York Dementia Strategy

2022-2027

Foreword

York has been awaiting a Dementia Strategy for some time. This document fills a vital space, setting 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 newly formed York Health and Care Alliance recognises a need to improve outcomes in the city in the broad areas of prevention, mental ill-health, and frailty. They aspire to see York as '*the best city in which to grow old…where adults have the best chance to stay healthy, and older citizens can live independently".*

In this strategy, we are pleased to introduce our vision for Dementia support in York, which seeks to improve outcomes for people with dementia and their families and carers. We know that people living with dementia face a variety of challenges and have a range of needs, everyone's journey is different. To achieve our vision, it is essential that organisations work together to transform the approach to dementia in York. The strategy provides the chance to reaffirm our joint commitment to do this, so that people can enjoy good health and wellbeing by achieving what matters to them.

The most important part of developing this strategy has been talking to people living with dementia. Our priorities have been shaped by the York Minds and Voices strategy, the former Dementia Action Alliance (now the York Dementia Collaborative), and through engagement research funded by the Joseph Rowntree Foundation. This research, led by Healthwatch York, has involved significant contribution from the following local organisations:

- Age UK
- the Alzheimer's Society
- Dementia Forward
- New Earswick Folk Hall
- Support groups for people with dementia and their carers, including Beetle Bank Farm, Clements' Hall, Deans Garden Centre Carers Group, and York Minds and Voices.
- Ways to Wellbeing Service (Social prescribers)
- York Teaching Hospital

We extend our thanks to all, and further gratitude to the Alzheimer's Society for their 2021 Local Dementia Profile report which has provided us with critical information about people living with dementia in the city; and much of their research is referenced throughout this Strategy.

Pivotal to making this Strategy work will be the delivery of its Action Plan. It is our aspiration that, on reading the action plan, those people who offered us vital feedback about our current services will hear their voice and will see our ambition to respond.

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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 Wellbeing Board. Its intended audience is the citizens of York, people leading local health and social care organisations and the health and care workforce, 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.

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 that 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.

There are different levels of accountability for the Strategy's delivery, but it provides the framework within which local services can deliver improvements to dementia services, address health inequalities, and deliver a shared vision for what dementia support should look like.

The strategy has been developed through collaboration between City of York Council, the Dementia Collaborative, Healthwatch York, local community and voluntary providers, our local NHS Mental Health service provider (Tees Esk and Wear Valleys Trust), the Vale of York Clinical Commissioning Group, and York Teaching Hospital. 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.

This strategy is a living document, which we hope will make a real and positive impact for people in the city. It is complemented 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 can live a life of my own
- I live in a dementia friendly community
- I know who/where to turn to for information, advice and support
- I know I have access to a timely and accurate diagnosis, delivered in an appropriate way

- 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.

