Stoke-on-Trent Dementia Strategy

2025 – 2029

Content page

Foreword

Dementia is a condition that touches the lives of millions of people, including those living with a diagnosis, their families and carers. As our population ages, the prevalence of dementia is expected to rise, making it imperative that we develop comprehensive strategies to address the challenges.

In Stoke-on-Trent, we have been working with our partners to improve services and support for people living with dementia and their carers. As a result, there has been great improvement in our diagnosis rates and the services available to support people with dementia and their carers.
There is still much to be done. With access to the right support, treatment, and care people can live well with dementia. This is the message that we want to spread loud and clear throughout the city. People with dementia and their carers must have a voice; be actively involved in shaping and developing services; and feel truly part of their communities.

We will continue to work closely with our partners through the Stoke-on-Trent and North Staffordshire Dementia Steering Group. We thank all members of this multi-agency group for their on-going commitment, support and contributions. The Dementia Strategy for Stoke-on-Trent is jointly presented by Stoke-on-Trent City Council and Stoke-on-Trent's Integrated Care Board. The strategy sets out our shared vision and aspirations for improving dementia services within the city over the next four years.

Thank you to everyone who has contributed to the development of this strategy. Your dedication and passion are the driving forces behind our efforts to make a meaningful difference in the lives of those affected by dementia. Working together with our partners, we are committed to making this strategy a reality.

Cllr Duncan Walker

Cabinet member for Adult services

As the Clinical Director for Mental Health, Learning Disabilities, and Autism within Staffordshire and Stoke on Trent Integrated Care Board (ICB), it is with great pride and commitment that I introduce our new Dementia Strategy. Dementia touches the lives of many individuals, families, and communities, and it presents us with both challenges and opportunities to make a profound difference in the quality of the care and support we provide. People with Down Syndrome have a higher prevalence of dementia, particularly Alzheimer's Disease, and at a younger age, compared with the general population. This strategy aims to address the health inequalities currently faced by people with Down Syndrome with a focus on early screening, diagnosis, and support.

This strategy represents our unwavering dedication to creating a holistic, person-centred approach to dementia care. Our vision is clear: to ensure that every individual living with dementia, as well as their families and caregivers, receive compassionate, timely, and effective support. We recognise that dementia is not just a medical condition but a deeply personal experience that affects every aspect of a person's life. Therefore, our approach must be equally comprehensive, integrating medical, psychological, and social care in a seamless and supportive manner.

In developing this strategy, we have listened closely to the voices of those directly affected by dementia, as well as to the experiences and insights of our healthcare professionals, carers, and partner organisations. Their input has been invaluable in shaping our priorities and ensuring that our plans are both ambitious and grounded in the realities of those we serve.

Our focus is on prevention, early diagnosis and intervention, promoting well-being, supporting independence for as long as possible and a dignified end towards the end of life. At the same time, we are committed to ensuring that when more intensive care is needed, it is delivered with dignity, respect, and sensitivity to the individual's unique needs.

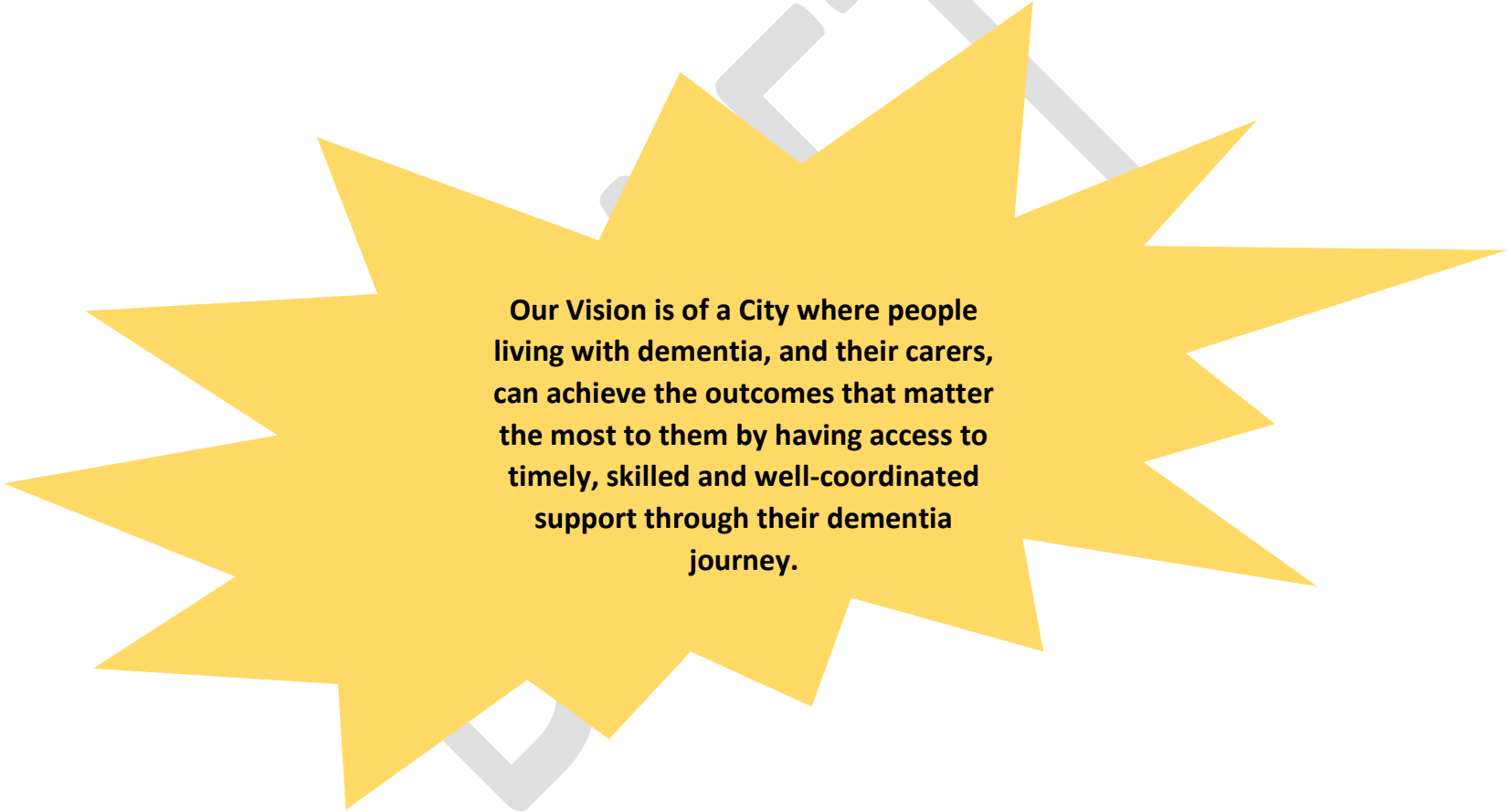
This strategy also acknowledges the importance of research and innovation. By staying at the forefront of emerging best practices and medical treatments in the form of disease modifying therapies (DMTs), we can continually improve the care we provide and offer hope to those diagnosed with early Alzheimer's and their loved ones.

