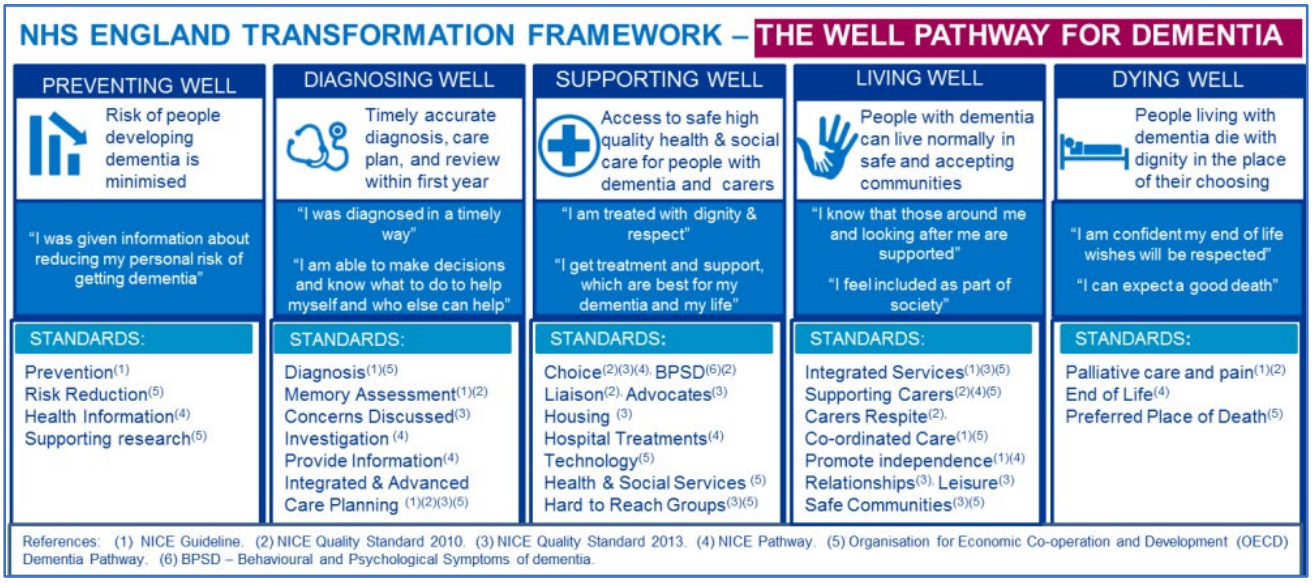
- Communication
- Information and advice
- Support
- Training and education
- Carers

The quotes within the strategy have been taken directly from the Healthwatch Suffolk dementia report 'A roundabout without signposts': People's experiences of dementia in Suffolk'[17] and from further engagement and co-production sessions co-ordinated by the Dementia Strategy Development & Implementation Lead. There are also quotes from professionals and those from the third sector, either on behalf of their service, or the voice of the person with dementia, carers, and families. Healthwatch Suffolk highlighted key learning points for the system which have been incorporated into the strategy, to ensure that the voice of those with lived experience is embedded throughout.

[17] https://healthwatchsuffolk.co.uk/news/dementiaresearch-2023/

As a result of the views expressed, the strategy follows the NHS England 'Well Pathway for Dementia'[18]

- Preventing Well
- Diagnosing Well
- Supporting Well
- Living Well
- Dying Well



[18] https://www.england.nhs.uk/mentalhealth/wp-content/uploads/sites/29/2016/03/dementia-well-pathway.pdf

Co-produced priorities and outcomes

The table below sets out the key priorities and outcomes we want to achieve through this strategy

- **Preventing Well:** Raising awareness, understanding and information
- **Diagnosing Well:** Improve assessment and diagnosis
- **Supporting Well:** Increased need as symptoms develop
- **Living Well:** Providing support for people with dementia and their families
- **Dying Well:** Having the opportunity to prepare for end of life

1.Preventing Well Raising awareness, understanding and information		
Themes	**Priorities**	**Outcome**
1a. Improve awareness of dementia	**Priority:** ensure that risk reduction messages are included in relevant public health campaigns, policies, and programmes.	**Outcome:** people will understand how to make changes to their own lifestyle where possible, limit the risk or delay the onset of certain types of dementia
1b. Improve training and education	**Priority:** ensure that people have the right skills to identify and support people earlier to ensure that a timely diagnosis is offered, reducing stigma through raising awareness of dementia.	**Outcome:** people will have increased awareness and understanding of dementia and the challenges it brings and know how to address them, including reducing stigma.
1c. Improve pre-diagnosis information, advice, and support	**Priority:** ensure that people (with memory concerns, pre diagnosis, diagnosis, and post diagnosis) can access the right information and advice, when it is right for them, so they are able to make informed decisions about their own health and wellbeing	**Outcome:** everyone in Suffolk will have the same opportunities for early intervention and support
2. Diagnosing Well Improve assessment and diagnosis		
Themes	**Priorities**	**Outcome**
2a. Improve timely diagnosis	**Priority:** ensure that services work together to increasing the number of people diagnosis with dementia	**Outcome:** people will be diagnosed earlier, enabling them to plan for their future and to access early support and care if needed.
2b. Improve accessibility and diagnosis for everyone:	**Priority:** ensure that the memory assessment services continue to develop access and provision to those with learning disabilities and young onset dementia	**Outcome:** people will be identified earlier and offered bespoke support, including their carers and families.
2c. Improve communication of assessment and diagnosis	**Priority:** ensure that services listen and don't ask people with dementia, carers, and their families to tell their story more than once.	**Outcome:** people will receive a compassionate assessment and diagnosis, including the benefits of assistive technology to help them live well.
3. Supporting Well Increased need as symptoms develop		
Themes	**Priorities**	**Outcome**

3a. Support for families and carers including home care, extra care, and personalised break	**Priority:** ensure that people have the right information and advice, provided when they want it, so they can make informed decisions about their own health and wellbeing as well as the person they care for.	**Outcome:** families will be supported by professionals in health and adult social care to ensure that the care given to the person with dementia in a place of their choice
3b. When there is a need for a care home placement	**Priority:** ensure the right level of personalised care and support is consistently offered once a person with dementia has been placed in a care home setting.	**Outcome:** care home staff will know who to contact in health and adult social care to ensure that any concerns they have are supported in a timely manner.
3c. When there is a need for a hospital admission	**Priority:** ensure that our acute settings are dementia friendly and that the right levels of training and education is provided to help communicate well with and support people with dementia and their families.	**Outcome:** carers, families, and the person with dementia will be involved in decisions around admission and discharge, as well as future care planning
3d. When there is a need for inpatient care for older people with mental health services	**Priority:** ensure there a jointly agreed clear pathway and way of working across health and social care with shared multi-disciplinary meetings, responsibility and shared care agreements which offer consistency of care for people with dementia and their families	**Outcome:** services will work together to jointly assess a person with dementia's needs holistically to ensure that they are supported in a safe and personalised way, alongside the needs of their families.
4. Living Well **Providing support for people with dementia and their families**		
Themes	**Priorities**	**Outcome**
4a. Improve lifestyles	**Priority:** ensure that people are provided with person centred, holistic support that empowers independence and healthy behaviours	**Outcome:** people with dementia, carers and families will know where to get support which will enable them to remain part of their community for longer by accessing inclusive groups and activities
4b. Support to stay well: with dementia	**Priority:** ensure that people with dementia can receive person centred care and support which is flexible	**Outcome:** people with dementia will be seen independent of their carer and provided with support within their community
4c. Support to stay well: as a carer	**Priority:** ensure that carers and families can receive person centred care and support which is flexible	**Outcome:** carers and families will be seen independent of the person with dementia that they care for and provided with support within their community
5. Dying Well **Having the opportunity to prepare for end of life**		
Themes	**Priorities**	**Outcome**