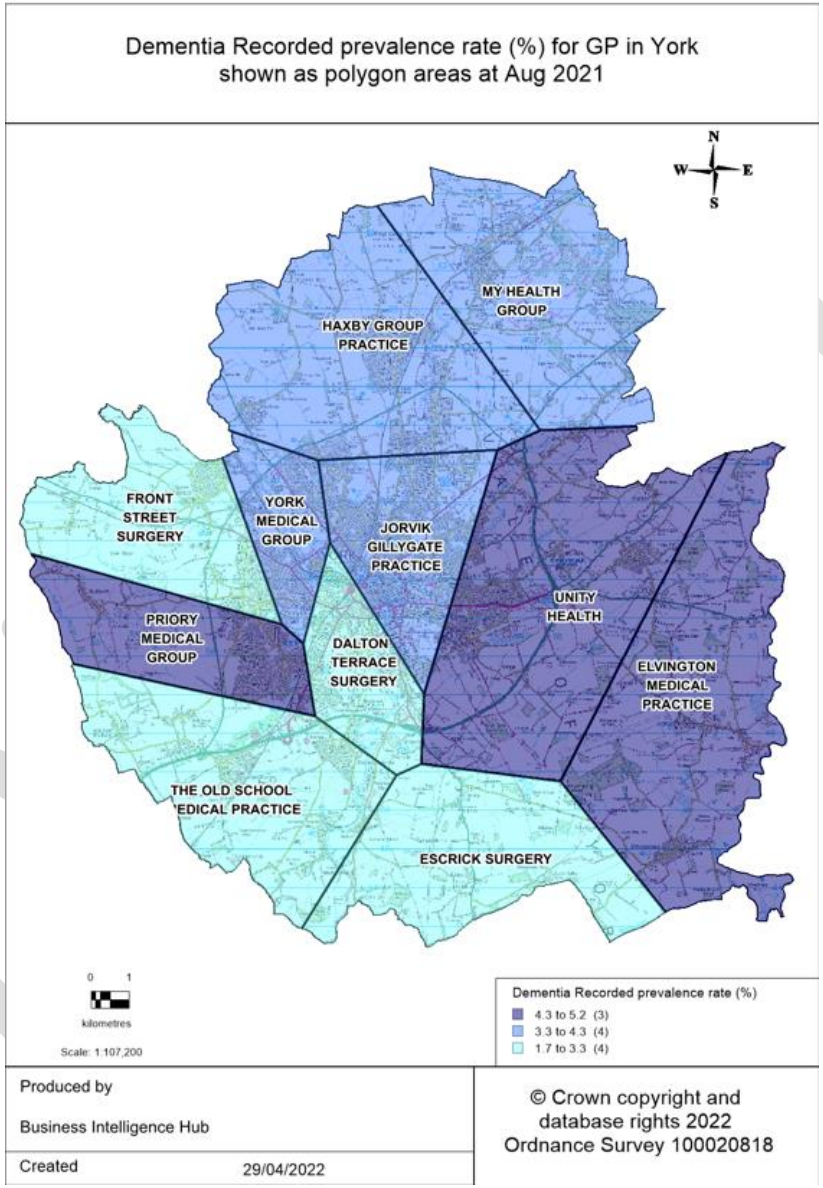
Dementia is not a natural part of growing old and, although dementia is more common in people over the age of 65, the condition can also be found in younger people. When a person develops dementia before the age of 65, this is known as 'young-onset dementia.'

As the number of people living with dementia, and the complexity of their situations steadily increase, 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, which 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 (advanced care planning), 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 York[2]

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

Of those 2,812, only **1,554 people have received a diagnosis**

The dementia **diagnosis rate for York is 54.4%** - 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 England[7]

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 2030[3]

By 2030, it is estimated that there will be **2,483 of people living with severe dementia** in York[4]

In York, 56.7% of carers spend 100 hours or more per week providing care[16]

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]

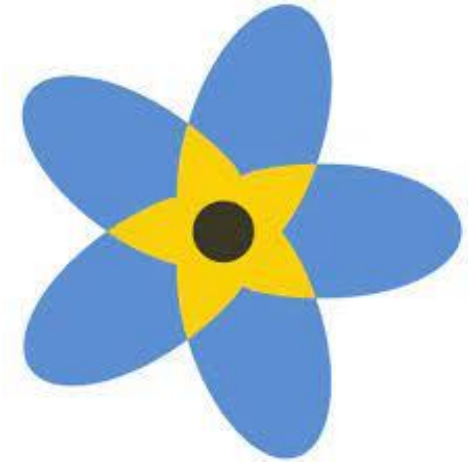
In York, **60% of carers reported feeling stress or anxiety**[21]

34.5% of all carers reported caring for someone living with dementia in York[17]

[1] NHS Digital Nov 2021
[2] NHS Digital November 2021
[3] Alzheimer's Society York Profile 2021 (NB 'severe dementia' refers to the later stages where there is a growing impact on movement and physical capabilities)

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 our 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 our 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 by 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' a person when they need it and is dependent upon how much they need at each point in time, sometimes close and intense, and sometimes more distant, but there if and when required.