The journey ahead will require collaboration, dedication, and a shared commitment to excellence. I am confident that with the collective efforts of our entire health and social care community, we will make significant strides in enhancing the lives of those affected by dementia. Together, we can build a future where individuals with dementia are supported to live well, with purpose and dignity, in communities that understand and respect their needs.

I invite you all to join us in this critical mission.

Dr Waheed Abbasi

Strategic Clinical Director for Mental Health, Learning Disabilities, and Autism Staffordshire and Stoke on Trent Integrated Care Board



Introduction

About our strategy

The Stoke-on-Trent Joint Dementia Strategy has been co-produced by Stoke-on-Trent City Council, Staffordshire and Stoke-on-Trent Integrated Care Board (ICB), Care providers, voluntary and community organisations, health and social care professionals, people living with dementia and their carers. This local strategy for the people of Stoke on Trent, leads on from 'Living Well with Dementia', and has been developed via extensive local engagement with key stakeholders. Our strategy sets out Stoke-on-Trent's vision and priorities for health and care services for the next four years. The key aims and outcomes which we want to achieve are based on what people living with dementia and their support networks have stated is most important to them. This invaluable feedback and co-production strengthen the strategic planning, service delivery and commissioning of support for people with dementia and their carers living in Stoke-on-Trent. It supports the Council's vision for the City set out in 'Our City, Our Wellbeing' on page 14.

The following key priorities, which underpin the strategy are:

1. **Prevention and Early Intervention – Spread the message 'Healthy Body, Healthy Mind'.**

2. **Diagnosis and Initial Support - Enabling equitable and timely access to diagnosis and support**

3. **Post Diagnosis Support – Ensuring access to appropriate support for people living with dementia, and their carers, enabling them to live well.**

4. **Future Care Planning – Ensuring safe and person-centred discussions about people's preferences for their future care**

An Implementation Plan will sit alongside this strategy to ensure that progress is made against the strategy and that relevant actions are taken to ensure we are working towards the above priorities.

Context

National Picture

Context

There are currently estimated to be 982,000 people living with dementia in the UK. There are projected to be 1.4 million people living with dementia by 2040. The cost of dementia in the UK is forecast to be £42 billion in 2024, increasing to £90 billion by 2040.

These numbers demonstrate the increasing scale and impact of dementia. There is an urgent need for action to be taken to meet current and future care needs.

Background

Rates of dementia are growing; Dementias, including those caused by Alzheimer's disease, are a leading cause of mortality in England, second only to coronavirus. Addressing these conditions is crucial for the NHS and Social Care services to alleviate the burden and enhance patient care. For example:

- 25% of acute hospital beds are occupied by people with dementia
- People with dementia stay in hospital twice as long as other people over age 65
- 90% of people with dementia found admission to hospital frightening and confusing
- 43% of people with dementia in hospital were due to urinary tract and chest infections (treatable in the community)
- 25% of people with dementia living in their own homes were admitted to hospital with a potentially treatable condition over a one-year period

Alzheimer's disease is the most common sub-type of dementia diagnosed. For December 2023 it was reported that Alzheimer's disease represented 44.6% of all dementia diagnoses.

A timely diagnosis of dementia is vital. It enables a person to access the advice, information, care, and support that can help them (and their carers) to live well with the condition. The national ambition for dementia, for at least two thirds (66.7%) of people with dementia to have received a formal diagnosis, was put in place in 2015. Prior to the pandemic, the dementia diagnosis rate (DDR) had tracked above the

ambition since 2016, however the pandemic had a significant impact on the numbers of people coming forward to primary care with dementia symptoms. In April 2020, the rate fell below the ambition.

In response to this, the December 2022 NHS Priorities and Operational Planning Guidance reinstated the focus on recovery of the DDR. We are now seeing a consistent, but gradual increase in the diagnosis rate. As of December 2023, the rate was 64.6%. With recent media focus on potential disease modifying treatments, we are also seeing an increase in referral rates to memory assessment services (MAS). From April to December 2023 there were 28,834 new referrals to memory clinics, a 17% increase compared to the same period in 2022.

National Policy and Strategy

Dementia has been the subject of a number of national policy documents and initiatives in recent years.

In 2009, the Department of Health published "**Living Well with Dementia**", a national dementia strategy which provided a framework to improve the development and delivery of dementia services. Three key areas were emphasised in the strategy which have guided service planning for a number of years:

- Improved awareness of dementia by the public and professionals
- Access to earlier diagnosis of dementia
- Support and empowerment to enable people to live well with dementia

These ideas were further developed in the **Prime Minister's Challenge on Dementia 2012 – 15** which contained a commitment to make England the best country in the world for dementia care, support, awareness, social action and research. This was followed up in 2015 by the **Challenge on Dementia 2020** which featured the **Well Pathway for Dementia**, outlining best practice in 5 areas:

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

A diagrammatic outline of the Well Pathway can be found within the appendices.

In August 2023, the DH published a policy paper entitled "**Major Conditions Strategy: Case for Change and our Strategic Framework".** At the time of writing a final strategy is being developed nationally. However, dementia features strongly in the paper as one of 6 identified major conditions that the strategy will seek to address.

