

Team Doncaster Dementia Strategy

2023-2025

Unlocking
possibilities:
A Person-centred
Dementia
Strategy



Doncaster
Delivering Together



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Foreword



Wendy Sharps

Person with dementia

**Co-chair of Doncaster
Dementia Collaborative**

My name is Wendy, I was diagnosed with Lewy Bodies Dementia over 10 years ago at 40 years old, and I am a passionate advocate for all things dementia.

Getting diagnosed was a long five-year process, and since then I have had lots of different experiences with professionals that have been both positive and negative. In my opinion, people with good quality dementia training have a good understanding, seem clued up and treat me like normal. For people that haven't had good quality training people, more education and awareness is needed to understand people like me and not put us all in the same box.

I am delighted to be involved with the development of the Team Doncaster Dementia Strategy. Currently, I co-chair the Doncaster Dementia Collaborative and attend the Dementia Strategy Group meetings where myself and others work with local Health and Social Care services to lobby, raise awareness, and support change to people effected by dementia living in Doncaster.

Attending these meetings, I am treated like a normal person and because dementia really matters to me, I am happy that people listen to my thoughts.

I personally think it is important for people experiencing dementia, with their own diagnosis or as a family member or carer(s), to have their views and opinions heard. To me, this strategy has given more people in Doncaster the chance to share their voice and I hope that it is used to help shape future dementia services in Doncaster. Everyone with dementia should be able to access the right health, care, and support for them- not just a one-size-fits-all approach.

This strategy has been coproduced with other people like me and my family and I look forward to seeing how it will make things better for people with dementia in Doncaster.



Anthony Fitzgerald
Executive Place Director
– Doncaster
NHS South Yorkshire
Integrated Care Board

With the ageing population expected to rise over the next 10 years, a timely diagnosis for people with dementia is vital not only for the person, but also for their family and friends. A timely diagnosis enables people to maximise control over their lives by planning ahead and accessing support to ensure that they can enjoy an active and independent life for as long as possible. This strategy has been drafted following extensive consultation with our partners and our population and sets out how we aim to make Doncaster the best place to live well with Dementia by working together across Health and Social Care.

The strategy sets out how we aim to do this and how we can provide the help and support that is needed in order to realise this aim. From prevention to diagnosis and to delivery of services, we must ensure that there is adequate and meaningful provision to help and support people with dementia, as well as their family and friends. Promoting self-care and self-empowerment is often a primary requirement for people who want to stay in their own homes. Family and friend carer(s) are influential in supporting people living with dementia and it is therefore key that we support them in their caring role.

I hope you will find this strategy informative and of interest. I believe that the more we work together with people who draw on our support, the better quality of life will be achieved for our population



Councillor Rachael Blake
Chair of the Health and
Wellbeing Board

Dementia Friends, a national movement sponsored by the Alzheimer's Society, has five key messages:

1. Dementia is not a natural part of ageing
2. Dementia is caused by diseases of the brain
3. Dementia is not just about memory loss
4. It is possible to live well with dementia
5. There is more to a person than the dementia.

This Dementia Strategy sets out how local organisations will work together to ensure timely information, diagnosis, treatment and support but the overall goal should be helping Doncaster people and their families live well. This isn't always easy. Dementia affects everybody differently and the challenges we face in our lives are not shared equally. But we can do much more to be dementia-friendly. We can help Doncaster people live with dementia in the place they call home with the people and things that they love, in communities where they look out for one another, doing things that matter to them. Achieving this doesn't only require high quality healthcare, it's also about good housing, being able to get out and about, remaining connected with people and being recognised for the huge contribution people living with dementia have made and can still make to Doncaster life.

Wendy, on the previous page, is living testament to that. If you ever meet her face-to-face you will have no doubt that there is more to a person than the dementia! This strategy is about dementia but it's also about all of us and our human right, whatever our circumstances, to be understood and valued.

What is Dementia?

Dementia is an ‘umbrella’ word used for the 200+ conditions that cause symptoms when the brain cells cannot work the same.

Often, people start with minor challenges like memory loss, difficulty performing familiar tasks, problems with language and changes in personality.

For a dementia diagnosis, these are severe enough to affect everyday life. There may also be changes in mood and behaviour.

There is currently no cure or prevention for dementia, but a range of support is available for people with dementia and their carer(s) including risk reducing advice and guidance.

This strategy will underpin Doncaster’s city-wide commitment to provide high-quality care and support for people with dementia and their carer(s).

Building on progress already made during the previous partnership strategy ‘Getting There’, this strategy seeks to improve the lives of people living with Dementia, their families and their carer(s) and will provide a call to action for continuous development in ensuring that people continue to live well and thrive.

This strategy has been co-produced with people living with dementia, their carer(s), commissioned and non-commissioned providers, the voluntary sector, Adult Social Care and other professionals, with a real focus on ensuring **dignity and compassion** is at the forefront of all care, treatment, support and decisions.

Vision

People living with Dementia and members of the Doncaster Dementia Collaborative agreed a vision statement to describe the aim of the strategy and its action plans:

“Striving to be the most Dementia Friendly City, adding years to life and life to years, for people living with dementia and their carer(s) living in Doncaster.”

While the strategy will be in place until December 2025, it is recognised that adding years to life is a longer-term goal and hope that it is adopted in future strategies for years to come. The vision success measurements will be captured by the data and performance workstream.

Published by the Alzheimer’s Society, the ‘Dementia Friendly Communities’ explores evidence from people with dementia about their experiences of living in their community and the ten key things they would like to see in a dementia-friendly community.