In York, we recognise that we have work to do in each section of the pathway, and we have used the 5 recognised stages 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 the expected prevalence of dementia within our population, and the actual number of people diagnosed. Primary care has a challenge to proactively seek and assess people who may be at risk, and identify the condition as early as possible to ensure the right people get the right support at the right time.
- Much of York's health and social care support starts with a person's strengths, and the city has a long history of building resilient communities, where it is understood that local people are best placed to understand and find solutions to their needs. This offers the opportunity to develop community networks to prevent, reduce and delay the need for formal support for people with Dementia.
- Recent survey results demonstrate that many older people in York experience loneliness, a distressing emotion which research links with dementia. Similarly, there is growing awareness that untreated depression can be a risk factor for dementia, and that treatment of depression in older adults is lower than treatment for those of working age.
- Works by the Alzheimer's Society tells us that language barriers, cultural perceptions of dementia and a lack of culturally appropriate diagnosis and support services can all affect how people interact with and receive services.
- People with a learning disability are at greater risk of developing dementia as they age, with higher numbers developing young-onset dementia.

What 'Good' Would Look Like

- People live, work, and socialise 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', and campaigns targeted on the basis of local public health data, are visible in the city to reduce the risk factors which can contribute to a third of dementia cases.
- Information and advice are available through GP practices and tools such as the Healthwatch Guide and Live Well York, to enable people to make informed choices which could potentially prevent, delay, or reduce the impact of dementia on their lives. People are aware that dementia can present differently when there is a learning disability.
- Over 75% of the over 65 population (including those with a learning disability) have an NHS health check where dementia is discussed. The uptake is monitored quarterly, and the percentage of those where dementia is discussed reported to the Integrated Care Partnership.
- Community connectors, such as Social Prescribers, Local Area Coordinators and Adult Social Care Talking Points, plus third sector organisations, ensure sufficient reach across the City (including reaching into Dementia Hubs) to get the right information to the right people in a timely manner.
- Primary Care services identify symptoms of conditions (such as depression and frailty), which may contribute to dementia in older adults and treat them appropriately.
- We proactively address issues such as language barriers and cultural perceptions on dementia to positively impact how people interact with and receive services.

Key Actions & Priorities

- Develop the work of the Ageing Well partnership around York being a Dementia Friendly City.
- Ensure Public Health services have a forward plan for preventative campaigns which include regular reference to reducing the modifiable risk factors linked to dementia, including making tangible progress towards York being a carbon net zero city.
- Develop a dedicated space for information and advice about Dementia on Live Well York (an information and advice community website for all adults in the city).
- Work with Public Health services and our local GP's to develop what is included in, and how performance is measured on, the NHS health checks in the city.
- Ensure in-reach from community connectors to Dementia Hubs to promote the support that people can access within their own communities, and according to their unique experiences.
- Develop assurance around diagnosis and treatment of depression in older adults in the city

Diagnosing Well

Timely accurate diagnosis, support plan and review within the first year

Current Challenges & Opportunities

- Our diagnosis rate (54.4%) is below the national average (61.7%) and the national target (66%). This means that there are significant numbers of people living in York with undiagnosed dementia.
- The fear of stigma can prevent a person from accessing a diagnosis, and we need to provide good information about dementia and the benefits of diagnosis
- We have a challenge to ensure we are taking all opportunities to diagnose young-onset (under the age of 65) dementia. People often face different challenges (e.g., continuing to work, having a young family), and there is often a long

What 'Good' Would Look Like

- 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. Likewise, they are aware of the impact of common physical health problems on cognition.
- The dementia work stream of the Humber and North Yorkshire Integrated Care System, will support and monitor targeted work in primary care where diagnosis rates remain low, with a target for diagnosis rates to be above 67% by the end of this Strategy's lifecycle.
- People working within dementia care promote inclusive practice at all times, and consider how they provide accessible information in appropriate formats.
- There are embedded processes for monitoring and reporting the average length of time people are awaiting diagnosis. The benchmark will initially be against pre-pandemic timescales, and the target will be a maximum of 6 weeks. This includes people under the age of 65, people with learning disabilities, people from BAME and minority groups, and people with alcohol-related dementia.
- People know what to expect of the diagnostic process, and diagnoses are delivered in a compassionate way, using positive hopeful language (which signals the beginning and not the end of a process). Diagnosis

wait for diagnosis as other conditions are explored. Follow-up is critical and the support designed for older people is often not suitable, meaning people with young-onset dementia can find themselves isolated within their community.