The paper:

- Highlights that 70% of older people living in care homes may have dementia or severe memory problems
- Highlights that 77% of people with dementia also have at least one other specific health condition
- Commits to recover national diagnosis rates for dementia back to the national target of 66.7%
- Commits to double funding into dementia research to £160m per year in the financial year 2024/25
- Focuses on reducing the risk of dementia and raising the public's awareness of the risk factors of dementia including the wider determinants of health
- Announces the commissioning of the Office for Health Improvement and Disparities (OHID) to develop a resource to support investigation into the current variation in dementia diagnosis rates nationally.

The paper's vision is stated as:

"Our vision is to improve the lives of those living with dementia and their carers now, as well as the lives of those who may be affected in the future. We must create a society where every person with dementia, their families and carers, receive high quality compassionate care from diagnosis through to end of life."

NICE Guidelines

The National Institute for Clinical Excellence (NICE) has published a number of guidelines relating to the care and support of people with dementia. These guidelines outline accepted best practice and it is expected that services commissioned and/or provided by the NHS or Local Authorities operate according to these guidelines.

NG97 – Dementia: assessment, management and support for people living with dementia and their carers

NG16 – Dementia, disability and frailty in later life – mid-life approaches to delay or prevent onset

Inequalities in Dementia

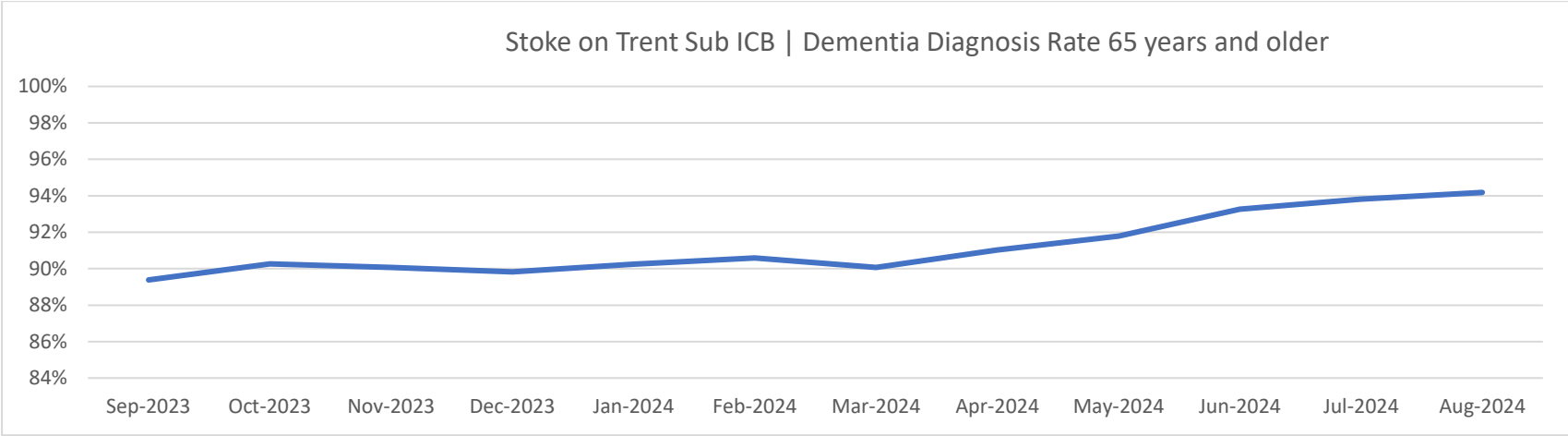
Alzheimers Research UK reports that although Dementia impacts people from all backgrounds and communities, there are significant inequalities in dementia risk, incidence, diagnosis and management. Some of these inequalities reported include:

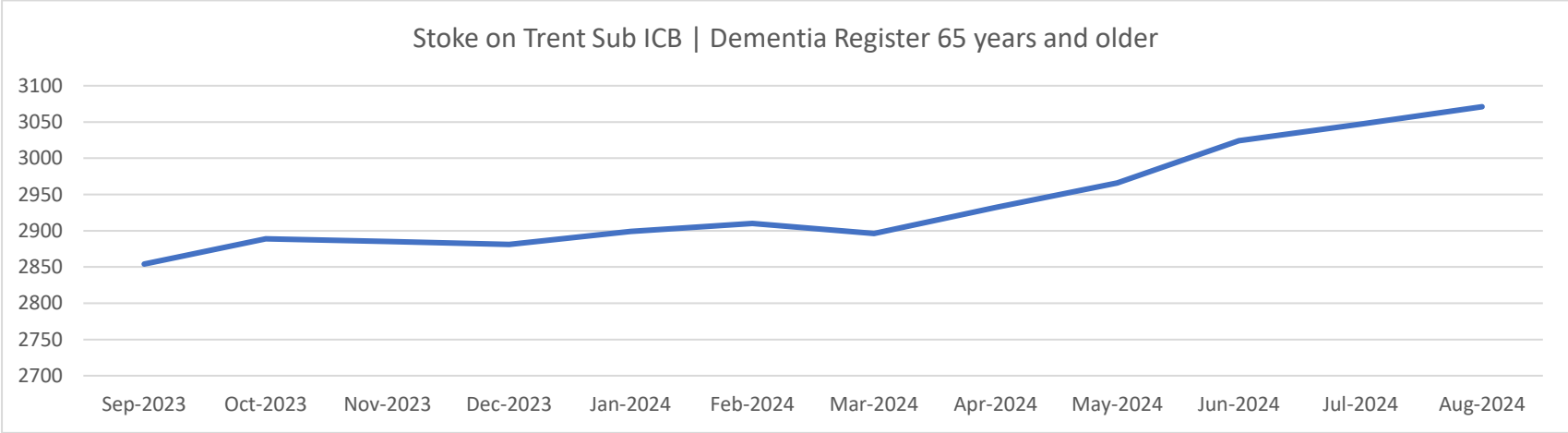
- Sex and Gender: Women are more likely to develop dementia than men, and they are more likely to become a carer for someone with dementia.
- Socioeconomic status: People in lower socioeconomic groups in the UK are exposed to a higher risk of developing dementia, and may face additional barriers such as limited access to healthcare services.
- Ethnicity: People from Black, Asian and minority ethnic communities living in the UK may be at a higher risk of developing dementia due to increased exposure to dementia risk factors.
- Down's Syndrome: People with Down's Syndrome are at a higher risk of developing dementia.
- You can read more from Alzheimers Research UK on and 'Tackling Inequalities in Dementia Risk'

Local Data

Summary of Overall ICB Performance - Patients aged 65 and over *(as of August 2024)* in Stoke on Trent.

