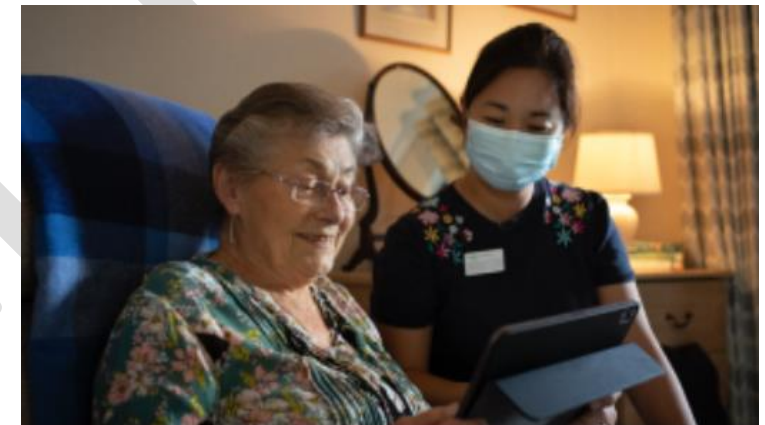


York Dementia Strategy

2022-2027



Foreword

To be written by Denise Nightingale and Jamaila Hussain. To reference:

- priorities determined by the former Dementia Action Alliance – now the York Dementia Collaborative
- the York Minds and Voices strategy

ANNEX A

- Our aspirations as a City to be Dementia Friendly, with a clear focus on tackling inequality and making sure no-one is left behind following the disproportionate impact the Covid-19 pandemic has had on people with dementia and their carers (identified in the Alzheimer's Society [report](#), September 2020).
- The priorities of the new York Health and Care Alliance
- The key role that people living with dementia have played in drafting the strategy, with acknowledgment of the contributions from:
 - Age UK and the Alzheimer's Society
 - The Ways to Wellbeing Service Social prescribers
 - York Hospital
 - New Earswick Folk Hall
 - Local support groups for people with dementia and their carers, including Deans Garden Centre Carers Group, Clements' Hall, York Minds and Voices and Beetle Bank Farm
 - Dementia Forward
- Gratitude to the Alzheimer's Society for their 2021 profile report which is referenced throughout
- The pivotal role of the Action Plan in demonstrating our progress towards our aspirations

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About the Strategy

This is a Dementia strategy for the City of York, and a priority of the [York Health and Well Being Board](#). Its intended audience is the citizens of York, local leaders, the health and care workforce (including those who commission and provide care and support), and community, voluntary and social enterprise organisations – in short everyone involved in the experience of both drawing on and offering support for people with dementia.

There are different levels of accountability for the Strategy's delivery, but it provides the framework within which local services can deliver quality joined-up improvements to dementia services, address health inequalities, and realise a shared vision for dementia support in York.

The strategy has been developed in collaboration with City of York Council, the Vale of York CCG, Healthwatch York, community and voluntary providers and the Dementia Collaborative. Through face to face conversations, online surveys and focus groups with people who have experience of living with dementia in York, and with those staff and organisations who have learned experience of the opportunities and challenges this creates, we have been able to better understand how York can become a better place to live, with better quality services for people with dementia and their carers.

We recognise that the participation and contribution from people with dementia and their families and carers is vital in designing and improving dementia care and support. The York Dementia Collaborative has had a key role in ensuring voices are heard, and through their knowledge and experience, they will continue to actively influence service development and provision, particularly highlighting gaps in services which lead to poor outcomes for people.

This strategy is a living document, which we hope will make a real and positive impact for people in the City. It is complimented by a detailed delivery plan, which considers the tasks required to reach our ambitions. As the Delivery Plan is a working document, it is available for anyone to see on request.