- People face unique challenges in seeking a dementia diagnosis (perhaps due to issues such as age, gender, race, culture and religion, sexual identity, caring roles and socioeconomic status), which need to be understood.
- We need to ensure that the diagnosis pathway is seamless and that we minimise bottlenecks to access the Memory Service and neurology.
- We have an opportunity to continue work already started to reduce delays in referral from GP's to the memory clinic, by making the process easier for GP's without compromising the quality of referrals.
- We must develop a post-diagnostic pathway of support, as consultation with citizens has told us that many people have felt unsupported after diagnosis, and feedback would suggest that there is inconsistency across the city.

is also timely, affording people the best opportunity to ensure their wishes are considered in the development of their support plan and more chance to take part in research if they wish to do so.

- We build upon the current diagnosis pilot with people 90+ and people considered vulnerable, and extend this to consider diagnosis for 'harder to reach' communities, such as those who can't leave their homes, those with other ill health complications, and those with delirium. We offer support to people discharged from hospital with delirium, to monitor their cognition and prevent deterioration.
- We have adapted referrals pathways between hospitals and importantly the A&E department, to make it easier to refer directly from these settings into Memory Assessment Services.
- There is integrated working between neurology, neuroradiology and psychiatry in assessment of young-onset dementia and Parkinson's disease Dementia (as per the NICE guidance). We are exploring the use of a Picture Archiving and Communication System within the Memory Assessment Service.
- People diagnosed with dementia and their family or friend carers have easy access to information on planning and making choices about their care at the end-of-life. Information and advice are easily accessible throughout the person's journey and as their needs change. This includes access to support and advice around medications routinely used following a new diagnosis of dementia, including written information to allow people to make informed decisions about treatment options.
- With support from the ICS, we explore and implement technological solutions to ensure that people with dementia have a single digital health and care record that is accessible to them and to all health and care professionals involved in their care. This includes access to advance care plans.
- Referrals made to the Memory Service are streamlined and efficient, with all involved understanding what is required to reduce the delay from referral to assessment as much as possible.
- Our Memory Service:
    - Accepts referrals from sources other than primary care, especially in urgent or crisis situations.
    - Builds on existing work to explore alternative diagnostic pathways, for example, using other professionals and tools such as DiADeM (Diagnosing Advanced Dementia Mandate), and proactive in-reach to care homes
    - Has clear pathways to enable effective and consistent access to psychiatrists, psychologists, occupational therapists, social workers and dementia advisers, as well as linguists and interpreters, during the diagnostic process.
    - Provides a choice of appointments such as telephone, video conference or face-to-face appointments where appropriate
    - Has a diagnostic pathway for young-onset dementia and GP's are responsive to symptoms
    - Has a post-diagnostic dementia adviser service, with automatic referral to the service unless people opt out.
    - When people have been prescribed medications, they have access to a named memory nurse within the service for advice, support and changes to their dose.

- People with dementia and their carers are able to influence the design of pre and post-diagnostic support through their involvement in the implementation of this strategy.

Key Actions & Priorities

- Deliver training to the health and social care workforce to ensure skills in identifying the symptoms of dementia, knowledge of the impact of common physical health problems on acute cognition, and knowledge of the steps required to take to assist someone to receive a diagnosis.
- Develop a programme of targeted support for GP practices to increase the rate of diagnosis, supported by Dementia Coordinators.
- Develop monitoring and reporting processes to track the time people have to wait between referral and diagnosis
- Set clear expectations around how and when diagnoses are delivered and what people can expect in terms of support and advanced care planning at this stage
- Raise awareness and increase the use of the DiADeM tool (the Diagnosis of Advanced Dementia) to support GP's in diagnosing advanced dementia.
- Work with the ICS to develop and implement technological solutions for shared care records
- Improve the integration of dementia advice and community support within GP practices.