Sub ICB Location	Total Expected Numbers	Total Number of Patients on Dementia Diagnosis Register	Diagnosis Rate	Target
STOKE-ON-TRENT SUB ICB - 05W	3,248	3,047	93.8%	66.7%





<u>Current predicted and past Dementia Statistics in Stoke-on-Trent</u>

People Aged Over 65

Across England it was estimated that just under 789,500 people aged over 65 were living with dementia in 2023. This figure is predicted to rise to 929,000 by 2030 and rise again to 1,149,455 by 2040. This is a rise of just over 45%.

In Stoke-on-Trent, the number of people aged over 65 is predicted to grow steadily between 2023 and 2040:

2023 – 46,100 people aged over 65

2030 – 51,300 people aged over 65

2040 – 56,000 people aged over 65[1]

This population increase is reflected in a predicted increase in the numbers of people aged over 65 in the City who will live with dementia:

2023 – 3,034 people aged over 65 with dementia

2030 – 3,416 people aged over 65 with dementia

2040 – 4,083 people aged over 65 with dementia

People Aged Under 65 – "Young Onset Dementia"

It must be remembered that although dementia is often characterised as a disease that affects older people in the population, dementia is not an age-related disease and is not a normal part of aging. Predicted figures for young onset dementia suggest that between 60 – 65 people in Stoke-on-Trent will be living with dementia whilst aged between 30 and 60 years old.[2]

2023- 65 people under the age of 65 with dementia

2030- 64 people under the age of 65 with dementia

2040- 60 people under the age of 65 with dementia

[1] POPPI website accessed Feb 2024
[2] PANSI website accessed Feb 2024

Learning Disabilities and Dementia

According to the Alzheimer's Society, 2 in every 3 people diagnosed with Downs Syndrome are more likely to be diagnosed with dementia and are at a greater risk of developing dementia during their lifetime. Looking at the predicted population for Stoke-on-Trent we can see that the number of people with Downs' Syndrome is predicted to remain static up to 2040:

2023 – 97 people aged 55 – 64 with Downs' Syndrome

2030 – 98 people aged 55 – 64 with Downs' Syndrome

2040 – 99 people aged 55 – 64 with Downs' Syndrome[3]

Using the Alzheimer's Society estimate referred to above, it is thought that there will be around 66 people in Stoke-on-Trent living with a learning disability and dementia.

Dementia Diagnosis Rates

NHS England has established and monitors a national target to ensure that at least 66.7% of people living with dementia in any given area receive a diagnosis and appropriate follow-up January 2024, the Dementia Diagnosis Rate in Stoke-on-Trent was over 90%, which is among the highest rates in England. This means that over 90% of the population in the City expected to have dementia have received a formal diagnosis of their condition.

There is some variation in dementia diagnosis rates across the City broken down by Primary Care Network (PCN). A PCN is a group of GP practices working closely together, aligned to other health and social care staff and organisations, providing integrated services to their local population. A PCN covers a patient population, of 30,000 – 50,000 patients, although by approval of the commissioner, this may be lower in rural and remote areas, and higher where it is appropriate. The lowest diagnosis rate for a PCN area is 71.6% which is above the national target rate.

[3] PANSI website accessed Feb 2024

This high diagnosis rate is the result of sustained investment and awareness raising into dementia services over a number of years, and an excellent example of joint working between health and social care services, and voluntary sector partners.

Technology

The technological landscape is being developed to include systems that will monitor activity and lifestyles. Wearable Devices can track physical activity, sleep patterns and vital signs. For example, smartwatches can monitor heart rate, steps taken and sleep quality. Home sensors installed in various parts of the home, these sensors can track movement, detect falls and monitor daily routines. For instance, sensors in the kitchen can track meal preparation activities, while those in the bathroom can monitor hygiene routines. Having such devices will assist in identifying areas of difficulty and to establish what support or technologies are needed, these systems will also identify any deteriorations in conditions. Based on data collected, personalised support plans can be developed and tailored interventions can be put in place. Ongoing monitoring allows for the early detection of any deterioration in the persons condition. Early identification of deteriorations enables proactive care, such as adjusting treatment plans or increasing support. This will support in creating a more responsive and supportive environment for individuals with dementia, helping them maintain their independence and well-being for as long as possible.

Our City, Our Wellbeing

Our Corporate strategy 'Our City, 'Our Wellbeing' organises our plans and visions against seven key themes below, each of which will contribute to improved community wellbeing.

The plan outlines our vision and key priorities to create a thriving city for everyone. We have identified these priorities based on the challenges and opportunities facing our community.

This strategy is a collaborative effort. Throughout the next four years, we'll be working closely with residents, businesses, and organisations to refine and implement these plans. By actively listening to people's needs, we'll ensure our resources are aligned with the priorities that matter most to you


1
Healthier
7
Skilled
2
Wealthier
6
Fairer
Community
Wellbeing
3
Safer
5
Cleaner
4
Greener

1. Healthier Creating a healthier standard of living for all our citizens

2. Wealthier Reducing hardship and enabling greater shared prosperity

3. Safer Building empowered communities, safe from the threat of harm

4. Greener Conserving our environment and living more sustainably

5. Cleaner Working together to clean up our city and our communities

6. Fairer Tackling inequality and improving life chances for everyone

7. Skilled Providing opportunities for people to improve their skills and education

Priority 1 of the 'Our City, Our Wellbeing' Strategy talks about establishing a healthier city which seeks to tackle loneliness and isolation, high numbers of poor mental health and poor rates of life expectancy. Some or all of these factors can impact on people living with dementia and those who care for them.