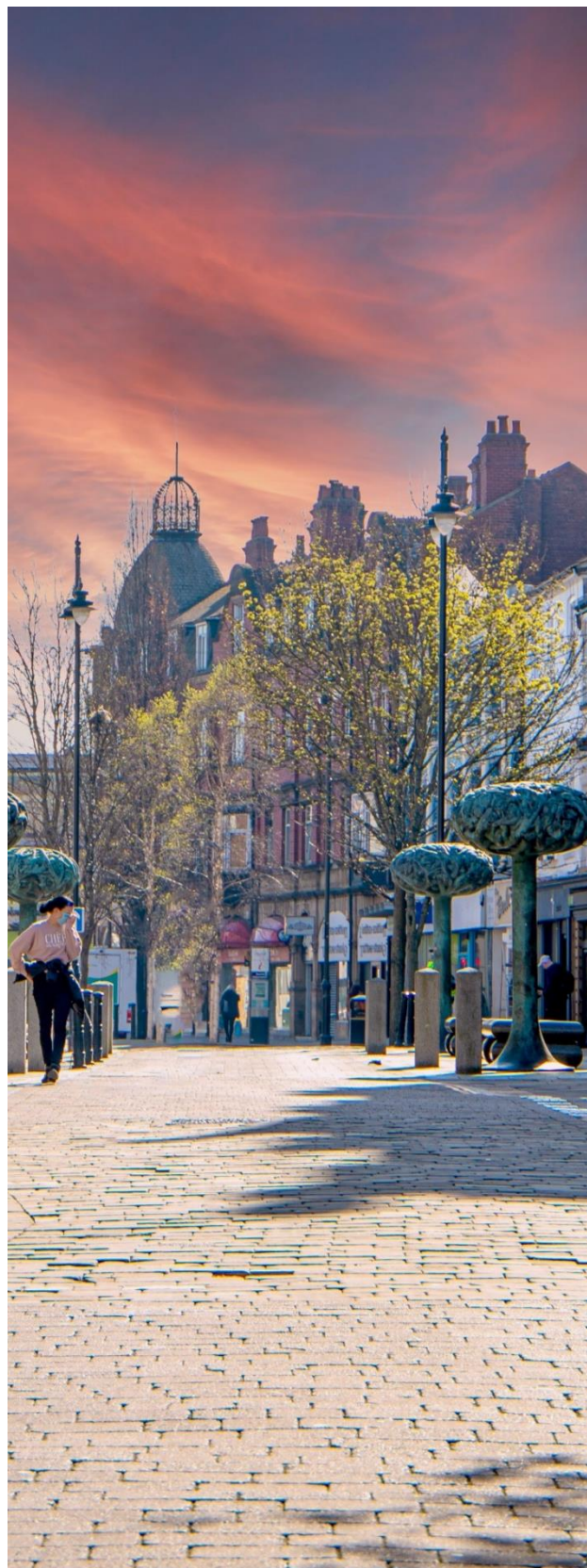
Dementia-friendly communities



What has been achieved so far

The following achievements have been made since the implementation of the previous Dementia Strategy providing good foundations to build upon.

1. Implemented the findings of the Blackfriars Consensus by producing a 'reduce your risk leaflet'
2. The Dementia Roadmap has been replaced with the Your Life Doncaster Dementia webpage which continues to provide advice and guidance
3. A pre-diagnosis service was commissioned in 2021 to compliment the already existing post-diagnosis service to strengthen the offer of support for people at differing stages of the dementia pathway
4. A total of 14091 people in Doncaster were trained to be Dementia Friends
5. A number of awareness raising events took (and continue to take) place
6. The Doncaster Memory Service (RDaSH) received accreditation through the Royal College of Psychiatrist's Memory Service National Accreditation Programme (MSNAP) and work to the standards
7. The Doncaster Dementia Collaborative group was launched in 2021 and continues to lobby for the rights of people with dementia and their carer(s)
8. Dementia is considered within a number of local strategies such as the Dementia Carer(s) Strategy
9. Specialist dementia roles are in place to provide specialist support to people with dementia and their carer(s)
10. The Voluntary Community and Faith sector have greater visibility and have been able to reach more people with dementia and their carer(s)
11. Lots of co-production and consultation work has been completed to understand the views of more people with dementia and their carer(s) which is helping to work towards true co-production



Co-production

This strategy has been coproduced with the following people:

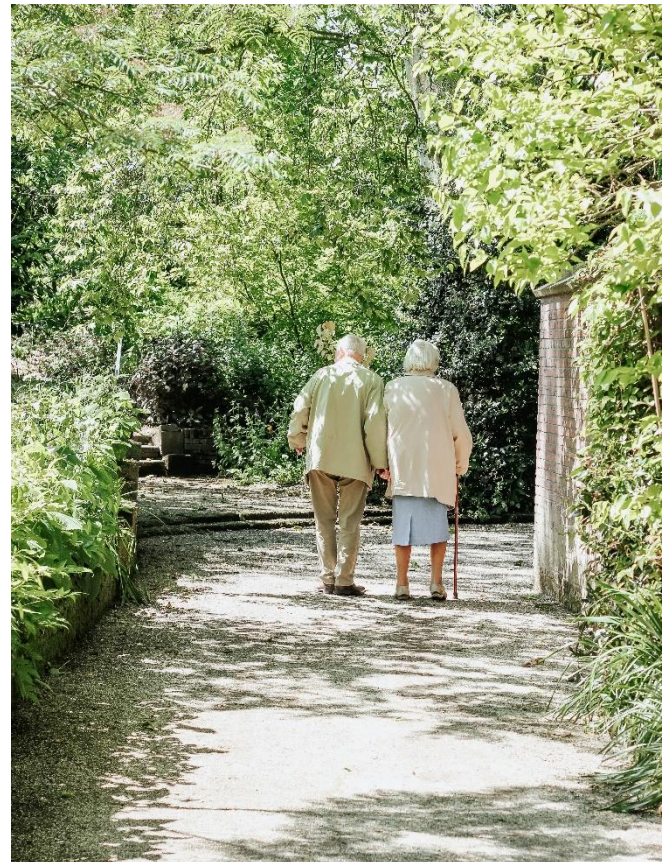
- People with lived experience of dementia
- Family and friends of people with dementia
- Carer(s)
- Accountable Care Partnership (current providers of commissioned services)
- Doncaster Dementia Collaborative (a group of people with dementia and people with an invested interest in dementia)
- Doncaster Dementia Strategy Group (a group of people with dementia and professionals from a wide range of organisations)

The co-production has focused on what is important to people with dementia.

A co-production exercise was commissioned by Doncaster Council and South Yorkshire ICB in summer 2022. This was undertaken by Healthwatch Doncaster and confirmed that much more work is required in Doncaster to support people and their carer(s) both prior to a potential dementia diagnosis supporting them through their journey and post diagnostically to ensure they receive the right information, advice, guidance, signposting, care and support. This co-production took in to account the views of over 200 people in Doncaster and formed the **Healthwatch Insight Report**.