Supporting Well

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

Current Challenges & Opportunities

- People need comprehensive support that encompasses medical, emotional and social wellbeing. Yet nationally these needs are not being met in a consistent and timely way.
- When support needs go unmet, crises – such as hospitalisation, carer breakdown and health deterioration – become more common.
- Apart from annual dementia reviews, there are no other performance metrics in England that look at the effectiveness of the care and support offered after diagnosis

What 'Good' Would Look Like

- People of York are able to make informed choices about the support they need, using readily available information, advice, and guidance, which is accessible in different formats and covers issues such as financial support, carers' rights, and local support options. Community connectors such as the Council's Talking Points, Local Area Coordinators, Social Prescribing and third sector organisations, are available to offer this in person.
- People with dementia are involved in planning their support, and different approaches are used to ensure their maximum contribution.
- Dementia support workers are available in each primary care network, as part of an overall, integrated 'stepped' model of care where people can easily access more specialist intervention within the community as their needs become more complex

- Diagnosis without sufficient post-diagnostic support leaves people living with a complex and potentially devastating condition with limited understanding, capability or tools to cope with or manage its symptoms
- The complexity of dementia requires a multidisciplinary approach to support, including both health and care providers, which is frequently lacking in primary care.
- People with dementia experience worse outcomes when admitted to hospital than those without the condition.
- Three in five (59.5%) of people affected by dementia in Yorkshire and Humber did not feel they had received enough support in the last 12 months[3].
- 35.6% of people affected by dementia in Yorkshire and Humber did not feel confident managing their or their loved one's condition
- One in five (20.5%) were unsure when they last had an annual review of their dementia care[3]. Over half (52%) of those who did have an annual review said it did not help them manage their condition
- Engagement research in York found many stories of services working well together, but some reported not receiving any support at all, and others gave examples of inflexible and impersonalised support.
- York's care and support market is facing unprecedented workforce challenges, both in terms of recruiting and retaining staff. This impacts both upon the available skills to deliver good quality dementia care and upon the number of spaces within care homes registered to support people with dementia.
- High land value in the city presents a further challenge which prohibits investment from larger specialist dementia services.
- There are challenges in discharging people with dementia safely from hospital because of issues such as finding the right level of support for people with complex needs, or

- Support stopped due to coronavirus precautions has been safely reinstated without the need for unnecessary further assessment, and the support required to aid recovery from the adverse effects of Covid-19 is considered. Annual reviews return to pre-pandemic levels of 75%.
- Annual reviews conducted in primary care take account of the NHSE Good Care Planning resource and are holistic, taking into account other health conditions, and involving other professionals where appropriate to consider needs beyond medical care.
- Work is underway towards a single digital health and care record, to help reduce the need for people to tell their story multiple times, and to increase their control over their situation. This work includes efforts to mediate the risks of digital exclusion. Health and social are records ensure that a system is in place to identify those with dementia who are most vulnerable and at risk of crisis, who can then be offered more frequent care plan reviews if needed.
- Everyone who has received a dementia diagnosis, and their informal carers where present, have immediate short-term support to help come to terms with their diagnosis and plan for the future.
- We have a dementia support worker for every primary care network.
- People with dementia who live alone are supported where needed and receive appropriate information and support to ensure they can maintain social networks, activities and live safely in their own home. Assistive technology is proactively considered.
- People are automatically referred to a dementia adviser in either the Memory Service or primary care (with the ability to opt out); and everyone with a dementia diagnosis has a named health or social care professional within one of these services, to support them to coordinate their care from the point of diagnosis to the end-of-life.
- Evidence-based, post-diagnostic support interventions are provided for people with dementia and carers/family members where present, including support to maintain inclusion, occupation and identity, and social relationships; and tools such as personal health budgets and assistive technology to increase choice and control. Where anti-psychotic medication is appropriate, its use is closely monitored to ensure safe and high quality practice.
- Support is provided in a strength based way to the person and not their 'dementia', and is delivered in a way which is considerate of their individuality. Decisions made about diagnosis, care or treatment are made collaboratively with the person and where there is a carer/family member, they will be included.
- Where a person with dementia has a carer, there is appropriate support available to enable that carer to have breaks from this role if needed, both on an emergency and planned basis