Place to be Strategy

This dementia strategy follows the key outcomes from the place to be strategy, for example, safety, healthy, fulfilled, included, being heard, and being cared for. This means creating safe environments, ensuring access to healthcare, providing meaningful activities, including people with dementia in the community, listening to their needs, and offering compassionate care. By aligning these goals, we can improve the quality of life for individuals with dementia within the broader adult social care framework.

Carers Strategy

Stoke-on -Trent City council is currently working on the renewal of the Carers strategy to go live in summer 2025. This dementia strategy links with the carers strategy by focusing on shared goals such as providing robust support systems, training and education for carers, integrated

care models, and mental and emotional health support. Both strategies advocate for policies that benefit dementia patients and their carers, ensuring comprehensive and continuous support to improve their quality of life.

Independent Living Strategy

Stoke-on-Trent City Council are producing an Independent Living Strategy. The dementia strategy links to the independent living strategy by focusing on enabling people with dementia to live safely and comfortably in their own homes. Both strategies emphasise supportive environments, assistive technologies, and integrated care services to help individuals maintain their independence and quality of life.

Engagement and Co-production

This strategy has been co-produced jointly by Stoke-on-Trent City Council, Staffordshire and Stoke-on-Trent Integrated Care Board, key stakeholders, including people living with dementia and their carers.

A number of engagement sessions have been held with people living with dementia, their carers and health and social care professionals to understand the experiences of people living with dementia in Stoke-on-Trent, and to obtain real life feedback. The purpose of the engagement was to establish what is working well, what needs to be developed further and what actions need to be delivered by partners to achieve the agreed vision.

Conversations were held with a range of local dementia support groups to openly discuss their experiences of their dementia journey the support available in the City and identify any gaps or barriers.

We recognise that some of this feedback may relate to pathways that already exist, which indicates that we need to review communication and awareness. This will all be considered in the development of the delivery plan.

Below are some examples of feedback and quotes from the local engagement sessions

- My time is precious as a person living with dementia, and if the delay for assessments continues, I feel I will struggle to keep my determination to stay well
- Don't treat me differently, I only need understanding
- I am feeling alone and disconnected
- I feel forgotten in the pathway after the Memory Clinic discharge, which causes worry, it would be helpful If there was a discharge support group or just a phone call
- I struggle to understand the language used in letters from health professionals, please write everything in plain English
- My last appointment is soon and I am worried
- North Staffs Carers group has made me feel like I'm not alone and I am able to offload to other carers whilst I might not be able to with my group of friends
- I feel like my voice matters at the Dementia Voices Support Group
- I want to do everything I can to prevent deterioration
- Networks and support groups are supporting and comforting

- There is a bigger impact on wellbeing when services and professionals work together

Objectives and Priorities

This dementia strategy is jointly presented by Stoke-on-Trent City Council and Staffordshire and Stoke on Trent Integrated Care Board (ICB) to reflect the local perspective within the wider regional and national context.

Our comprehensive dementia strategy aims to address the complex challenges associated with dementia through a multifaceted approach.

By addressing the priorities, our dementia strategy aims to enhance the quality of life for those affected by dementia, support their families, and advance the overall understanding and treatment of the condition.

Priority 1 - Spread the message 'Healthy Body, Healthy Mind'

Priority 1 is focused on prevention and early intervention. We need to support people to have a better knowledge around staying healthy to reduce the risk of getting dementia which will lead to better prevention. This strategy will set out our aim to work with partners & Stakeholders to support people with dementia to stay healthy.

Our Aims and We Will statements

- Raise awareness amongst communities to create inclusion and acceptance. **We Will** continue raising awareness and knowledge amongst communities to create inclusion and acceptance of Dementia through events, public hard copies for information and advice and also having an accessible version online
- Raise awareness of dementia risk factors and prevention. **We Will** Include a section on brain health on the Stoke-on-Trent City Council website and the Integrated Care Board website. Ensure our information and advice is accessible and readable to people living with dementia and their carers throughout the journey of their condition, including social and wellbeing opportunities in their local community.
- To ensure that the relevant professionals receive Dementia Awareness training. **We Will** - Stoke-on-Trent Council and Integrated Care Board where possible will factor in Dementia awareness training into all contracts with Care providers
- To understand the needs of carers to support people to remain active and well. **We Will** make links with any Carers groups
- To help people living with dementia to continue their independence, physical, emotional and mental wellbeing. **We Will** Continue to work with organisations who support people living with dementia to share best practice and form a delivery plan
- To identify gaps within the community that provide social and wellbeing support. **We Will** review opportunities across the city for increasing physical activity for people living with dementia. Raise awareness of the community lounges

Priority 2 - Enabling Equitable and Timely Access to Diagnosis and Support

Priority 2 explores what will be changed to enable an equitable and timely diagnosis, in addition to post diagnosis support. This was a common theme during engagement and co-production sessions, which has been acknowledged. It enables people to prepare for their future, receive advice, manage their symptoms, live well with dementia and avoid crisis. By addressing both the emotional and practical needs of caregivers, you can help them maintain their well-being and continue to provide effective support to the person receiving care. Ensuring that diagnosis rates for dementia remain above the national target, ultimately leading to better outcomes for individuals and their families.