5a. Improve understanding of end-of-life care for the carer	**Priority:** ensure that carers and families are aware if the process of dying	**Outcome:** families will be more prepared at end of life and what options are available
5b. Improve the needs at end of life for the person with dementia	**Priority:** ensure that the people are aware of the options they have at end of life	**Outcome:** people will be aware of what the end-of-life options are earlier, which supports how they wishes and can be communicated to families and professionals
5c. Improve palliative and end of life care	**Priority:** ensure that people with dementia, and their families, receive person centred care and support that adapts as the needs of an individual increases	**Outcome:** systems will work together in a person-centred holistic way that is supportive to people with a diagnosis of dementia and their families

1. Preventing Well
Raising awareness, understanding and information

1a. Limiting risk and delaying onset dementia

There is growing evidence that people can reduce their risk of developing certain types of dementia, or delay onset by 40%, by making changes to their lifestyle, particularly in mid-life. Evidence shows the benefits of addressing the twelve modifiable risks[19] and how this can reduce the risks of getting dementia as below:

- Having regular **hearing** and **sight tests**
- Maintaining a **healthy weight** by **eating a balanced diet** and **exercising** regularly, which also **reduces the risk of falls**
- Keeping **alcohol** within recommended limits
- Reduce or **stop smoking**
- Monitoring your **blood pressure, cholesterol, and blood sugar** to ensure it is within recommended limits
- Given the ability to **stay socially connected** in the community to **improve wellbeing** and **reducing stress**
- **Reducing intake of air pollution** by not exposing yourself to areas of heavy traffic
- Having the support and opportunity to **remain in education**

Making changes to your lifestyle is beneficial no matter when you decide to make them, even after diagnosis.

Priority 1a. Improve awareness of dementia: ensure that risk reduction messages are included in relevant public health campaigns, policies, and programmes.

Outcome 1a. Improve awareness: people will understand how to make changes to their own lifestyle where possible, to limit the risk or delay the onset of certain types of dementia.

1b Increasing awareness and understanding of dementia

The Healthwatch Suffolk dementia report[20] and engagement with the wider statutory and voluntary sector found that there was a reluctance for people to seek help and advice when they started to experience early signs of dementia, due to fear, stigma and discrimination that can come with that diagnosis.

209,600 people will develop dementia this year in the UK, that's one every three minutes. It is estimated that 70 per cent of people in care homes have dementia or severe memory problems[21].

"I can't believe I've got that disease." *person with dementia*

People with dementia said that having a diagnosis can make them feel excluded and less welcome in the activities they used to enjoy, leading to feelings of loneliness and isolation.

Some carers and families also felt that as the dementia progressed there was less tolerance

[19] https://www.thelancet.com/infographics-do/dementia-risk

[20] https://healthwatchsuffolk.co.uk/wp-content/uploads/2023/05/Healthwatch-Suffolk_Dementia-report-2023.pdf

[21] https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

from the wider community, and they were left feeling there was nowhere to go for support.

"How hard and alone you are - there is no support, and no one cares. There is no treatment and there is little hope." family carer

For some people there was also a lack of understanding from family, friends, their community and even among health and adult social care professionals including their own GPs.

"In our society, there isn't a diagnosis of dementia." family carer

Priority 1b. Improve training and education ensure that people have the right skills to identify and support people earlier to ensure that a timely diagnosis is offered, reducing stigma through raising awareness of dementia.

"Nobody else in the family could see what I was seeing... that was the worst part..." family carer

In Suffolk we know from feedback from those with lived experiences, that there can be

further challenges for those with protected characteristics including some groups from ethnic minority backgrounds.

"She used to get confused. We just thought it was because of the language barrier." family carer

Outcome 1b. Improve training and education: people will have increased awareness and understanding of dementia and the challenges it brings and know how to address them, including reducing stigma.

1c. Pre-diagnosis acknowledgement and identification of dementia

We know that having initial conversations about dementia can make some people feel anxious, which can often delay the diagnosis process and the benefits that an early diagnosis can bring.

We need to ensure that people understand the benefits of an early diagnosis and have the confidence to begin conversations with their doctor or other professionals.

one in two of the population will be affected by dementia in our lifetime, either by caring for someone with the condition, developing it or both[22]

We want professionals, voluntary and the wider statutory sector to know how to recognise the signs of dementia earlier and have the knowledge of the options available to support and treatment if they refer someone for a formal diagnosis.

Key learning from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers
- Find ways to make dementia less hidden
- Make it easier to find early help
- Provide information and raise awareness
- Include people without a diagnosis

"It was hard to get help. Nobody would listen to me." family carer

We know that the early signs of dementia can be difficult to identify, often mistaking symptoms for getting older, even though dementia is not a normal part of ageing,[23] further delaying the diagnosis process. Some symptoms can occur for other reasons; stress, thyroid problems, menopause, head injuries or vitamin deficiencies, such as vitamin B12.[24] An early assessment is important to identify

[22] https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

[23] https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/how-dementia-progresses/is-it-getting-older-or-dementia

[24] https://cks.nice.org.uk/topics/dementia/diagnosis/differential-diagnosis/

the cause of the symptoms to provide the right treatment and support, along with regular reviews.

'*What's the point? There's no support, it's just a label.*' *family carer*

We also recognise that not everyone wants a formal diagnosis of dementia. We need to ensure that people and professionals know how to access advice, support, and information, to help individuals to make informed decisions. If they do have concerns about what is causing their symptoms and wish to have a formal diagnosis, they are supported throughout their journey.