knowing whether their support is primarily to be provided by health or social care.

- There are gaps in provision for people with young-onset dementia. Carers of people with young-onset dementia report a lack of age-appropriate activities and support, and the need for support to be flexible to accommodate employment.
- There are gaps in provision for people with alcohol-related dementia.
- York's rate of emergency hospital admissions for people with dementia is lower than the national average (3375 per 100,000), but people with dementia are staying in hospital twice as long as other older people.
- There is a challenge in finding crisis support around the clock.
- There is a challenge to ensure that all health and social care staff who may support someone with dementia, have the appropriate level of training,

- The risk of a crisis is prevented wherever possible and where a crisis occurs there is a comprehensive joined-up offer of support. This means that where admission to hospital, inpatient facilities or residential care cannot be avoided by a community response, the person receives compassionate and skilled support in dementia and carer friendly environments, and is discharged without unnecessary delay (utilising the Mental Health Liaison team and specialist nurses in primary and secondary care).
- Opportunities have been taken from the creation of the Integrated Care Board to simplify the funding arrangements for support for people with severe dementia.
- People who live in care homes receive appropriate assessment, diagnosis, and subsequent care planning, as clinical leads are able to identify the needs of their population and the right pathways for support. The Care Homes and Dementia Team are able to provide clinical input and quick access to advice and support for care home staff, which will enhance health, enabling residents to thrive and to avoid unnecessary hospital admissions.
- We have a diverse workforce (including peer supporters and newer roles to the dementia field), with a broad skill set. Every health and social care professional directly supporting people with dementia should be trained to at least Tier 2 of the NHS-backed Dementia Training Standards Framework, and we learn from people with dementia themselves, actively drawing on their expertise to improve the training offered. We utilise our community assets for their support.
- The Council has a Market Position Statement which promotes collaborative approaches to delivery of services, and all commissioned support is required to use a dementia-specific approach to care delivery, that promotes equal rights and access.
- We have the appropriate system-wide data to inform planning and commissioning of high-quality dementia support services, including regular engagement and ongoing conversation with people with dementia. We promote active engagement in research by people with both lived and learned experience of dementia to build an evidence base for practice (e.g. Dementia Enquirers).

Key Actions & Priorities

- Ensure that information, advice and guidance is readily available, accessible and provided in different formats, including in person. Explore the idea of Dementia Hubs, which provide a physical space for people with dementia and their carers to visit to access information, advice and support.
- Audit health and care records to establish where support may have been suspended due to the coronavirus and seek assurance that work is underway to remedy this.
- Monitor and contribute to work underway to develop a local shared care record.
- Work to develop a clear pathway of support following diagnosis, both in the short term and throughout the person's lifespan

- Work to develop evidence-based, person-centred interventions and support for people with dementia and their carers
- Implement an automatic referral to Dementia Support workers, at the point of diagnosis (with the option to decline)
- Work to improve the way systems supports people through crises, to ensure choice and control and minimise the negative consequence of intervention.
- Develop the work of the Care Homes and Dementia Team and the skills of clinical leads within care homes to ensure appropriate diagnosis, assessment, support planning and review for care home residents.
- Work to embed the Dementia Standards Training Framework across dementia support providers in the city, and ensure that there are contractual obligations to deliver a dementia-specific approach
- Work to develop a minimum data set which allows us to monitor progress in how we support people with dementia and their carers, and to consider gaps in knowledge or provision which warrant research.
- Learn from good local hospital discharge practice, to increase the number of people who have a safe discharge from hospital at the right time, to the right place, with the right level of support.