Our Aims and We Will statements

- Improve pre-diagnosis so that people's conditions maintain while waiting for their assessment, and may also delay people having a social care need. This will also support to reduce crisis. **We Will** the Integrated Care Board will review the current specification and pathway for the Memory Clinic. This is planned for 2025-2026. Work with our partners to improve access to interpretation services to ensure pathways are more culturally appropriate.
- Reduce waiting times for the Memory Clinic assessment service. **We Will** Look at the demand and capacity model on the memory service by reviewing all referrals and what resources are needed to meet this demand.
- Provide proportionate diagnosis, ensuring those with the highest needs can access a clinic-based pathway by working with GPs to improve pre-screening before referral. **We Will** work with GP practices to ensure people with dementia are identified and recorded correctly to support other interventions and ensure reasonable adjustments are available to them when accessing services.
- To define what a timely diagnosis means. **We Will** work with partners and people living with dementia to research what a timely diagnosis means to them.
- To support carers to keep on supporting the person with dementia. **We Will** provide Emotional Support including active listening and access to Support Groups. Provide Information and Resources and share information on dementia, caregiving strategies, and local resources. Understanding the condition can help caregivers feel more equipped and less isolated. Encourage Self-Care by Promoting Health and Wellness and reminding caregivers to prioritise their own health, including regular exercise, healthy eating, and adequate rest. Raise Awareness and support efforts to improve policies and services for caregivers at local and national level and provide feedback avenues for caregivers to share their needs and experiences with policymakers and service providers.
- Continue to keep the diagnosis rates above the national target of 66.7%. **We Will** Increase Public Awareness and education and enhance Healthcare Professional Training. Streamline Referral Processes and utilise digital health tools and apps. Work with dementia advocacy organisations to promote awareness and support initiatives aimed at increasing diagnosis rates. Support community-based

programs that educate and assist individuals in recognising and addressing dementia symptoms. Regularly monitor and evaluate diagnosis rates to identify trends and areas for improvement. Gather feedback from healthcare providers and patients to understand barriers to diagnosis and address them effectively. Provide resources and training for family members and caregivers on recognising dementia symptoms and seeking diagnosis.

Priority 3 – ensuring access to appropriate support for people living with dementia, and their carers, enabling them to live well

Priority 3 ensures the right access for people with dementia to other health and care services to guarantee their needs are met, from diagnosis through to end of life. Caring for a loved one with dementia can be stressful and sometimes challenging. Carers should have the right support to enable them to continue to care and maintain their own physical, emotional and mental health wellbeing. This will help to prevent carers hitting crisis. When people are diagnosed with dementia a plan is created with them which will be reviewed, this therefore can lead to referrals to other services that can have an advantage to a person's life. We also know people with learning disabilities and dementia, and people with Young Onset Dementia need access to health and care services appropriate to their specific needs. During a carers assessment the key points are how can we support a carer to continue their caring role, this takes in to consideration the demand on a carer and the support or respite that would offer the support they need. It also gives the carer the recognition they deserve.

Our Aims and We Will statements

- To work with colleagues to ensure appropriate dementia support information is within the carers strategy 2025-2029. **We Will** work to ensure delivery of our carers Strategy reflects the needs of people affected by dementia
- Increase the percentage of dementia plan reviews and annual health checks for people affected by dementia. **We Will** work with Primary Care to increase annual health checks for people with dementia throughout the time of this Strategy.
- Support organisation with the transition as people living with dementia move across to post diagnosis support. **We Will** Establish clear timelines for transitioning from diagnosis to post-diagnosis support, including milestones and key actions. Ensure that relevant information about the person's diagnosis, care needs, and preferences is communicated effectively between all parties involved, including healthcare providers, support organisations, and family members. Provide training for staff on dementia care, including understanding the condition, effective communication strategies, and managing transitions. Develop a streamlined referral system to connect individuals with appropriate post-diagnosis services and support. Gather feedback from healthcare providers and patients to understand barriers to diagnosis and address them effectively. Provide resources and training for family members and caregivers on recognising dementia symptoms and seeking diagnosis.
- We need to ensure that people affected by dementia have access to the other services they need, such as community health services for people in care homes, and can access the right services at the right time. **We Will** review services that provide post diagnostic support to ensure a seamless pathway

- Ensure people with dementia have reasonably adjusted access to other primary and secondary health services. **We Will** review the dementia pathway with the aim to simplifying processes following dementia diagnosis e.g. benefits including council tax, and health records.
- To make sure that any literacy is communicated in plain English and in an accessible format. **We Will** review the literacy in a discharge letter and any memory pathway documents for GP's and other professionals to ensure it gives a clear pathway to support

Priority 4 - Ensuring safe and person-centred discussions about people's preferences for their future care

People affected by dementia need information about the options available to them as their dementia progresses. If they wish to, people should be supported to make plans for what they want to happen as their illness progresses, or if they are in crisis.

Our Aims and We Will statements

- To make End of Life (EOL) services more dementia friendly. **We Will** Continue to work with the integrated Care Board looking at existing EOL services to make them more dementia friendly.
- Ensure people with dementia have good quality end of life care and are supported to die with dignity in the place of their choosing. **We Will** look at current EOL and Palliative services and Work across hospital discharge pathways to ensure access to enablement services when people are discharged from hospital.
- Create a stronger link with Admiral nurses. **We Will** work with admiral nurses to identify any gaps when future care planning is discussed
- Promote the toolkit which will help people to plan for end of life. **We Will** ensure a link on the Stoke-on-Trent Council website and the integrated Care Board website for the toolkit

Future for Dementia

At the time of writing this strategy it is expected that new treatments for dementia will shortly be licensed for use in the UK by the regulator. Should these treatments be licensed, then this will affect current dementia services and also patient's expectations around treatment and support.

Following years of extensive research into the causes of Alzheimer's dementia (the most common form of the disease), there are now a number of promising new drug treatments on the horizon, the first of which is expected to be licensed for use by regulators and evaluated for use in the NHS by NICE during 2025.

The disease modifying drugs (DMTs) are expected to prevent the lesions that develop in the brain that cause the symptoms of dementia while also being used as an intervention before dementia is diagnosed, i.e. people with Mild cognitive impairment. This will clearly be a significant breakthrough for eligible patients and their families in at least preventing the onset of the disease, it will also impact on future needs of patients in terms of both health and social care. It is likely that as these drugs are new, that there will be a need to develop new services to identify, diagnose and treat patients at risk of developing the disease, that currently don't exist.

The Staffordshire and Stoke-on-Trent ICS is therefore committed to closely following these developments and supporting early uptake of these treatments in accordance with national guidance when it arrives.