Priority 1c. Improve pre-diagnosis information, advice, and support: ensure that people (with memory concerns, pre diagnosis, diagnosis, and post diagnosis) can access the right information and advice, when it is right for them, so they are able to make informed decisions about their own health and wellbeing

Outcome 1c. Improve pre-diagnosis information, advice, and support: everyone in Suffolk will have the same opportunities for early intervention and support

2. Diagnosing Well
Improving assessment and diagnosis

We know that the longer people wait to be diagnosed the less choice they have about their future care and support. The impact this can have on them, and their families can be catastrophic, resulting in carer breakdown and crisis hospital admissions.

Getting the right information, support and guidance early can have a significant impact on someone's emotional health, wellbeing, and ability to manage their own condition and live independently in their local community.

The national target rate for dementia diagnosis in those aged 65 and over in England is 66.7%. In comparison, in August 2023 in Suffolk, the rates were 57.6% in Ipswich & East Suffolk, 55.3% in West Suffolk and 58.3% in Waveney. It is important that we continue to work together as one system to improve this.

Priority 2a. Improve timely diagnosis: ensure that services work together to increasing the number of people diagnosis with dementia

Outcome 2a. Improve timely diagnosis: people will be diagnosed earlier, enabling them to plan for their future and to access early support and care if needed

"Dementia was not just a diagnosis for me but for the whole family" *person with dementia*

For many people, including carers and families, receiving a diagnosis of dementia can be hard to accept. However, there are others who feel that having a diagnosis has helped them to understand the changes they have been experiencing and this has contributed to improvements in their wellbeing. Knowing their diagnosis enables people to research more about the condition and can motivate them to participate in research studies with other national organisations[25]. How a person, family member or carer feels when they receive a diagnosis of dementia is very personal. Feedback from engagement suggests people want someone to talk to about the diagnosis at a time that is right for them; this may be at the point of diagnosis or a time when it is more suitable to them.

Not all diagnoses are given at memory assessment services. In Suffolk, work has

Although dementia diagnosis rates are below the 66.7% target, since the COVID-19 pandemic the number of people referred to the memory services with concerns about their cognition has significantly increased. However, this has resulted in longer waits for people, which can be detrimental to health and wellbeing for them and their families. Evidence shows there are a number of challenges for people being able to attend a clinic including access to public transport, and the cost of private transport. Dementia diagnostic services continue to work with partners across the system to offer appointments elsewhere, including those in more rural parts of the county, but are challenged by the availability of clinical space and the associated costs.

Priority 2b. Improve accessibility and diagnosis for everyone: ensure that the memory assessment services continue to develop access and provision to those with learning disabilities and young onset dementia

Outcome 2b. Improve accessibility and diagnosis for everyone: people will be identified earlier and offered bespoke support, including their carers and families

[25] https://www.joindementiaresearch.nihr.ac.uk/

begun on “delivering a diagnosis well,” working with people with dementia and carers, to improve the experience of receiving a dementia diagnosis from any professional.

We know from talking to people with dementia and professionals in health and adult social care, that inconsistencies in the dementia pathway across Suffolk are impacting on people getting a timely assessment and diagnosis. This then delays access to the support, advice and care they and their families may need. Closer working relationships are needed with professionals across health, adult social care, community services, voluntary sector, and the wider system, for earlier identification of people who are most at risk of developing dementia.

“I’m afraid I’m going to forget who I am and the things that I can do” *person with dementia*

Following a diagnosis, many people and families described a lack of support available and how alone they felt as a result. Key findings from the Healthwatch Suffolk dementia report identified a lack of post-diagnostic and follow-up support, including annual reviews from their GP or health professional. Where people had received a review, the outcome was inconsistent, ranging from feeling reassured and more confident to continue with their everyday lives, to feeling let down by lack of support and empathy.

Key learning from the Healthwatch Suffolk dementia report and Dementia Strategy Development Lead from conversations with people with dementia and carers

- Listen to carers
- Improve cross-service communication
- Compassionate diagnosis delivery
- Transport to clinics especially in rural areas

“I cannot believe that with what is a terminal condition patients are not routinely offered a review with a doctor, I have finally booked one for Mum this month, but not without a fight.”
family carer

It is important that health and adult social care professionals know what support and advice there is across Suffolk, both pre- and post-diagnostic. This would give confidence to those they care for, and their families; that they can have access to the right support, at the right time and in the right place throughout their dementia journey. Health and adult social care professionals need to be supported to ensure they have the right levels of knowledge, skills, and training to be able to make an appropriate diagnosis or referral to specialist services for assessment of cognitive changes.

Priority 2c. Improve communication of assessment and diagnosis: ensure that services listen and don’t ask people with dementia, carers, and their families to tell their story more than once

Outcome 2c. Improve communication of assessment and diagnosis: people will receive a compassionate assessment and diagnosis, including the benefits of assistive technology to help them live well

3. Supporting Well
Increased need as symptoms develop

We understand that many people with a diagnosis of dementia have a strong desire to remain in their own home for as long as possible. Hospital admissions, particularly lengthy ones, increase the risk of a person with dementia losing independent living skills and not returning home. To reduce the risk of this happening, organisations, and services, across health and social care will need to work closely, in a timely way, to manage and de-escalate complex and / or crisis situations. This could be via community assessments[26], home treatments[27], virtual wards[28] or a planned hospital admission.

"It always feels like health blame social care, social care wants health to take it up, and there's no accountability" *family carer*

3a Support for families and carers including home care, extra care, and personalised break

Carers and families have a key role when it comes to supporting and enabling a person with dementia to remain living at home for as long as possible. The support carers provide typically includes managing daily activities including medication, supervision, nighttime support as required, as well as supporting the person with dementia's overall physical and emotional wellbeing. In Suffolk, we should value the role of unpaid carers. The Suffolk All Age Carers' Strategy commits to ensuring that carers of all ages are heard and supported.

Unpaid carers supporting someone with dementia save the UK economy **£14.6 billion** a year.
By 2040 this will rise to **£35.7 billion**[29]

As dementia progresses, many carers fed back through the engagement that they became more isolated and did not know who to turn to or what support they were eligible for. We recognise too that the desire to retain independence for as long as possible places enormous pressure on family carers and that this strain may lead to conflicting desires between the cared-for and the carer.

Under the Care Act 2014, all carers are entitled to a statutory carer's assessment which considers the impact of their caring role on their own health and wellbeing. Caring for anyone can be difficult at times, carers should therefore be offered additional support through home care, extra care, and breaks[30] from their role as a carer. This enables them to remain independent and keep their own identity, to allow them to continue in their caring role for as long as possible.

A longer break for a carer can be facilitated by the person with dementia receiving support elsewhere, either through a day centre, or by a temporary stay in residential care. It is important to balance the needs and wishes of the carer with those of the person with dementia. At times these can be different, and so need careful discussion and consideration. Any support provided needs to be person centred and flexible to meet the individual needs of the person with dementia, their family, and carers, who will all have different expectations and needs.