To build on the findings above the **Doncaster Dementia Survey 2023** was carried out in March by Doncaster Council that gained insight from over 400 people in Doncaster. This built on the Healthwatch findings highlighting 5 key areas for priority as follows:

- Cross Cutting Themes
 - Coproduction
 - Health Inequalities
 - Workforce
 - Data and Intelligence
 - Dignity and Compassion
- Information Advice and guidance
- Receiving a diagnosis
- Support following diagnosis
- Support for carer(s).



Areas of Priority

Priority 1 – Cross-cutting Themes

What people with Dementia and their family/carer(s) told us

1.1 Co Production (see below co-production ladder)

Co-production is an equal relationship between people who use services and the people responsible for services. They work together, from design to delivery, sharing strategic decision-making about policies as well as decisions about the best way to deliver services. The co-production ladder below (inspired by Think Local Act Personal's 'ladder of co-production') depicts how co-production should work. In Doncaster we are working towards co-production, but it is recognised there still is work to be done with us currently operating around the engagement and co-design stages.

Where we need to be

Where we are now



Co-production - an equal relationship between people who use services and the people responsible for services.

Co-design - People have genuine influence in designing services based on their experiences and ideas, but not involved in 'seeing it through'.

Engagement - in addition to 'consultation' people are given more opportunities to express their views and may be able to influence some decisions.

Consultation- People may be asked to fill in surveys or attend meetings, which may be considered tokenistic if they do not have the power to influence change.

Informing - The people responsible for services inform people about the services and decisions and explain how and why they work.

Educating - The people who use services are helped to understand the service design and delivery so that they gain relevant knowledge about it.

Coercion - people are passive recipients of services with little to no say.

¹ Ladder of Coproduction, Think Local Act Personal, 2021: [Ladder of Coproduction | TLAP | social care \(thinklocalactpersonal.org.uk\)](#)

1.2 Health Inequalities

It is recognised that health inequalities impact people with dementia in Doncaster. These are avoidable, unfair, and systematic differences in health between different groups of people within society. Health inequalities can lead to unequal outcomes, varied access to services, and poor experiences of care. leading to disparate outcomes, varied access to services, and poor experiences of care.

In Doncaster, 24 Communities have 50% or more of their population living in the most deprived 20% of the country. People living in deprivation will:

- lead shorter lives,
- typically live one third of their lives in poor health
- be less likely to attend outpatient hospital appointments

To tackle health inequalities, more co-production needs to be undertaken with these groups of people to fully understand barriers that need to be broken down.

The Health Inequalities and Inclusion Steering Group Launched June 2022 to:

- Build relationships, trust and connections across health and care, including residents and patients
- Increase awareness of services and support available to people – reiterating that does not always have to be health
- To reduce demand on health and care and improve outcomes

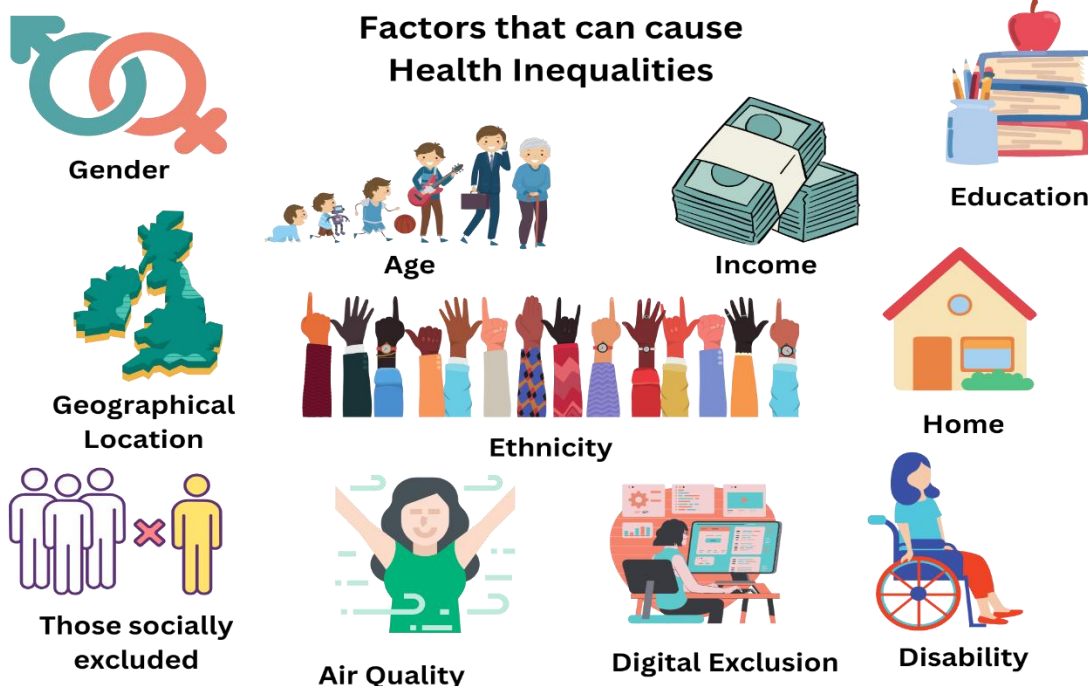
An example of the affect health inequalities may have on dementia is that of the LGBTQ+ population. Research suggests that LGBTQ+ people will experience difference challenges and concerns about dementia compared to the general population. The LGBT Foundation state that:

“LGBT people with dementia may experience additional layers of distress due to life-long health inequities and barriers to accessing healthcare. They may, even before being diagnosed with dementia, have felt unsafe expressing their identity for fear of discrimination and how others will treat them.

Some LGBT people may not remember that they have ‘come out’ and re-live fears and concerns about their sexual orientation including internalised homophobia or biphobia.”

Championed by Care England and with accompanying training endorsed by Skills for Care, the **#PrideInCare** quality standard that enables organisations to be assessed as providing quality care and support to older LGBTQ+ people.

By researching and signing up to schemes like this, work can be done alongside partners, providers, and the voluntary/community sector in Doncaster to ensure people from all different backgrounds are able to live full, vibrant, and respected lives, free from isolation, loneliness, discrimination, and prejudice.



1.3 Workforce and Awareness

People in Doncaster feel the workforce could be better equipped to work with people with dementia. It is reported that sometimes, people with dementia and their carer(s) are treated poorly by staff through lack of insight and knowledge of dementia. People feel that staff should be more highly skilled to ensure that a high standard of care and support is delivered.