Our Vision

Our vision is to make sure that people with dementia, their families and carers, are supported to live life to their full potential. We want the people of York to be able to say:

- I live in a dementia friendly community
- I know who/where to turn to for information, advice and support
- I can live a life of my own
- I have access to the right support that enables me to live well at home for as long as possible
- My voice is heard and makes a difference
- I know that when the time comes, I can die with dignity, in the place of my choice

National Context

An estimated 675,000 people in England have dementia, the majority of whom are over 65 and [have underlying health conditions](#). They are supported by a similar number of carers, many of whom are older people themselves. It is estimated that a quarter of people in acute hospitals and three quarters of the residents of care homes have dementia; yet 200,000 people with moderate and severe dementia do not get any kind of funded or professional support (Health and Social Care Committee's 7th report 2021-22). The number of people living with dementia in the UK is set to rise to 1.6 million by 2040.

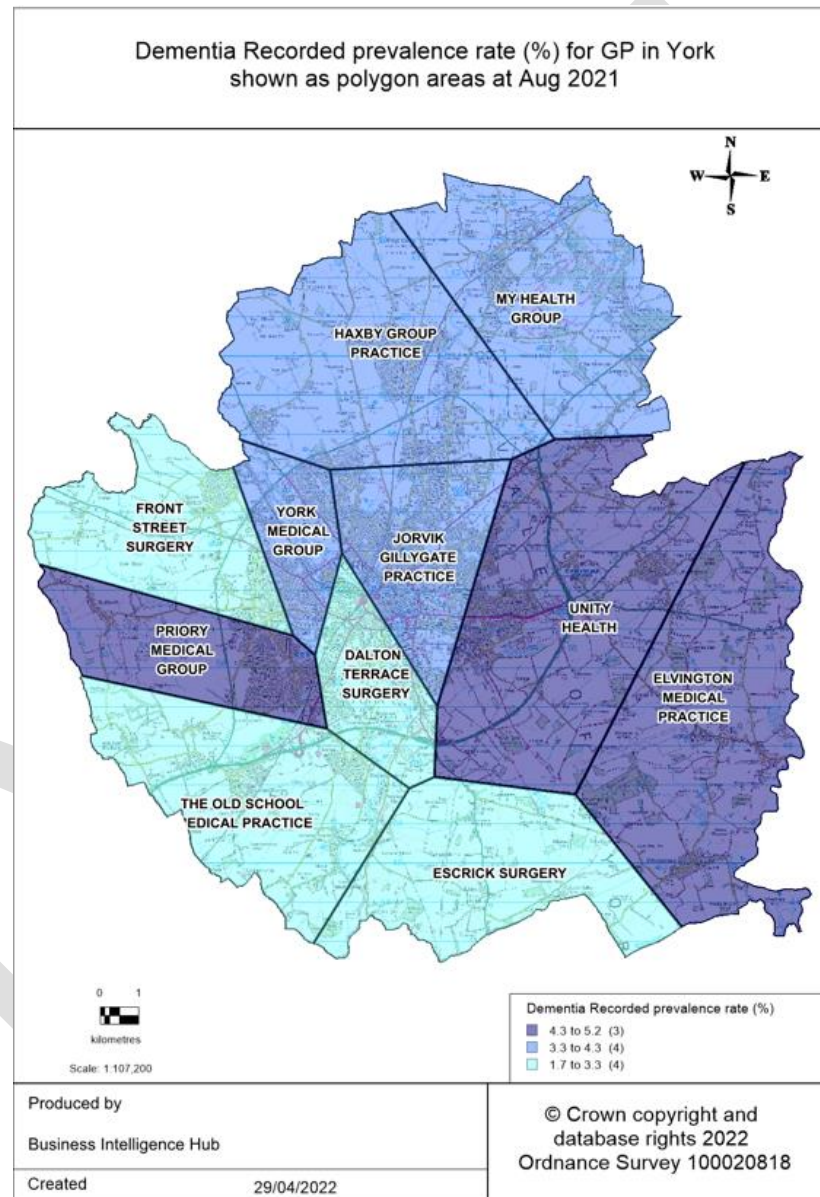
As the number of people living with dementia, and the complexity of their situation, steadily increases, the government and NHS England have pledged to make improvements to dementia care a key priority. The scale and the need to prevent, diagnose, support, live and die well with dementia will only become greater (Alzheimer's Society, 2021).