26 https://www.suffolk.gov.uk/care-and-support-for-adults

27 https://www.suffolk.gov.uk/care-and-support-for-adults/help-to-stay-at-home

28 https://www.england.nhs.uk/virtual-wards/

29 https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

30 https://www.suffolk.gov.uk/care-and-support-for-adults

"Oh, you're self-funded. Well, you've got funding yourself, you just need to get care." *family carer*

We know from the Healthwatch Suffolk dementia report that many carers felt like they were unable to cope. Despite local authorities being able to access and offer guidance and advice to people who are self-funding[31], there was a perception from some carers that they did not feel listened to and dismissed by health and adult social care.

There needs to be better awareness of when continuing health care[32] need to be involved if the cost of care does need to be funded.

'The carers chop and change constantly.' *family carer*

Carers reported that the provision of home care can also create challenges, not least because having different carers everyday can cause more confusion for those with dementia, who may already be unwilling to accept additional help. Where possible, this can be assisted by having a consistent carer(s), who are able to get to know that individual and family, and hence provide more personalised care. Consistency of care also means the carer(s) are more likely to notice any changes in the person with dementia, and work with the family and other professionals to manage any physical, health or emotional wellbeing before it escalates.

Key learning about from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers

- Help people to know how social care can support them
- People who can fund care still need help to find social care support
- Trust and continuity really matter
- Help people with the transition to care
- Make sure staff are trained to care for people with dementia
- Improve support for long-distance carers
- Improved coordination of care when people move between areas

Priority 3a. Support for families and carers including home care, extra care, and personalised break: ensure that people have the right information and advice, provided when they want it, so they can make informed decisions about their own health and wellbeing as well as the person they care for

Outcome 3a. Support for families and carers including home care, extra care, and personalised break: families will be supported by professionals in health and adult social care to ensure that the care given to the person with dementia in a place of their choice

3b Care home setting

Not all care can be provided in a person's own home and there may be a time when, even with additional support, a person with dementia can no longer remain in their own home. Going into a different environment can sometimes be overwhelming for a person with dementia. Where possible, provision for transition from home to care home should be gradual and sensitively approached for all involved, including the person with dementia, their carer, and their family. In some cases, if the person has had day care, or a temporary break in the same setting, the transition from home to care home can be much easier. There is also potential in the future to use virtual reality to show a person around the home before their stay.

Sometimes the decision to move to a care home will be triggered by a hospital admission for the person with dementia. At this point (if the person is deemed to have lost capacity to

[31] https://www.suffolk.gov.uk/care-and-support-for-adults/self-assess-your-needs

[32] https://www.gov.uk/government/publications/national-framework-for-nhs-continuing-healthcare-and-nhs-funded-nursing-care

decide how their care and support needs will be met), a best interest's decision will be made under the Mental Capacity Action legislation[33] assessing if a care setting would be in the best interest for the person with dementia and their carer.

From the Healthwatch Suffolk dementia report, we know that families sometimes felt pressured to find and accept a home placement quickly and for many carers they found the transition of moving their relative into a care home difficult to manage, not just for them but for the person with dementia. It is therefore vital that health and adult social care colleagues work closely with care homes and families to support the transition for everyone involved.

The cost of adult social care for people with dementia is set to nearly treble by **2040**, increasing from **£16.9 billion** to **£45.4 billion**[34]

Placements in care homes can often be more complex if a person with dementia has been in hospital for an extended period. This may have an impact on the way that they present, which could be through distress or lack of engagement, both needing more care and support than when they first came into hospital.

To understand the individual, potentially complex, needs of the person with dementia, health and adult social care professionals need to have open, honest, and transparent conversations with carers and care homes to ensure that the right level of care and support can be made available for that person. We know from conversations with care homes, that they feel there is limited support offered once a person with a diagnosis of dementia is placed in their care home. There can often be limited information about the person's needs, which means that care home staff are not equipped or trained to best support that person. This can result in escalation to the point where emergency services are involved, and a return to acute care which will increase the anxiety and distress for that person with dementia.

"We are not a crisis intervention team, we are a care home, we need the right levels of training and support from other professionals when people are in distress." *care home manager*

It is vital that care home managers and staff have the right training to understand and manage more complex situations, as well as having robust and accessible links with specialist services within health, mental health, and adult social care. This should include the availability of specialist training and face to face support for care homes, including oversight from GP practices as part of the Enhanced Health in Care Homes (EHCH)[35] model. Enhanced Health in Care Homes ensures that the best quality care is offered by all residential and nursing homes. This includes supporting the physical and mental health of people living in a care home, reviewing medication, including anti-psychotics, and ensuring that advance care plans[36] are already in place. In Suffolk there are also GP Care Home Leads who support care homes to diagnose people living with advanced dementia in a care home setting using the DiADeM (Diagnosing Advanced Dementia Mandate) tool,[37] to ensure that they get the right care and support they need without having to attend a memory assessment clinic.

"She is a different person, she's happy, she's settled, she's cared for and blessed. There is still things that are not perfect but just the level of care and it's like they really treat her like they want her there and she's cherished." *family carer*

Priority 3b. When there is a need for a care home placement: ensure the right level of personalised care and support is consistently

[33] https://www.legislation.gov.uk/ukpga/1983/20/contents

[34] https://www.alzheimers.org.uk/about-us/news-and-media/facts-media

[35] https://www.england.nhs.uk/community-health-services/ehch/

[36] https://www.dementiauk.org/information-and-support/financial-and-legal-support/advance-care-planning

[37] https://www.alzheimers.org.uk/dementia-professionals/resources-gps/diadem-diagnosing-advanced-dementia-mandate

offered once a person with dementia has been placed in a care home setting

Outcome 3b. When there is a need for a care home placement: care home staff will know who to contact in health and adult social care to ensure that any concerns they have are supported in a timely manner

3c. When there is a need for a hospital admission

We recognise that not all care can be provided in the community and there may be a time when a person needs to access acute care on a planned urgent or emergency basis in an acute hospital bed.

there may be a time when a person with dementia needs to access urgent and emergency care in an acute hospital bed.

Health and adult social care providers need to work together swiftly and cohesively to support the person with dementia who will often be at their most vulnerable. This will include ensuring that their individual needs and care plans are reviewed to prevent unnecessary admissions. If an admission is unavoidable, then health and social care professionals should work together to look at ways to reduce the length of stay for that person. If there is a possibility to use a virtual ward[38] to support that person in their own environment with regular contact from health professionals, then this should be considered.

"He was on a trolley in the corridor in A&E for ages, not knowing what was going on and very confused, and disorientated." family carer

Evidence from NICE guidance hospital care[39] states that people with dementia will often experience longer hospital stays, delays in leaving hospital and reduced independent living. Hospital admission can trigger distress, contributing to a decline in functioning and a reduced ability to return home to independent living.

From the Healthwatch Suffolk dementia report we heard of issues experienced by carers in hospital due to limited resources, including beds, equipment, staffing and lack of dementia knowledge and training.