In addition to this, there is a lack of general awareness of dementia and associated symptoms by the wider community (in shops, restaurants and public places) which prevents community inclusion.

“My husband enjoys participating in normal family outings and events and playing his part, but we find staff particularly when we are eating out rush him to choose his food and don’t understand when he wants to eat things in a bit of a different way” – wife of person with dementia, Dunsville.

1.4 Data and Intelligence

Data and Intelligence remains important to complement co-production and inform governance and future decision making around dementia. South Yorkshire ICB currently host a Dementia Dashboard used as part of contract monitoring. Partners should work collaboratively to provide relevant and up to date data and intelligence that is understandable to people with dementia and their carer(s).

1.5 Dignity and Compassion

People with dementia and their carer(s) have a right to be treated with dignity and compassion. In Doncaster, people with dementia feel they are often ‘put in a box’ with factors presumed on their behalf. Some people report that they are overlooked by professionals in appointments who assume the person with dementia lacks capacity and talk directly to the carer(s) or family member. Other people report that people with

dementia, through lack of support, are put in positions where their dignity is compromised. In addition, people should be aware, empowered and supported to get the care they want at all stages of their dementia journey including at the end stages of their life.

What will we do to better address cross cutting issues?	
	Cross-cutting issues will be addressed to reduce health inequalities and help people with dementia live better for longer. People with dementia and their carer(s) will be supported by well trained professionals and treated with dignity, compassion, respect and kindness.
1	Doncaster will strive to work to strengthen co-production for dementia to ensure services and strategies are driven by people with dementia and their carer(s).
2	Ensure that dementia services are inclusive of everybody including people with protected characteristics, people experiencing significant poverty (core20 population), people from ethnic minority communities and inclusion health groups.
3	Promotion of courses for people with dementia, unpaid carer(s), family members, care and support staff, professionals and the wider public. Training provision in Doncaster will be co-produced with people with dementia and their carer(s) and evaluated to ensure training and development is of a high standard.
4	Develop health and social care Dementia Reporting Dashboards in line with the strategy and service implementation.
5	Ensure people with dementia are treated with dignity, respect and compassion, at service level with health, social care and support staff but also on a wider awareness-raising level with communities across Doncaster.

Priority 2 – Information, Advice and Guidance

What people with Dementia and their families/carer(s) told us.

People with dementia and their carer(s) feel that there are some good quality services available in Doncaster, but these are not promoted very well resulting in being overwhelmed, feeling helpless and not knowing where to turn.

"Often there are great opportunities out there but again, information, and getting that information to people, is key." – carer(s), Doncaster

People in Doncaster want to be able to access all relevant information relating to dementia support in one place, at a time that suits them. At present, people are finding out different pieces of information from a wide range of people at different times which can feel overwhelming. In addition, people want to be able to access information at their own pace, when they feel ready to do so.

"My mum has had dementia for years and have no idea of any support both socially or financially she could be entitled to." – family member, Hatfield

Information, advice, and guidance relating to social and finance support is lacking too, with people wanting to be given each piece of the 'jigsaw' to allow them to consider what is important to them. This also applies to information relating to future care options – people with dementia and their carer(s) should not only be aware of their current situation but how their needs may change in the future and what that might mean in terms of future support. This will allow people to make informed decisions and consider a range of different options.

"It takes far too long to get information on what is out there, doctors could have a list of what is out there and hand a folder to the patient with all the info they need." – family member, Bessacarr

The Your Life Doncaster Dementia Information web page is a good starting point, however, the information could be strengthened. Of the 409 people that completed the Dementia Survey, 66% did not know about the page and 19% felt it could be strengthened. People also felt that a lot of current information, advice and guidance is not simple to read and contains too many big words.

Risk-reduction and prevention information, advice and guidance could be strengthened in Doncaster in line with new data and research.

What will good information, advice and guidance look like?

People with dementia and their carer(s) will have improved access to information, advice and guidance relevant to the Well Dementia Pathway.

- | | |
|---|--|
| 1 | Information, advice and guidance will be of a good quality, written in simple to read language, accessible to anyone who needs it at a time that suits them. |
| 2 | Advice on reducing the risk of dementia will be available and stakeholders will strive to promote this messaging. |
| 3 | Access to information digitally will be available in one place (Your Life Doncaster). Access to information will also be available across locality hubs. |

Priority 3 – Receiving a Diagnosis of Dementia

What people with Dementia and their families/carer(s) told us

Some people with dementia and their family/carer(s) have positive feedback about the actual diagnostic process, but it is felt that the diagnosis process is lengthy and difficult to achieve which can be frustrating and invalidating.

"In my personal experience initial diagnosis of dementia is very difficult to get. Access to support for families may be available but only if you know what to look for and to access any of the above needed Mum to see a GP- 240 phone calls to be told there's no appointments available." – friend of person with dementia, Branton

People in Doncaster also feel that more urgency should be given to diagnosing dementia to allow intervention as early as possible and reduce the risk of ending up in crisis. It is evident that there is a lack of signposting to pre-diagnostic services which would help to reassure and support people with dementia and their carer(s).

"I think there should be more of an urgency for the diagnosis, the tablets, once given really help (or in our case have) there is no help or understanding from their local doctors." – Carer(s), Cantley

It is also felt by people with dementia and their carer(s) that following diagnosis, there is often a delay with receiving support, causing people to feel lost in the system with no idea where they can turn for support.

"Once a person has a diagnosis of dementia, there is very little professional support and advice. Services do not respond quickly enough, and the support given is somewhat variable between areas." – family member, Bennetthorpe

The estimated prevalence of people in Doncaster with a dementia diagnosis is currently between 61% and 65%. This is slightly below the national ambition of 66.7% and below our South Yorkshire neighbouring authorities.

What will a good diagnosis of dementia look like?

People with memory concerns will receive a timely diagnosis, which will trigger referrals to any relevant services.

- | | |
|---|--|
| 1 | Doncaster will strive to improve the diagnosis rate to 75% in line with other South Yorkshire authorities. |
| 2 | Reduce the delay from the point of raising concerns to receiving a diagnosis, by working with health partners (GP Access, Clinics and Health Provision). |
| 3 | Ensure the timely start of treatment and services for people diagnosed with dementia and their carer(s). |

Priority 4 – Support with Diagnosis

What people with Dementia and their family/carer(s) told us.