Living Well

"People with dementia can live normally in safe and accepting communities"

Current Challenges & Opportunities

- The Alzheimer's Society's 2021 survey found that 13.9% of carers in York reported feeling socially isolated. Loneliness associated with social isolation can increase the risk of dementia.
- York citizens have reported a need for improved way-finding and signage in some public buildings

What 'Good' Would Look Like

- People are enabled to live at home through dementia friendly communities and tailored home support. Dementia awareness is improved through dementia friends training, media communications and social networking. Assistive technology is used wherever helpful.
- We identify people living with dementia from marginalised groups and ensure they have equal opportunity to inform best practice dementia care in the city.

Community spaces and building-based support is accessible and dementia-friendly, and local universal services (e.g. opticians, hGPairdressers) have the opportunity to build their skills to be dementia friendly.

- People affected by dementia and their carers (where present) feel accepted, supported and understood in their communities. They can maintain and develop their relationships and are able to contribute to their community.

• There is a challenge to address the stigma associated with dementia and reduce the fear of diagnosis and social exclusion • People living with dementia from marginalised groups can be further oppressed without clear understanding of their unique experience and challenges. • There can be a challenge to support people at home with dementia as their condition progresses, but equally, a challenge for a person to leave their home and their familiar environment. Both can impact upon familial relations.	• There are mechanisms for an open and ongoing conversation between people with dementia and service providers so we are constantly striving for better conditions in which people with dementia can live a good life. • York's employers support and value people living with dementia and their carers, and people are able to make meaningful contribution. • York has an Inclusive Transport Strategy, which recognises that not all disabilities (including dementia), are visible. • The Disabled Facilities Grant (DFG) is used to support those who are eligible, to adapt their homes to make them safe and suitable for their individual needs. There are suitable housing options for people who need to move to somewhere with support but who do not necessarily require a 'care home'. • We positively influence how people perceive living with dementia through active campaigns and intergenerational projects. Discrimination and disabling language, attitudes and environments are challenged. • We support established peer support groups and similar initiatives to help build resilience, ensure the availability of support which accounts for people's individuality (e.g., Nursing with Pride, Free to Be Me in Care), protects human rights, and develop social action solutions. • There are ongoing opportunities for people with dementia and carers to access support interventions, information and education following diagnosis, to help them to live for longer in the way that is important to them. This includes age-appropriate activities &/or support to access mainstream activities for people with young-onset dementia. • Our Carers' Strategy includes a specific focus on carers of people with dementia (including those with young-onset), detailing the support available to them, including access to evidence based interventions, psychological support, practical training, bereavement support and vital breaks where needed. • Unpaid carers are routinely offered a flexible assessment of their own needs (virtual or face-to-face) and are treated as partners in the care of the person living with dementia.

Key Actions & Priorities

- Contribute to the work of the Ageing Well Partnership, meeting an objective of the City of York Council's Plan to promote dementia friendly services and buildings.
- Improve the use of equality data to ensure targeted work is undertaken where required, to reduce health and social care inequalities for people living with dementia and their families.
- Contribute to York's Inclusive Transport Strategy to ensure that the issue of non-visible disabilities is acknowledged and addressed.
- Information, guidance and advice are developed to address the different stages of the Dementia Well Pathway.
- Consideration is given to the spaces, places and people who can encourage open and ongoing conversations about creating the sort of city in which people with dementia and their carers can live good lives.
- Contribute to campaigns and intergenerational projects being developed through the Ageing Well Partnership.

- Ensure symbiosis between the Dementia Strategy Delivery Plan and the Carers' Strategy Delivery Plan to ensure that the right opportunities and support are available for carers of people with dementia.