'I had to tell them my wife had dementia.' family carer

Key learning from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers
Admission avoidance and step-down support
- Improve dementia knowledge in hospitals
- Prevent rapid deterioration by providing the right care environment
- Improve discharge planning with families
- Listen to carers

"It's not that we don't want to help more but we do not always have the time needed, skills, or knowledge to support the specific needs of a patient with dementia or their family, we need more help to support people with dementia and their families" nurse

Hospital staff also fed back that they were sometimes unable to provide the support that they wanted to due to time pressures and lack of training to support people with dementia and their carers. This often led to an escalation in distress for the person with dementia, particularly when confined to a bed

[38] https://www.england.nhs.uk/virtual-wards/

[39] https://www.nice.org.uk/about/what-we-do/into-practice/measuring-the-use-of-nice-guidance/impact-of-our-guidance/niceimpact-dementia/ch3-hospital-care

for too long or when they received a lack of attention to manage their daily needs.

"I had to fight my case to stay with my mum, but then, after trying to communicate with my mum, they realised that I did need to be there." *family carer*

Family members and carers also told us that hospitals should listen to them more and allow them to support a person whilst in hospital should they wish to. There should also be more flexibility for a person with dementia. This includes:

- when meals are provided and choice around finger foods over a main meal
- allowing people to sleep and wake when they want to
- varied visiting times for carers and families
- providing activities that are meaningful to the person and support their emotional wellbeing whilst staying in hospital
- support for families and carers to remain engaged and continue to support that person whilst in hospital
- looking at how to improve the "dementia friendliness" of the hospital environment, and any tools which would help better communicate a person's needs
- reviewing all aspects of a person especially if they display distress, including physical health and medication together with the symptoms of their dementia diagnosis. This should include ensuring people are screened to identify delirium, which is common for people with dementia so that can be appropriately treated.

"...in the end, I took my own whiteboard marker and filled it in, so that they knew... because it sounds simple, but some of those things (people's preferences in hospital) are so vital." *family care*

It is important to ensure that staff have the right level of training throughout the trusts, so that they have the confidence to support and communicate with people with dementia, allowing them to remain physically and emotionally independent during their stay in hospital, reducing the risk of physical and cognitive decline.

Staff also need to be able communicate and work with carers and families to ensure that the person with dementia's needs are met whilst staying in hospital. Where there are decisions to be made about a person's future care needs, everyone should be part of these discussions including the person with dementia.

We also heard from the Healthwatch Suffolk dementia report that carers and families are not always involved in discharge planning, often resulting in a poor experience and negative impact on both the person with dementia and their family. It is important that professionals involved in discharge planning take into consideration factors such as the potential impact of what time of day a person is being discharged, whether they have the right equipment available before leaving the hospital and, if they are going back to familiar, or new, surroundings. We recognise that health and adult social care professionals are frequently under pressure, and it is important that we listen to them to ensure they have the right support and training to enable them to deliver the best quality care to people with dementia and their families.

Priority 3c. When there is a need for a hospital admission: ensure that our acute settings are dementia friendly and that the right levels of training and education is provided to help communicate well with and support people with dementia and their families

Outcome 3c. When there is a need for a hospital admission: carers, families, and the person with dementia will be involved in decisions around admission and discharge, as well as future care planning

3d. When there is a need for inpatient care for older people with mental health services

Sometime people with a diagnosis of dementia will require additional specialist care necessitating admission to an older person's mental health inpatient unit or dementia assessment bed in hospital. As with any healthcare setting, care should be delivered in a person-centred, holistic, and respectful way. The Healthwatch Suffolk report identifies that carers often experience challenges in transfers of responsibility of care, and many carers felt they were being passed from service to service without any real progress.

Priority 3d. When there is a need for inpatient care for older people with mental health services: ensure there a jointly agreed clear pathway and way of working across health and social care with shared multi-disciplinary meetings, responsibility and shared care agreements which offer consistency of care for people with dementia and their families

Outcome 3c. When there is a need for inpatient care for older people with mental health services: services will work together to jointly assess a person with dementia's needs holistically to ensure that they are supported in a safe and personalised way, alongside the needs of their families

4. Living Well
Providing support for people with dementia and their families

4a. Keeping independent for longer

Lived experiences of those with dementia, including their carers and families are key to changing the way we think about dementia in Suffolk. Through comprehensive engagement with the wider statutory and voluntary sector we have listened carefully to what people with dementia are experiencing and heard how individuals, families and carers manage the changes that they encountered and the diverse ways they cope.

Key learning about from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers
- Improve integrated care
- Coordinate resources
- Support families to participate
- Improve communication between services

"You're still the same person you were before you got the diagnosis of dementia." person with dementia

To enable people to live well with dementia we need to meet the needs of the individual and create a support system around them, delivered in their own community that:

- enables them to remain at home and live independently for as long as possible
- enables them to access services in person which are visible, delivered locally, and at a place that is familiar
- responds to the individual needs of the carers and families
- responds to the language, cultural beliefs, or specific needs such as those with young onset dementia, learning disabilities or sensory issues.

"Make life about the 'I can dos not the can't dos." person with dementia

We know that everyone's needs are different, and how we support one person to live with dementia will be very different to another. We need to continue to work with, and listen to, the dementia advisors from our pre and post diagnostic service[40] who already provide support in the community, along with our third sector organisations who support people on a day-to-day basis.

Key learning about from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers
- Communicate about the services consistently
- Help people to know how to access support
- Be clear with people about the service offer
- Aim for services to be a guide
- Support people to find digital solutions that help
- Clarify and differentiate support for those with young onset dementia

The pre and post diagnostic service should continue to work flexibly with the community and wider system to provide a multi-disciplinary approach, contributing to the individual needs of the person with dementia, their carers, and families to ensure:

- that people have the right information to identify the signs and symptoms[41] of

[40] https://www.alzheimers.org.uk/support-services/Suffolk%20Local%20Services/Dementia%20Connect%20-%20Suffolk/regional norfolk@alzheimers.org.uk

[41] https://www.alzheimers.org.uk/about-dementia/five-things-you-should-know-about-dementia

dementia and what steps they need to take should they wish to have a diagnosis.