People with dementia and their carer(s) were generally complimentary about staff and services but said the dementia pathway is difficult to navigate, resulting in feelings of confusion as to where they can turn for help. There are often long waiting times, and some people find support to be inaccessible.

"Takes too long to get support for dementia patient with very little accessible support and funding" – carer(s), Balby

People with dementia and their carer(s) are often passed from service to service before they are speaking with the relevant person who can help them. This sometimes leads to people 'giving up' and withdrawing from available support as it is too difficult to access. It is felt that the dementia pathway would be more easily accessed if people are provided one key contact with a vast local knowledge who could signpost to the right place.

"I then had to ring every department of Doncaster Council for help and was passed from pillar to post. Again, a central contact who can signpost you to the help required." – family member, Bessacarr

There are a number of issues with transport across the City for people with dementia and their carer(s) reporting that public transport buses have been cut, particularly in rural areas, which limits how accessible the community and services are.

In addition to this, people with dementia report quite a decline in the passenger transport services available to people who rely on such, whereby there are now less buses provided (some of which aren't accessible to people with mobility issues), and the reliability is lacking. It is confirmed

that people are often picked up from home late and picked up from their service early to fit around other driver commitments which cuts down valuable time spent accessing necessary services and support.

"There is only one bus (leger), which is very safe and nice drivers, but the buses quite often don't turn up when they have been booked, and we have no alternative to use taxis when the client is vulnerable." – family member, Mexborough

It is recognised that people with dementia that live alone are at higher risk of being isolated and being in crisis.

It has been raised by people with dementia and their carer(s) that the dementia pathway is difficult to navigate, this barrier will be much larger for people living alone with no informal support network. Organisations and services could work more collaboratively to prevent people living alone being left in vulnerable situations.

People with dementia and their carer(s) also feel there are disparities with services delivered varying between areas. Services can often be concentrated more centrally and in more evolved/urban/connected areas. As the demographic in each area is different, there is a need for future services to meet locality need.

"Lack of funding and services, certainly once you get outside the main towns or Cities like Doncaster. Insufficient specialised care for dementia patients in local areas. Taking someone out of their own area is frustrating as they don't know where they are going prefer not to have to go far" – family member, Thorne

People with dementia have expressed the need for the availability of differing levels of support for people on different parts of the dementia pathway. It is felt that currently there is not much provision for people at the start or middle of the dementia pathway who are more physically able. This could present an opportunity for further stimulating activities and to help keep people living well at home for longer. Included in this is provision for people with Young Onset Dementia.

"There seems to be little in the way of activities for people in the early/ middle stages of the condition. More services should be available to access e.g. swimming." – person with dementia, Conisbrough

People with dementia and their carer(s) feel support around future care and support options could be more holistic and better personalised to allow people to live well after their diagnosis. People with dementia are not always made aware of what is available to them as an option (e.g. Direct Payments) which prevents more personalised care and support from taking place.

Activities offered can be very limited, particularly within a residential home setting and people are not provided with realistic expectations when they are considering their options. In addition to this, feedback highlighted that they were unaware of how the needs of a person with dementia can change over time leading to implications for people making decisions (e.g. selecting a home that offers both residential and nursing care to avoid a potential future move).

What will good support with diagnosis or memory concerns look like?

People with dementia and their carer(s) will receive the right support for them to live well. People will be empowered to make informed decisions. Support will be easily accessed and tailored to meet the outcomes of people with dementia.

- 1 People will have access to one point of contact for ongoing navigation to ensure they feel continually supported throughout their journey. This support will be available to people with dementia, people in the pre diagnosis pathway and their carer(s)/supporter.
- 2 Strengthen transport links in Doncaster for people with dementia to increase accessibility of services.
- 3 A multi-agency approach will be taken towards people with dementia that live alone to coordinate and ensure they have the same quality of care and support as people with an informal support network.
- 4 Work will be done to consider the impact of social isolation on people living with dementia or memory concerns.
- 5 Align services/support with the locality way of working to ensure support is built on assets within Doncaster Communities and gaps identified and addressed.
- 6 Support will be based on needs rather than a one-size-fits-all approach. People with dementia will receive support that they wish to receive aimed at their own level of need and interests.
- 7 People with dementia and their carer(s) will be fully supported to make informed decisions in relation to future care and support options.

Priority 5 – Support for Carer(s)

What people with Dementia and their family/carer(s) told us

Carer(s) of people with dementia do not feel well supported within their role and often struggle to access information, advice and guidance.

"Lack of support for families, particularly close family members of dementia sufferers." – family member, Bentley

Carer(s) of people with dementia feel too much is expected of them and that their needs are not considered during conversations and decisions about people with dementia.

"Too much care is expected from the husband / wife of the sufferer leading to mental health issues of the other partner" – family member, Sprotbrough

"Carer(s) needs should be included in all discussions" – professional, Doncaster

Some professionals feel that some carer(s) and family members aren't prepared enough to fully understand the effects of dementia.

"I've also recognised for a long time that families are unprepared for the change to their loved ones and the day-to-day routine, brought on as a result of dementia. Often worsening the outcome in relationships." – professional, Doncaster

What will good support for carer(s) and families look like?

Carer(s) and family members of people with dementia will receive support to help maintain their role to the best of their ability. Carer(s) will have better access to information, advice and guidance. Carer(s) will be aware of the Carer Service in Doncaster and their rights to a carer conversation.

- 1** In line with the Doncaster Carer(s) Strategy, carer(s) will be identified at the earliest opportunity to enable them to connect with support.
- 2** Carer(s) and family members will be fully prepared for the signs, symptoms, and emotional effects of dementia on them and the person with dementia.
- 3** Carer(s) and family members will have the skills and knowledge to be proactive when supporting the person with dementia.



Well Pathway

The Well Pathway (below) for Dementia is the NHS' five-year implementation plan which covers five key areas: Preventing Well, Diagnosing Well, Supporting Well, Living Well and Dying Well.

Our Strategy aims to align itself with this transformational framework and ensure that all Doncaster residents can live well with dementia within the community of their choosing and with the right support and care around them.