Dying Well

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

Current Challenges & Opportunities

- We need more understanding of the barriers to people receiving appropriate end-of-life care that considers them as the individual beyond their diagnosis, and to planning care and support in advance. This is a global need, but we need to ensure that we consider adults who live alone, and the needs of people who are caring for a friend or family member with dementia, but who also have dementia themselves.
- A lack of common discussion of matters around death and dying among the public means that the wishes of people with dementia, even on basic matters, are often unknown as they reach the end of their life. People with dementia in York have told us that they want to know where to go to for support when dementia progresses and they would like more time with involved professionals to plan for the end of their lives.
- There can be a challenge for clinicians to support people with dementia who are in pain or discomfort at the end of their life, due to the difficulties with communication. There can also be challenges in supporting those with other health conditions, and to make decisions about when to withhold or withdraw treatment.
- It is recognised nationally that there can be difficulties identifying that a person with dementia is approaching the end of their life. This can be because symptoms are complicated by other health conditions, and/or changes to how a person communicates. It's important to educate all involved in supporting the person at the end of their life, to avoid missing important moments in the last days.

What 'Good' Would Look Like

- We work in partnership with people with lived and learned experience to break down barriers to good quality health and social care at the end-of-life.
- Everyone has the chance to have the right support and setting at the end-of-life, and to be as comfortable as possible. There is support for people to die with dignity in a place of their choice, and all efforts are made to avoid unnecessary obstructions to this.
- People with dementia have choice and control, and are included in decisions relating to their end-of-life care. Where the person themselves lacks the mental capacity to make decisions, family and carers will be provided with the relevant information and tools to support best interests decisions.
- All people living with dementia and their carers have the opportunity to discuss advance care plans at each stage of their pathway.
- We have appropriate information, advice and guidance to enable people to make early and informed decisions around planning for the future and end-of-life care. We also have information which supports families, friends and carers to identify signs of a changing condition, where to go and what to do.
- Advance care planning training is offered to any professional working within the field of dementia care and we have effective tools, including improved nonverbal communication strategies and use of people's life stories, to ensure person-centred support.
- All directly delivered or commissioned services meet agreed and recognised standards for end-of-life care. Work has been done to assess the use of the Gold Standards Framework, One Chance to Get It Right, and Priorities of Care

- We know that in the advanced stages of dementia there is often a hidden cost to those who provide support, as their caring role can increase, they can feel more isolated, and they can feel extra pressure if involved in making significant decisions on a person's behalf. We want carers to feel valued and supported, and able to get support when needed.
- Nationally there is some research to suggest concern about the number of professionals who visit a person when dying at home.
- It is recognised that dementia is a terminal condition (in 2020, it was the leading cause of death in England and Wales after COVID-19) but work needs to be done to better understand the standardised rate of mortality for people living with dementia in York. It is currently lower than the national average (794.2 as opposed to 849.3) for people over 65.

for the Dying Person as national frameworks which could ensure best practice locally.

- We have an agreed best practice protocol for assessing pain, which can be utilised widely to assess the impact of pain and discomfort in people who have difficulty vocalising their needs.
- Families and carers are provided with timely coordinated support before death, at the time of death, and during bereavement.
- There are opportunities for people with dementia, their families, and staff from key stakeholders, to share knowledge and experience to inform best practice, and consider research opportunities to improve this.
- We have ongoing audit and monitoring of services to identify gaps in service delivery in order to ensure that capacity of specialist palliative care provision meets demand in all settings.

Key Actions & Priorities

- Alongside people with lived experience of dementia, undertake research to identify the barriers to people receiving appropriate end-of-life care and support, and work to address these
- Develop information and guidance to support people with dementia and their carers to make decisions about the support they want at the end of their life
- Alongside people with lived experience, identify and deliver appropriate workforce development around advanced care planning and end-of-life care
- Ensure we have the appropriate support in place for families and carers when their loved one is diagnosed as being at the end-of-life.
- Audit and monitor the availability of palliative care in community, health and care home settings, and set out a framework of monitoring and review to ensure sufficiency.