- that the person with dementia can express who they are and their needs to the people who care and support them, using documents such as "This is Me"[42]
- that the needs of the carer and other family members or friends are included in a carers assessment[43].
- that support is available for healthy behaviours, including exercises to reduce falls, advice on healthy eating, reducing smoking and drinking.
- that memory is also supported, realising the benefits of cognitive stimulation.
- that people are aware of the benefits of making decisions earlier in their diagnosis so they can choose how they are supported in the future, including lasting power of attorney, My Care Wishes (Yellow Folder) or My Care Record[44] ReSPECT[45] and Advance Care Plans (ACP)[46]
- that people are connecting with their local community by accessing Suffolk Infolink[47] and Alzheimer's Dementia Voice[48] to find local peer to peer support networks, groups and activities that promote inclusive communities

Priority 4a. Improve lifestyles: ensure that people are provided with person centred, holistic support that empowers independence and healthy behaviours

Outcome 4a. Improve lifestyles: people with dementia, carers and families will know where to get support which will enable them to remain part of their community for longer by accessing inclusive groups and activities

4b. Support to stay well: with dementia

For people to live well and independently with a diagnosis of dementia we need to ensure that they are listened to and that their voice is heard, by offering the right support and advice to keep them safe. This should include:

Staying Safe in the home

Housing agencies and the Independent Living Suffolk service[49] should support people with dementia to continue to live independently, by providing a range of housing or extra care facilities and access to physical adaptations along with digital solutions in existing home utilising the care technology offer from Cassius[50].

Supporting people with dementia experiencing distress

People with a diagnosis of dementia may experience times when they are fearful, frustrated, or distressed, often when they are unable to communicate an unmet need. This can also have an impact on carers and family members if they are unable to help that person at their most vulnerable.

An understanding of the changes in a person's behaviour needs to be developed by taking into consideration their environment, physical and mental health, underlying

[42] https://www.suffolkuserforum.co.uk/this-is-me-a-support-tool-to-enable-person-centred-care/ https://carersmatternorfolk.org.uk/this-is-me/

[43] https://www.suffolk.gov.uk/care-and-support-for-adults/caring-for-someone/carers-assessments https://suffolkfamilycarers.org/carers-resources/carers-assessments/

[44] https://suffolkandnortheastessex.icb.nhs.uk/health-and-care-professionals-area/care-home-support/my-care-wishes-yellow-folders/ https://www.nnuh.nhs.uk/publicatioriorityPn/norfolk-and-waveney-my-care-record/

[45] https://suffolkandnortheastessex.icb.nhs.uk/health-and-care-professionals-area/support-for-primary-care/respect/ https://wearenchc.nhs.uk/news/respect/

[46] https://www.health-ni.gov.uk/advance-care-planning-now-and-future

[47] https://infolink.suffolk.gov.uk/kb5/suffolk/infolink/home.page

[48] https://www.alzheimers.org.uk/get-involved/dementia-voice

[49] https://www.suffolk.gov.uk/care-and-support-for-adults/how-social-care-can-help/independent-living-suffolk

[50] https://www.suffolk.gov.uk/care-and-support-for-adults/help-to-stay-at-home/technology-to-help-you-live-independently

medical issues such as pain or infection, and reviewing any medication they are on. Having this information will help health and adult social care providers develop a plan to support a person's needs. This will help others understand why they are experiencing distress and how to respond to them, to improve the quality of their life and help them to live independently.
At times, if a person's level of distress impacts on their own safety and is a risk to themselves and others, it may be appropriate, after all other psychosocial interventions have been utilised, to use medication such as 'anti-psychotics.' This should be seen as a last option and only as a short-term intervention, audited and monitored carefully by health professionals to ensure that it meets published guidelines by NICE (National Institute for Excellence)[51] and recommendations from NHS England[52]. Anti-psychotics should not be overused and seen as a long-term solution to manage any person's distress.

Herbert Protocol

The 'Herbert Protocol'[53] can be used should an adult go missing.

A form can be completed to provide pertinent information about the person with dementia, such as any health issues, and include a recent picture of them.

The form can then be handed to the police to help the investigation to locate them more quickly, safeguard them more effectively, and return them to safety.

The Herbert Protocol has been used many times to trace missing people with a diagnosis of dementia and return them home. It is another example of how emergency and care services are working together to keep those with dementia safe.

Advocacy

Advocacy and advocate can mean something different to different people. Friends and family may see themselves as an "advocate" for the person with a diagnosis of dementia to ensure that their wishes are met and professionals in health and adult social care may need to advocate for people they support. However, in some situations the need for a professional independent advocate is necessary to help understand the rights they have and support them to communicate their own choices and challenge a decision.

Suffolk Advocacy Service is delivered by a partnership which includes POhWER[54], Suffolk Family Carers[55], ACE Anglia[56] and Suffolk User Forum[57] who provide professional independent advocates to work with individuals across Suffolk.

Capacity

The purpose of the Mental Capacity (Amendment) Act 2019[58] is to reform the process under the Mental Capacity Act 2005 ("MCA")[59] which protects individuals who lack capacity to make specific decisions. It also ensures that they can still participate as much as possible in any decisions made on their behalf and in their best interests. The MCA also allows people to express their preferences for care and treatment, and to appoint a trusted person to decide on their behalf should they lack capacity in the future.

Safeguarding

It is important to recognise that people with dementia and protected characteristics, including learning, sensory and communication difficulties are often at a higher risk of abuse or neglect.

---

51 https://cks.nice.org.uk/topics/dementia/prescribing-information/antipsychotics/

52 https://www.england.nhs.uk/london/wp-content/uploads/sites/8/2022/10/Antipsychotic-Prescribing-Toolkit-for-Dementia.pdf

53 https://www.suffolk.gov.uk/care-and-support-for-adults/caring-for-someone/family-carers-emergency-plan

54 https://www.pohwer.net/suffolk-advocacy-service

55 https://suffolkfamilycarers.org/

56 https://www.aceanglia.com/

57 https://www.suffolkuserforum.co.uk/

58 https://www.legislation.gov.uk/ukpga/2019/18/enacted

59 https://www.legislation.gov.uk/ukpga/2005/9/contents

Dementia UK is projecting that it will receive **9 times** more safeguarding calls in **2023** that it did in **2021**.

It is also important that we continue to engage with services that support and work with vulnerable people about dementia. Including probation, homeless, traveller communities, refugee / asylum seekers (where English may not be their first language), substance misuse, mental health and those people who live on their own and are isolated. Giving choice and control is at the heart of planning, commissioning, and delivery of health and adult social care support in Suffolk. The Care Act 2014[60] and the White Paper, People at the Heart of Care[61] strengthen and support existing safeguarding arrangements and are embedded in all work and training across the workforce.