[The NHS Five Year Forward View](#) and the [Prime Minister's challenge on Dementia](#) 2020 set out a clear rationale for providing a consistent standard of support for people with dementia and their family and carers. The [Well Pathway for Dementia](#) has five elements based on the themes outlined in the Prime Minister's Challenge - they reflect the breadth of the experience of people with dementia, their families, and carers, from prevention to end of life care.

Ageing well and caring for people with dementia are both key priorities in [The NHS Long Term Plan](#). The Plan focuses on the need for people to be helped to stay well and to have control over their support, using tools such as personal health budgets and assistive technology. It also calls for a transformed workforce with a more varied and richer skill mix, integration between health and social care, and the expansion of service models such as Anticipatory Care, Enhanced Health in Care Homes, and Urgent Community Response Teams. The aim of these initiatives is to ensure that everyone receives the right care, in the right place, at the right time.



Local Context





There are an estimated **2,812 people over 65 living with dementia** in York²

1 in 20 people over 60, & 1 in 5 people over 80 has a form of Dementia



Of those 2,798, only **1,554 people have been diagnosed**
The dementia **diagnosis rate for York is 53.2%** - the average for England is 61.7%¹



It is estimated that **2/3 of people with dementia in York are living in the community, whilst 1/3 are living in care** ²



Currently there are **15,006 people under the age of 65 living with dementia** in England⁷



The value of dementia support provided by **unpaid carers in York is £71.3m**³



3,860 people will be living with dementia in York by 2030³



By 2030, it is estimated that there will be **2,483 of people living with severe dementia** in York⁴



In York, **56.7% of carers** spend 100 hours or more per week providing care¹⁶



The value of dementia support contributed by unpaid carers in York is **£71m**¹⁵



It is predicted that the cost of dementia care in York by 2030 **will be £171m**⁶



Currently, the annual cost of dementia care in York is **£108m**⁵



In York, **60% of carers reported feeling stress or anxiety**²¹



34.5% of all carers reported caring for someone living with dementia in York¹⁷

¹ NHS Digital Nov 2021

² NHS Digital November 2021

³ Alzheimer's Society York Profile 2021

Age Friendly, Dementia Friendly City

We recognise that it is important to support people living with dementia to live the life they choose and to feel included in the community. Through the dementia-friendly communities programme, organisations in York have agreed to try to make the city 'dementia friendly', making it a good place to live for people with dementia and their carers. York's Dementia Friendly Communities programme is working to improve four key areas in the City:

- **Improving the place:** Making York as easy as possible to move around and enjoy, with uncluttered and clear signage, and making public transport and facilities comfortable, easy to use and accessible. York already has many assets in terms of leisure, cultural and spiritual resources, which we can enable and encourage people with dementia to enjoy.
- **Improving the people:** With training for staff who provide key services in the wider community, such as in banks, libraries and shops, we can improve customer service and 'understanding of needs', and remove stigma.
- **Improving resources:** Using the 'dementia friendly' forget-me-not symbol to denote dementia-friendly services and venues (theatres, cinemas, cafes) we can support businesses to become dementia-friendly and recognise such credentials. We can consider the needs of people with dementia when developing all services, not just health and care services.
- **Improving networks:** By encouraging people with dementia and carers to network and share experience and creating a York Dementia Action Alliance partners can commit to action within their own organisations and support this movement, building a sense of corporate responsibility across all sectors.

The Dementia Pathway in York

A dementia pathway will begin at the point that someone becomes aware of changes to their memory, or other symptoms associated with dementia, and will progress through diagnosis, post-diagnosis support, living well with dementia, and eventually end of life care (Alzheimer's Society, 2021). The national Dementia Pathway describes how support should 'wrap around us' when we need it and is dependent upon how much we need at each point in time- sometimes close and intense, and sometimes more distant, but there if we need it.