It must be emphasised that the new treatments are not a cure for dementia. They may have the effect of slowing down progress of dementia in people who are in the early stages of the disease or currently don't have the diagnosis. This in turn makes early identification and diagnosis of dementia even more important.

If DMTs are licensed for wide usage in England, then commissioners and providers in the NHS will need to work together closely to facilitate access to these new treatments for those who may benefit from them.

This strategy document will be updated as and when we know more about DMTs and how they will be made available to people in Stoke on Trent.

Opportunities and Risks

Achieving a dementia strategy presents several key opportunities & challenges

1. **Improving Public Awareness and Education**: By increasing awareness about dementia, we can reduce stigma and encourage early diagnosis and intervention. Public education campaigns can help people recognise the early signs of dementia and seek help sooner.
2. **Early Diagnosis and Preventative Care**: Early diagnosis can significantly improve outcomes, but many people are diagnosed late due to lack of awareness or access to healthcare. Promoting preventative care and early intervention is essential.
3. **Equity in Care and Communities**: Ensuring that all individuals, regardless of their background, have access to quality dementia care is a major challenge. Social determinants of health, such as race, socioeconomic status, and geographic location, can create disparities in care. Creating supportive environments where people with dementia can live safely and participate in the community life is key
4. **Supporting Carers**: Providing resources and support for carers can help them manage the emotional, physical, and financial challenges they face. This can include respite care, support groups, and financial assistance
5. **Integrated and Person-Centred Care**: Providing care that is coordinated across different services and tailored to the individual's needs can be difficult to implement but is vital for effective dementia management
6. **Research and Innovation**: Continued investment in research can lead to breakthroughs in understanding, preventing, and treating dementia. This includes exploring new therapies, improving care practices, and finding ways to delay the onset of symptoms.
7. **Leveraging Technology**: Technology can play a significant role in dementia care, from telemedicine and remote monitoring to assistive devices that help people with dementia maintain independence
8. **Training and Education**: Ensuring that healthcare professionals are well-trained to diagnose and manage dementia is essential. This includes ongoing education and training to keep up with the latest advancements in dementia care.

By focusing on these opportunities & challenges, we can create a more supportive and effective pathway for managing dementia. To address these challenges, we will use a multiagency approach involving local authorities, health colleagues, voluntary and community organisations and continue to engage with people living with dementia. This will inform the strategic delivery plan.

Governance, Monitoring, Evaluation and next steps

Good governance enables organisations to build a sustainable and better future for all of us. It adds value, is open, transparent, and ethical. Good governance focuses on achieving the best outcomes for our residents by helping to address any issues, challenges and obstacles (operational or otherwise) to progress. There are clear and established governance arrangements across both Stoke-on-Trent City Council and the Integrated Care Board that will monitor the progress of this Strategy and its Delivery Plan.

Stoke-on-Trent City Council and Integrated Care Board have joint responsibility to manage the Dementia Steering group. This group will include various stakeholders who will have responsibility, oversight and manage improvements in services, systems and processes that are detailed in the Strategy and Delivery Plan. Quarterly updates will be provided by the Dementia Steering group so that progress can be measured, and achievement highlighted.

As part of our first steps in achieving positive outcomes for our Dementia population, a co-produced Delivery Plan will be developed, that starts to take a more practical approach in how our vision and aims will be achieved. There will be specific actions detailed to specify how we will meet the aims of this strategy, and this document will also be iterative in order for amendments to be made as needed.

The Delivery Plan shall be based on the initial data analysis, engagement and feedback that we have obtained from a range of stakeholders in the development of this Strategy. Over time the detail of the Delivery Plan will continue to be co-produced and developed in partnership with key stakeholders and will be refreshed annually.

It is imperative that we measure how successful we are in making progress against our commissioning priorities. We will identify key indicators linked to each of the priorities. This will reflect and measure the impact our joint commissioning decisions have on the lives of people and their carers living with dementia.

The Strategy will be published on Stoke-on-Trent City Council website along with the Integrated Care Boards Website. An accessible version of this strategy will also be made available.

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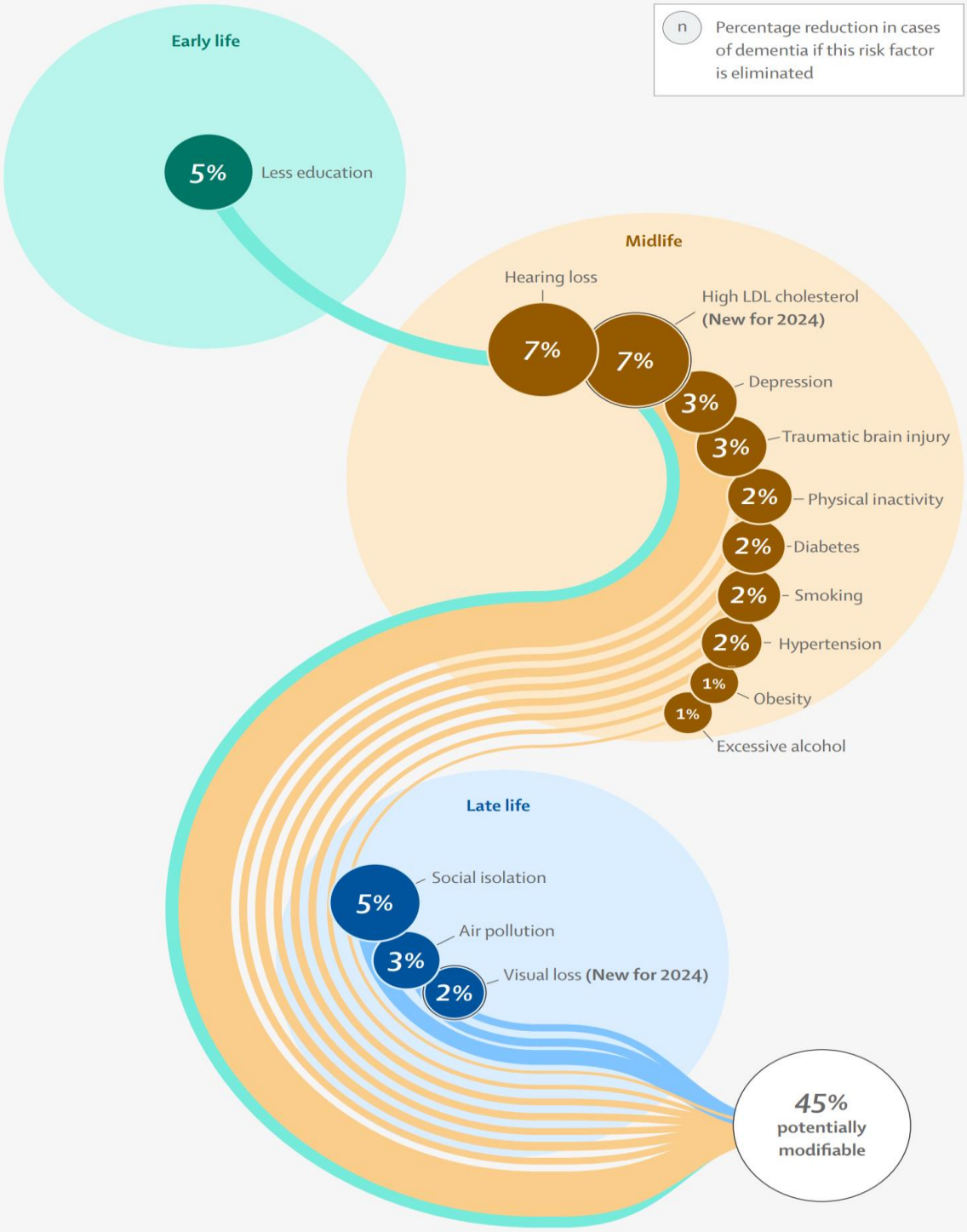
Appendices