Key learning about from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers regarding support from healthcare professionals
- Make sure people receive an annual review
- Compassion and empathic responses are important
- Make reasonable adjustments
- Help people to access support

Priority 4b. Support to stay well: with dementia: ensure that people with dementia can receive person centred care and support which is flexible

Outcome 4b. Support to stay well: with dementia: people with dementia will be seen independent of their carer and provided with support within their community

4c. Support to stay well: as a carer

"It is unrelenting. A day will arrive when I cannot cope. I cannot make plans for future events. I am not equipped or educated to deal with his decline, but I am doing my best on a daily basis." *family carer*

We know from the Suffolk All Age Carers Strategy[62] that caring looks different from carer to carer and circumstances. The definition of carer can also be very different it could mean someone who is a paid to care for someone, a paid carer[63] or unpaid carer[64] usually a family member. Unpaid carers are all ages from young carer, sibling carers, young adult carers, adult carers, sandwich carers, working carers, older adults, carers over 75 and those after caring/between caring. It is important that the wellbeing of the unpaid carer should not be forgotten when caring for a person with dementia, there is often an assumption that the family will automatically be responsible for the continued care of an individual and feel that they have no choice but to care, but in reality, for example they may have to work or have their own health concerns. It is therefore important to for professionals to acknowledge the support unpaid carers and families undertake and identify when there is a need for their unpaid carer to manage their own physical health and emotional wellbeing, as well as the person they care for, or when there is a need for additional care and support to be put in place.

[60] https://www.legislation.gov.uk/ukpga/2014/23/contents/enacted

[61] https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper/people-at-the-heart-of-care-adult-social-care-reform

[62] https://www.suffolk.gov.uk/asset-library/imported/digital-version-aacs-2022-2027-1.pdf

[63] https://www.nhs.uk/conditions/social-care-and-support-guide/care-services-equipment-and-care-homes/homecare

[64] https://www.england.nhs.uk/commissioning/comm-carers/carers/

Priority 4c. Support to stay well: as a carer: ensure that carers and families can receive person centred care and support which is flexible

Outcome 4c. Support to stay well: as a carer: carers and families will be seen independent of the person with dementia that they care for and provided with support within their community

This includes:

Family Carer Emergency Plan

Carers are encouraged to complete a Family Carer Emergency Plan[65] in advance, identifying contingency plans for what needs to happen to the person cared for in the case of an emergency. This includes identification of an alternative emergency contact if the main carer for someone is unable to provide care for whatever reason. Once completed, the plan is held on Suffolk County Council's case management system within the records of the person being cared for.

[65] https://www.suffolk.gov.uk/care-and-support-for-adults/caring-for-someone/family-carers-emergency-plan

5. Dying Well
Having the opportunity to prepare for death

End of Life and Palliative care

The Office of National Statistics reported that dementia and Alzheimer's disease had been the leading cause of death in England for 24 consecutive months since June 2021. In July 2023, dementia and Alzheimer's disease was the second leading cause of death, (coronary heart disease (CHD) being the first) with 75.5 deaths per 100,000 in England (3,782 deaths)[66].

The Cicely Saunders International Centre paper "A right to be heard"[67], reported that 'Dementia is frequently not recognised as a life-limiting condition nor considered suitable for palliative care. Too often people affected by dementia have limited access to support in the community and experience high hospital use and a high burden of suffering. They deserve better.'

"I didn't just lose my wife, I lost her a long time ago when she forgot who I was" family carer

Due to the complexities of dementia, it can be difficult to know when a person is nearing the end of their life as dementia can be slow to progress, sometimes over a number of years. Many carers, families and friends told us that they experienced prolonged grief with multiple losses, including the progression of dementia, the person not being able to recognise or remember who they were, and then finally when the person with dementia passed away.

Priority 5a. Improve understanding of end-of-life care for the carer: ensure that carers and families are aware if the process of dying

Outcome 5a. Improve understanding of end-of-life care for the carer: families will be more prepared at end of life and what options are available

"I'm not gonna be a carer for the last few days of my dad's life. I want to be his daughter."
family carer

Priority 5b. Improve the needs at end of life for the person with dementia: ensure that the people are aware of the options they have at end of life

Outcome 5b. Improve the needs at end of life for the person with dementia: people will be aware of what the end-of-life options are earlier, which supports how they wishes and can be communicated to families and professionals

From the Healthwatch Suffolk dementia report and engagement, carers and families shared that they felt that there could have been more done to support them and the person they were caring for, throughout their dementia journey and at the end of their lives. Many carers reported feeling alone when delivering care at the end of life with fragmented support from the system. These findings were also reflected in the Suffolk Healthwatch End of Life care report[68]

"I don't care whose role it is I just need help."
family carer

[66] https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/deaths/bulletins/monthlymortalityanalysisenglandandwales/july2023#:~:text=Dementia%20and%20Alzheimers%20disease%20had,in%20Wales%20(250%20deaths)

[67] https://www.kcl.ac.uk/nmpc/assets/a-right-to-be-heard-policy-brief.pdf

[68] https://healthwatchsuffolk.co.uk/wp-content/uploads/2021/07/End-of-life-care-in-Suffolk-and-north-east-Essex-1.pdf

Priority 5c. Improve end of life care: ensure that people with dementia, and their families, receive person centred care and support that adapts as the needs of an individual increases

Outcome 5c. Improve end of life care: systems will work together in a person-centred holistic way that is supportive to people with a diagnosis of dementia and their families

Key learning from the Healthwatch Suffolk dementia report from conversations with people with dementia and carers and recommendations from the Healthwatch Suffolk End of Life care report

-Prevent people from being passed between services at the end of life

- Ensuring people have access to the information and tools they need to prepare for death.

- Exploring the opportunities that digital offers bring to helping people to access information about services and support.

- Helping people to understand more about what to expect when a person is at the end of their life (signs, symptoms, and support).

- Improving communication and integration between the services providing support, and ensuring people know what to expect from each of them.

- Making sure people understand what they have been told about their prognosis.

- Ensuring that all conversations with professionals (at all levels within organisations), are compassionate.

- Ensuring people have the option of support from someone they know, or a professional, at key moments

How we will achieve this

An action plan will be co-produced with those with lived experiences of dementia, the wider statutory and voluntary sector and health and social care partners to ensure that governance and ownership of the commitments within this strategy are upheld. We will continue to build on established relationships in the community, learning from existing local approaches to dementia to ensure that people with dementia, their carers, families, and friends are at the centre of everything we do.

We are continuing to review communication, awareness, and accessibility to make it easier for people to access all forms of information, advice, support, and we will work together to offer consistency of service across county boundaries.

By reviewing population health management data and integrated care management[69] we will ensure we understand the challenges across Suffolk now and in the future and are monitoring our progress in addressing them.

Implementation of the strategy via the action plan will focus on priorities over the next five years and will be overseen by the Dementia Action Partnership. Progress will be reported to the Suffolk Health and Wellbeing Board and other boards and committees across health and social care as required. After two years a review will be undertaken by Healthwatch Suffolk to engage with both services and people with lived experience to understand the progress made.