In York, we recognise that we have work to do in each section of the pathway, and we have used the 5 recognised steps to illustrate our strategy to provide better support for those living with Dementia in the City.



Preventing Well

"The risk of people developing dementia is minimised"

Current Challenges & Opportunities

- York has a larger than national average gap between actual and expected prevalence of dementia.

What 'good' would look like

- People live, work, and play in communities that promote health and wellbeing, and reduce social isolation
- Campaigns, such as 'What's good for your heart is good for your head', are visible in the city to reduce the risk factors which can contribute to a third of dementia case (such as smoking, lack of physical activity, alcohol, and poor diet). Some campaigns are targeted on the basis of local public health data.
- We have a good uptake of NHS health checks for over 40/65s, and for people with learning disabilities (>75%), where dementia is discussed
- Information, advice, and guidance is available to enable people to make informed choices and potentially prevent, delay, or reduce the impact of dementia on their lives.
- People are connected to their community and to support through the Council's Talking Points, Local Area Coordinators and Social Prescribing
- City of York Council and the CCG have a clear recovery plan to help people living with dementia and their carers to recover from the adverse effects of Covid-19

Key Actions & Priorities



Diagnosing Well

Timely accurate diagnosis, care plan and review within first year

Current Challenges



The dementia diagnosis rate for York is 54.7%, the average for England is 61.7%¹⁰



1,537 people have received a dementia diagnosis in York¹⁰

- Our diagnosis rate is below the national average and the national target (66%)
- There are significant numbers of people living in York with undiagnosed dementia and many people who feel unsupported following diagnosis. Many described having unanswered questions about the diagnosis, what will happen, the help available, the future, and relationships

What 'good' would look like

- People receive a personalised diagnosis and pathway which is appropriate to their age and stage
- People know what to expect of the diagnostic process, and diagnoses are delivered in a compassionate way, using positive language and a message of hope.
- Organisations involved generally in care and support, are skilled in identifying the symptoms of dementia, and know what steps to take to support people to receive a diagnosis.
- Support is offered to people who have been discharged from hospital with delirium, to monitor their cognition and prevent deterioration

Key Actions & Priorities



Supporting Well

“Access to safe high-quality health and social care for people with dementia and carers”

Current Challenges & Opportunities

- There is some fragmentation between services and support organisations
- Challenges within the care market around recruiting and retaining health and social care staff (particularly nurses)
- Limited availability of long-term specialist dementia care;
- Gaps in provision generally for people with young onset or alcohol related dementia

What ‘good’ would look like

- Post- diagnostic support is provided to the person and they have choice in how they meet their outcomes.
- People are enabled to live at home through dementia friendly communities and tailored home support. Community spaces and formal building-based care and support is accessible and dementia-friendly.

Key Actions & Priorities

-



Living Well

“People with dementia can live normally in safe and accepting communities”

Current Challenges



In York, 13.9% of carers reported feeling socially isolated²¹

What ‘good’ would look like

- There are ongoing opportunities for people with dementia and carers to access support interventions, information and education following diagnosis, to help them to live in the way that is important to them for longer.
- The Council has a Market Position Statement which promotes collaborative approaches to delivery of services
- Our Carers’ strategy includes a specific focus on carers of people with dementia, detailing the support available to them, including access to evidence based interventions, psychological support, practical training, bereavement support, and vital breaks where needed.
- York is dementia friendly and safe for those living with dementia to live well and remain part of their community.

Key Actions & Priorities



Dying Well

“People with dementia die with dignity in the place of their choosing”

Current Challenges & Opportunities

What ‘good’ would look like

- Everyone has the chance to have the right support and setting at the end of life, and to be as comfortable as possible.
- All people living with dementia have the opportunity to discuss advance care plans at each stage of their pathway.
- There is support for people to die with dignity in a place of their choice
- Families and carers are provided with timely coordinated support before death, at the time of death and bereavement
- We have appropriate information, advice and guidance to enable people to make early and informed decisions around mental capacity, planning for the future and end of life care

Key Actions & Priorities