Modifiable risk factors

According to the 2024 Lancet Commission on dementia prevention, intervention, and care, there are 14 potentially modifiable risk factors for dementia: low level of education, hearing impairment, traumatic brain injury, hypertension, alcohol, obesity, smoking, depression, low social contact, physical inactivity, diabetes, air pollution, untreated vision loss and LDL cholesterol. There is no single specific activity that can protect against dementia. However, it is recommended to keep cognitively, physically, and socially active in midlife and later life. Using hearing aids appears to reduce the excess risk of hearing loss, thus potentially reducing the dementia risk. Sustained exercise in midlife, and possibly later in life, protects from dementia, perhaps through decreasing obesity, diabetes, and cardiovascular risk. Depression might be a risk for dementia, but in later life, dementia might cause depression. Although behaviour change is difficult and some associations might not be purely causal, individuals have a huge potential to reduce their dementia risk.

Risk factors for dementia — 2024 update

The 2024 update to the standing Lancet Commission on dementia prevention, intervention, and care adds two new risk factors (high LDL cholesterol and vision loss) and indicates that nearly half of all dementia cases worldwide could be prevented or delayed by addressing 14 modifiable risk factors.



Read the full commission update at thelancet.com/commissions/dementia-prevention-intervention-care

Livingston G, Huntley J, Liu KY, et al. Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission. *The Lancet* 2024; published online July 31. https://doi.org/10.1016/S0140-6736(24)01296-0.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL

Risk of people developing dementia is minimised

"I was given information about reducing my personal risk of getting dementia"

STANDARDS:

- Prevention[1]
- Risk Reduction[5]
- Health Information[4]
- Supporting research[5]

DIAGNOSING WELL

Timely accurate diagnosis, care plan, and review within first year

"I was diagnosed in a timely way"

"I am able to make decisions and know what to do to help myself and who else can help"

STANDARDS:

- Diagnosis[1][5]
- Memory Assessment[1][2]
- Concerns Discussed[3]
- Investigation [4]
- Provide Information[4]
- Integrated & Advanced Care Planning [1][2][3][5]

SUPPORTING WELL

Access to safe high quality health & social care for people with dementia and carers

"I am treated with dignity & respect"

"I get treatment and support, which are best for my dementia and my life"

STANDARDS:

- Choice[2][3][4], BPSD[6][2]
- Liaison[2], Advocates[3]
- Housing [3]
- Hospital Treatments[4]
- Technology[5]
- Health & Social Services [5]
- Hard to Reach Groups[3][5]

LIVING WELL

People with dementia can live normally in safe and accepting communities

"I know that those around me and looking after me are supported"

"I feel included as part of society"

STANDARDS:

- Integrated Services[1][3][5]
- Supporting Carers[2][4][5]
- Carers Respite[2],
- Co-ordinated Care[1][5]
- Promote independence[1][4]
- Relationships[3], Leisure[3]
- Safe Communities[3][5]

DYING WELL

People living with dementia die with dignity in the place of their choosing

"I am confident my end of life wishes will be respected"

"I can expect a good death"

STANDARDS:

- Palliative care and pain[1][2]
- End of Life[4]
- Preferred Place of Death[5]

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

RESEARCHING WELL

- Research and innovation through patient and carer involvement, monitoring best-practice and using new technologies to influence change.
- Building a co-ordinated research strategy, utilising Academic & Health Science Networks, the research and pharmaceutical industries.

INTEGRATING WELL

- Work with Association of Directors of Adult Social Services, Local Government Association, Alzheimer's Society, Department of Health and Public Health England on co-commissioning strategies to provide an integrated service ensuring a seamless and integrated approach to the provision of care.

COMMISSIONING WELL

- Develop person-centred commissioning guidance based on NICE guidelines, standards, and outcomes based evidence and best-practice.
- Agree minimum standard service specifications for agreed interventions, set business plans, mandate and map and allocate resources.

TRAINING WELL

- Develop a training programme for all staff that work with people with dementia, whether in hospital, General Practice, care home or in the community.
- Develop training and awareness across communities and the wider public using Dementia Friends, Dementia Friendly Hospitals/Communities/Homes.

MONITORING WELL

- Develop metrics to set & achieve a national standard for Dementia services, identifying data sources and set 'profiled' ambitions for each.
- Use the Intensive Support Team to provide 'deep-dive' support and assistance for Commissioners to reduce variance and improve transformation.