[69] https://www.england.nhs.uk/integratedcare/what-is-integrated-care/phm

Appendix 1. Protected characteristics and dementia

Everyone is different and to ensure that Suffolk meets the needs of the whole population, the following themes and actions have been identified as areas warranting particular attention across the dementia pathway. All areas of service development arising from this strategy must acknowledge, accommodate, and address these.,

Young onset dementia
People who are diagnosed with dementia at a younger age will often have different needs to those diagnosed later in their lives. Many may:

- be carers for children, parents, or their partner
- working full time and have financial commitments, some may be the main or sole provider of income
- be more physically active, fitter, and stronger than those who are much older

There are over 42,000 people under 65 with dementia in the UK. This is known as young on-set dementia[70]. However new figures show a 'hidden population' of 70,800 people in the UK who are currently living with young onset dementia — a rise of 28,800 (69 per cent) since 2014[71].

Learning disabilities and dementia
People with learning disabilities[72] have a higher risk of getting dementia compared to the rest of the population. The Alzheimer's Society reported that people with a learning disability are more likely to get dementia at a younger age. About 1 in 5 people with learning disabilities who are over the age of 65 will develop dementia. People with Down's Syndrome have an even higher risk, with about 2 in 3 people over the age of 60 developing dementia, usually Alzheimer's disease[73].

Making a diagnosis of dementia can be more difficult for people who have a condition that may limit the way they communicate the symptoms they are experiencing, and have difficulties with short term memory, or clarifying information.

Sensory and physical impairment and dementia
People with dementia may have a form of sensory impairment (such as Deafness, blindness, visual impairment, hearing impairment and Deaf blindness) or physical impairment (such as physical functioning, mobility, dexterity, or stamina). Services need to ensure that reasonable adjustment is made to ensure people have time to communicate their individual needs and how they wish to be supported.

Gender
65% of the 944,000 people living with dementia in the UK are women. Two-thirds of unpaid carers for those with dementia are women. By the age of 60, 1 in 5 women will have provided unpaid care to an elderly friend or relative[74].

Lesbian, Gay Bisexual, Transgender, Queer, Intersex, and Asexual (LGBTQIA+)
The Bring Dementia Out programme from the LGBT Foundation suggests that there are around 68,000 LGBTQIA+ people living with dementia in the UK. People who are diagnosis with dementia will often have concerns about future personal care and how services will support them based on their individual needs. The Alzheimer's Society reports the difficulties that impact LGBTQIA+ people with a diagnosis of dementia, which includes not being able to remember they have transitioned, are in the process of transitioning or that they have shared their sexual

70 https://www.alzheimers.org.uk/about-dementia/types-dementia/young-onset-dementia

71 https://www.dementiauk.org/news/new-figures-show-70800-uk-adults-are-affected-by-young-onset-dementia/

72 https://www.alzheimers.org.uk/about-dementia/types-dementia/learning-disabilities-dementia

73 https://www.mencap.org.uk/learning-disability-explained/learning-difficulties

74 https://dementiastatistics.org/about-dementia/prevalence-and-incidence/

orientation of gender identity. This can cause the person with the diagnosis of dementia further anxiety. It is therefore important that health and social care professionals understand the impact that memory loss can have on an individual and how they identify themselves[75].

Ethnic Minority Background (EMB) (including Gypsy, Roma, and Irish Traveller groups).

There are more than 25,000 people currently living with dementia from Black, Asian and minority ethnic groups, which includes the Travelling community in England. This is expected to exceed 172,000 people by 2051 – a seven-fold increase in comparison to a two-fold increase among the wider population.[76]

In Suffolk, census data indicates 93.1% of the population were classified as White (compared to 81.0% for England). Whilst Suffolk is less diverse than England, diversity has increased compared to the last census. There is variation within Suffolk, with Ipswich having the lowest percentage of White population at 84.3% and Mid Suffolk having the highest percentage of White population at 96.8%[77].

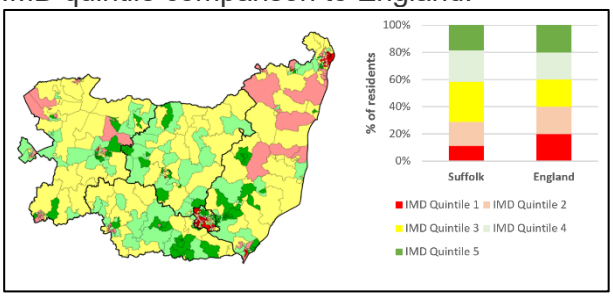
Ensuring people from an EMB background can access services when they need to easily is key to reducing the stigma and fear that may relate to a diagnosis of dementia. In some cultures, and faiths there may not be a word or meaning for dementia which can lead to a reluctancy to access services. It is therefore important that information, advice, and support is provided in a format that is culturally appropriate and meaningful when it is needed.

Socio-economic disadvantage

Alzheimer's Research links socioeconomic deprivation, including neighbourhood disadvantages and persistent low wages, to higher dementia risk, lower cognitive performance, and faster memory decline. Findings, from four separate studies, also show that people who experience high socioeconomic deprivation are significantly more likely to develop dementia compared to people who live in more affluent areas[78].

The English Index of Multiple Deprivation (IMD) was published in 2019 and provides a way of comparing relative deprivation across small areas in England. The 20% most deprived areas are shown in red in the map below. 11.3% of small areas within Suffolk fall within the most deprived areas nationally and are situated primarily within Lowestoft and Ipswich.

Figure 2: Suffolk IMD map by LSOA area and IMD quintile comparison to England.



Source: English indices of deprivation 2019

Rural and remote areas

Rural areas tend to be inhabited by more older people and thus have a higher prevalence of dementia. Combined with lower population densities and more sparse geography, rural areas pose numerous barriers and costs relating to support and resource provision.[79]

Suffolk is a predominantly rural and ageing county, where 1 in 4 people (23.6%) are aged 65 and over, compared to around 1 in 5 for England (18.6%). Furthermore, the population aged 65 and over is forecast to increase over the next 20 years – when 1 in 3 people are predicted to be aged 65 and over.

Being part of a rural / remote community can have its benefits for a person with a diagnosis of dementia, it can provide familiarity, established trusted community networks as well as green spaces which can benefit well-being.

[75] https://www.alzheimers.org.uk/get-support/help-dementia-care/lgbtq-dementia-memory-problemS

[76] https://www.dementiauk.org/dementia-care-gypsy-roma-travelling-communities/

[77] https://www.suffolkobservatory.info/

[78] https://www.alzheimersresearchuk.org/bolder-government-action-is-needed-to-address-inequalities-in-dementia-risk-says-alzheimers-research-uk/

[79] https://www.alzheimersresearchuk.org/bolder-government-action-is-needed-to-address-inequalities-in-dementia-risk-says-alzheimers-research

However, some people who live in rural / remote areas with a diagnosis of dementia, may experience further challenges such as isolation due to lack of transport and access to services which may not be local. Carers may also experience further isolation if they are unable to drive or access public transport as the persons condition progresses, due to increased anxiety or changes in mood, meaning they are restricted as to when they can leave their house, impacting on their own health and wellbeing.