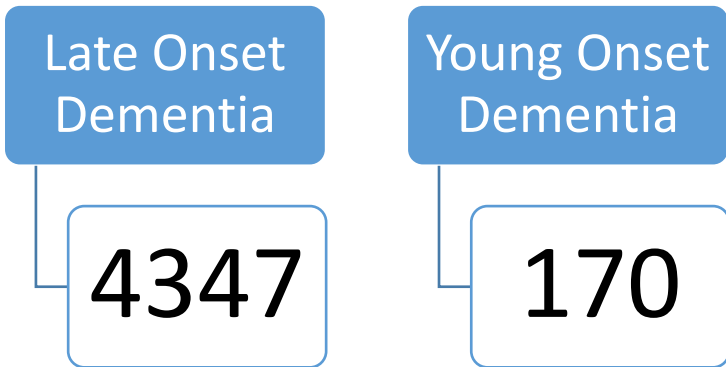


Photo Credit: Hannah Baines, City of Doncaster Council

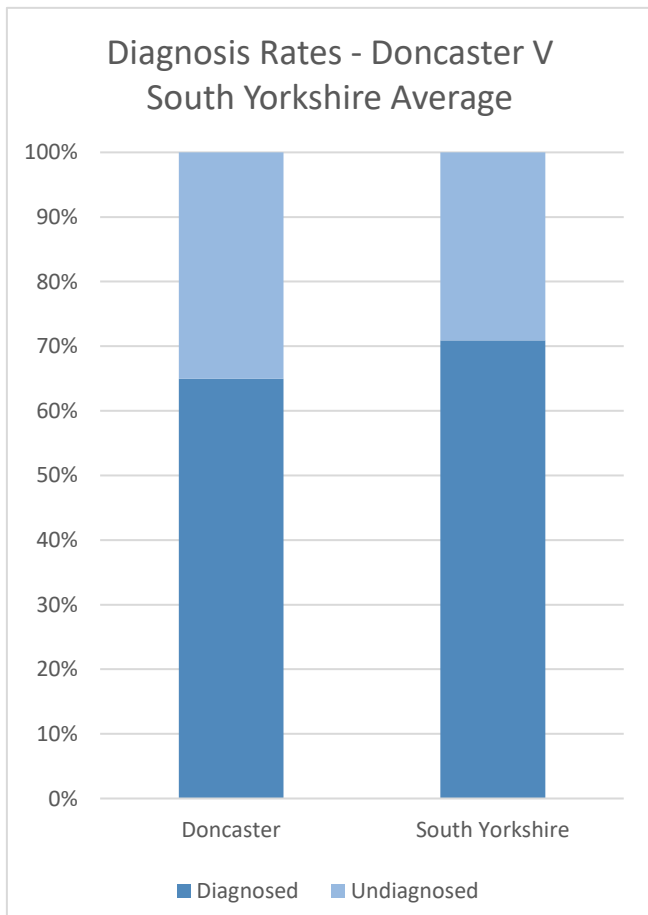
NHS England Transformation Framework – THE WELL PATHWAY FOR DEMENTIA				
PREVENTING WELL	DIAGNOSING WELL	SUPPORTING WELL	LIVING WELL	DYING WELL
Risk of people developing dementia is minimised.	Timely accurate diagnosis, care plan, and review within first year.	Access to safe high-quality health & social care.	People with dementia can live normally in safe and accepting communities.	People living with dementia die with dignity in the place of their choosing.
<i>"I was given information about reducing my personal risk of getting dementia."</i>	<i>"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."</i>	<i>"I am treated with dignity & respect." "I get treatment and support which are best for my dementia and my life."</i>	<i>"I know that those around me and looking after me are supported." "I feel included as part of society."</i>	<i>"I am confident my end of life wishes will be respected." "I can expect a good death."</i>
WHAT DOES THIS MEAN FOR DONCASTER?				
<ul style="list-style-type: none"> Awareness raising & risk reduction Education Public Health campaigns Yourlife Doncaster Page Accessible information to everyone 	<ul style="list-style-type: none"> Increased diagnosis rates Pre-diagnostic service Identification and referral Working with Primary Care Networks Development of Best Practice protocol Harmonisation of GP registers and secondary care Improve patient flow 6 weeks RTT Supportive assessment tools Pro-active case finding Diagnosis in care homes 	<ul style="list-style-type: none"> Work across the wider system to support people living with dementia and their carer(s) Holistic MDT approaches Improve information sharing/decision making Ensure support is available to people with dementia and their carer(s) to navigate the system and understand their options for health, care and support. Acute wards – effective discharge planning Virtual wards Ensure there is equity and availability of service Coproduction of services, ensuring people living with dementia and their carer(s) are involved in designing, developing and renewing services Personalised care Promotion of self-care and self-treatment Care planning and advanced care planning (ReSPECT) 	<ul style="list-style-type: none"> End of life care Enhanced care in care homes Woodfield 24 Advanced care plan (ReSPECT) 	
Health Inequalities, Digital & Social Isolation, Coproduction				

Data and Intelligence

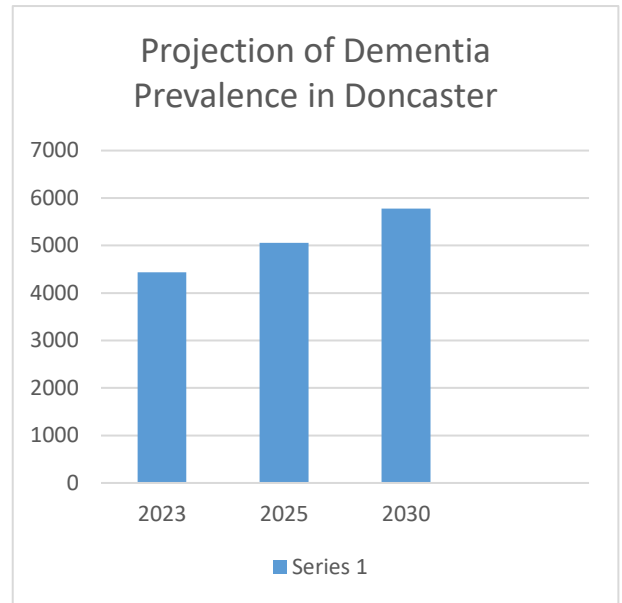
There is an estimated 4517 people of all ages with Dementia in Doncaster. This can be split by older people (65+) and younger people (30-64) as below:



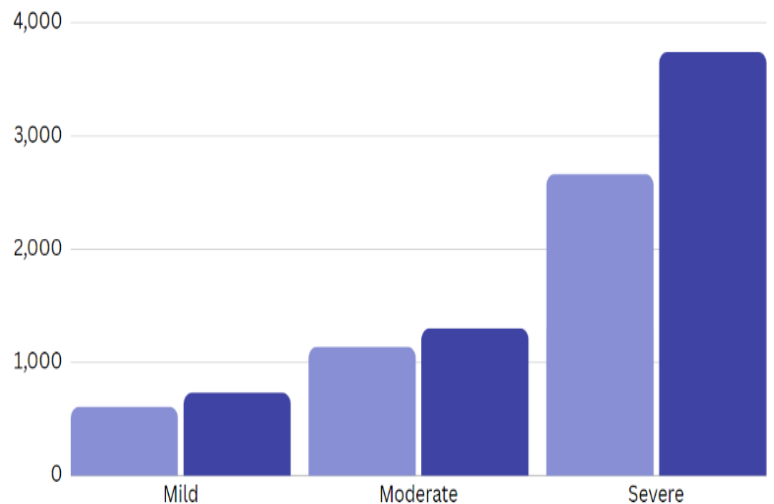
Of the figures above, 65% of people have a diagnosis of Dementia with 35% being undiagnosed. The South Yorkshire average of Barnsley, Doncaster, Sheffield and Rotherham is 70.9% of people diagnosed.



The number of Doncaster residents living with Dementia is estimated to increase 30% by 2030.

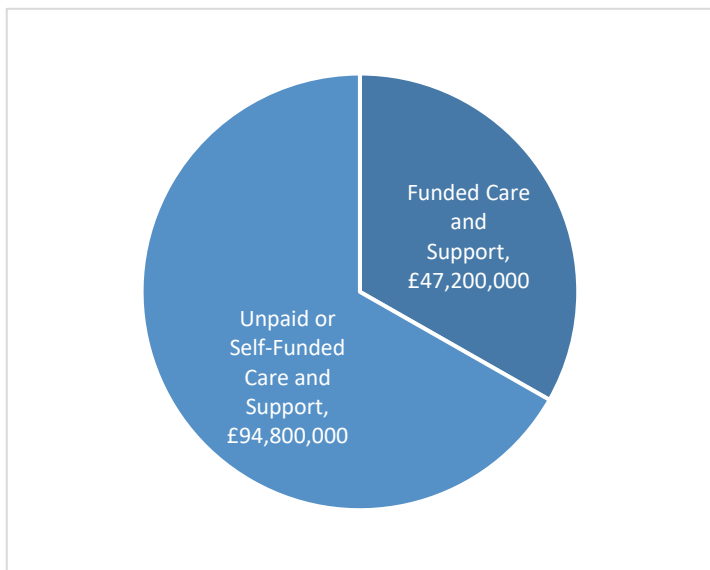


In line with the projected increases, it is also estimated that the number of people with “advanced” dementia will increase over double the rate that mild and moderate severities will.

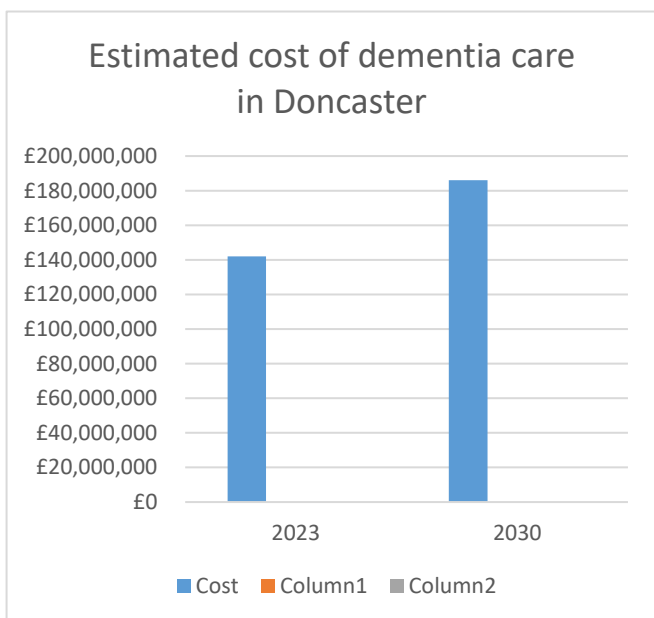


According to the Alzheimer’s Society², the cost of dementia care is currently £32,250 per person which totals to £143million in Doncaster. Data suggests two thirds of this cost is being currently met by people living with dementia and their families through unpaid or self-funded care and support.

In 2019, the Alzheimer’s Society commissioned the London School of Economics to undertake research around the cost of dementia care in the UK. The findings, Projections of older people with dementia and costs of dementia care in the United Kingdom, 2019–2040³, can be found online.



With the projected increase of 30%, this would see the cost of dementia in Doncaster rise to an estimated £186million by 2030.



What does the data mean for Doncaster?

Data suggests that people will live longer with dementia in Doncaster and could be the reason it is projected that there will be more people living with “advanced” dementia.

As the forecasted data reveals financial pressures alongside increasing numbers of people needing support, it is vital to consider models of care and support which will maximise people's independence and well-being and effectively manage demand for statutory services.

Work should be done locally, in collaboration with health colleagues, to fully understand the changing need in order to capture data and intelligence to inform future key decisions.

² <https://www.alzheimers.org.uk/blog/how-much-does-dementia-care-cost> Alzheimer’s Society, 2021

³ https://www.alzheimers.org.uk/sites/default/files/2019-11/cpec_report_november_2019.pdf 2019–2040, London School of Economics, 2019

National and Local Context

At present there are currently around 900,000 people in the UK with Dementia, which is projected to rise rapidly over the coming years. This will also see the cost of social care increase too.

Doncaster's Dementia Strategy has been developed in the context of other key national and local policies, which inform the way in which the plans are developed and put in place. National and local plans are focused on ensuring people are supported in the best way and to reach their health and wellness potential.

The strategy will be in place for 2 years to consider emerging national guidelines such as the upcoming National Dementia Strategy and Major Conditions Strategy which will seek to increase and improve life expectancy of people living with major conditions, including Dementia.

Following the government's **All our Health** call to action, guidance was released in 2022 to help health and care professionals prevent ill health, promote wellbeing and use their trusted relationships with individuals, families and communities to promote the benefits of focusing on dementia. This guidance also sets out clear and important actions that managers and staff holding strategic roles can take.

Health and Wellbeing Board Strategic Priorities and Wellbeing vision is:

'A strong local economy, progressive, healthy, safe and vibrant communities. All residents will be able to achieve their full potential in employment, education, care and life chances. 'All residents to be proud of Doncaster'

The ambition for Dementia in Doncaster is for people to agree with the following 'we' statements:

- *"We have the right to be recognised as who we are, to make choices about our lives including taking risks, and to contribute to society. Our diagnosis should not define us, nor should we be ashamed of it".*
- *"We have the right to continue with day-to-day and family life, without discrimination or unfair cost, to be accepted and included in our communities and not live in isolation or loneliness".*
- *"We have the right to an early and accurate diagnosis, and to receive evidence based, appropriate, compassionate and properly funded care and treatment, from trained people who understand us and how dementia affects us. This must meet our needs, wherever we live".*
- *"We have the right to be respected, and recognised as partners in care, provided with education, support, services, and training which enables us to plan and make decisions about the future".*
- *"We have the right to know about and decide if we want to be involved in research that looks at cause, cure and care for dementia and be supported to take part".*



Photo Credit: Hong Lok (Happy & Healthy) Luncheon Group

NHS England's **Long Term Plan** sets out a plan for improvement providing the opportunity to engage with people utilising such services to explore gaps and issues in order to improve them. This sees the NHS commit to the following vision and aims:

"We will go further in improving the care we provide to people with dementia and delirium, whether they are in hospital or at home."



Carer(s) support

- Evidence based interventions for carer(s)



Joined up coordinated care and inter Trust collaboration

- Integrated working: neurology, neuroradiology, and psychiatry in assessment of young onset dementia and Parkinson's Disease Dementia
- Personalised care planning and care coordination



Getting people home without unnecessary delay

- People with dementia stay in hospital twice as long as other older people
- Support delayed discharges for people with dementia



Primary care networks

- Improve dementia diagnosis pathways
 - Improve diagnosis in frail/housebound
- Monitoring equipment



Care homes

- Improve diagnosis rates and advance care planning
- Support new models of treatment – specialist intervention for behavioural and psychological symptoms -as well as primary care models



Community MDTs

- Equitable access for people with dementia
- Staff training in dementia/personalised care delivery



Reducing unwarranted variation

- Targeted work on some Integrated Care Board's to improve diagnosis rates
- Memory service audits
- Black, Asian and minority ethnic groups
- NICE guidance implementation – access to post-diagnostic treatment and support
- Work to reduce discrimination against the oldest old



Other considerations

- Primary prevention – what's good for your heart is good for your head
- Transforming outpatients – difficulties for people with dementia to attend
- Stroke rehab – ensure dementia diagnosis is embedded in pathway
- Waste reduction – streamlining memory service pathways
- Volunteers – specific support / training
- Workforce training – use national Dementia Standards

In 2017, the All-Party Parliamentary Group published a **Creative Health Report** which demonstrated that the arts can keep us well, aid recovery and support better lives longer lived. The report recommended that clinical commissioning groups, NHS Provider Trusts and local authorities incorporate arts into their commissioning plans and redesign care pathways where appropriate.

Locally, the **Doncaster Culture Strategy, 2030**, builds on the Team Doncaster Borough Strategy setting a vision for Doncaster to flourish by expressing their own creativity and connecting through shared cultural experiences of power and meaning.



Photo Credit: James Mulkeen, darts

Making It Real (2018) describes a framework and a set of statements describing what good, citizen focussed, personalised care looks like from the point of view of people themselves. We want everyone in Doncaster to live good lives. As such, we fully support the shared vision of a better, brighter future adopted by #SocialCareFuture and we adapted this vision to make it our own. To help us make our vision a reality, we are embracing the Making It Real framework. We are tapping into 'Making it Real' to help us evaluate where we are now and understand what we need to do on our journey of continuous development.

The COVID-19 pandemic had a substantial impact on the ageing population which can be seen in both Alzheimer Society's '**Worst hit: dementia during coronavirus**' and Age UK's '**Impact of Covid-19 on older people's mental and physical health: one year on**'

reports. The impact of COVID-19 on people with dementia is reported as follows:

- Increase in loneliness and isolation
- Deterioration in physical and mental health and cognitive function
- Increased pressure for paid and unpaid carer(s)
- Increase in the impact of the above on people with Health Inequalities

Launched in September 2021, **Doncaster Delivering Together** provides the guiding coalition document for Doncaster via our Borough Strategy. Developed in partnership with residents, elected members, public, private and third sector organisations. DDT focuses on understanding the variety of needs and aspirations within the borough, as well as what matters to people when it comes to improving the wellbeing of people and places.

The **Doncaster Place Plan, 2023-24**, lists Dementia as one of its key priorities under Mental Health in which it seeks to improve dementia diagnosis rates in Doncaster and achieve a 5% year-on-year increase in the number of adults and older people accessing community mental health services.

South Yorkshire ICS' Five Year Plan sets out the goal to improve care pathways for patients with dementia, with ongoing work in each Place to provide better support in the community for people living with dementia. As part of the out of hospital approach, each Place is developing and implementing plans to support people to age well.

Improving our digital services across Doncaster is also an essential enabler for the delivery of high-quality integrated care and seamless working for our health and care professionals. The Integrated Care Partnership in Doncaster have come together to develop a **digital strategy** to get the best use of technology across Doncaster to support service transformation and integrated, neighbourhood-based care.

The **Doncaster's All Age Carer(s) Strategy 2022- 2025** references carer(s) of people living with dementia as carer(s) with additional disadvantage declaring the need to improve these challenges faced. Actions from this strategy will be aligned to people of the carer(s) strategy to improve outcomes for carer(s) of people living with dementia.

Doncaster's **Locality Plans** initiate a way of locality working to ensure a consistent and co-ordinated service is provided to Doncaster residents but is also reflective of the needs of each locality. Services will be developed accordingly to reflect the needs of the population within each of Doncaster's localities.

The **Get Doncaster Moving Strategy** provides opportunities for partnership working to keep people living with dementia active, independent and to ultimately live more healthy years of life.

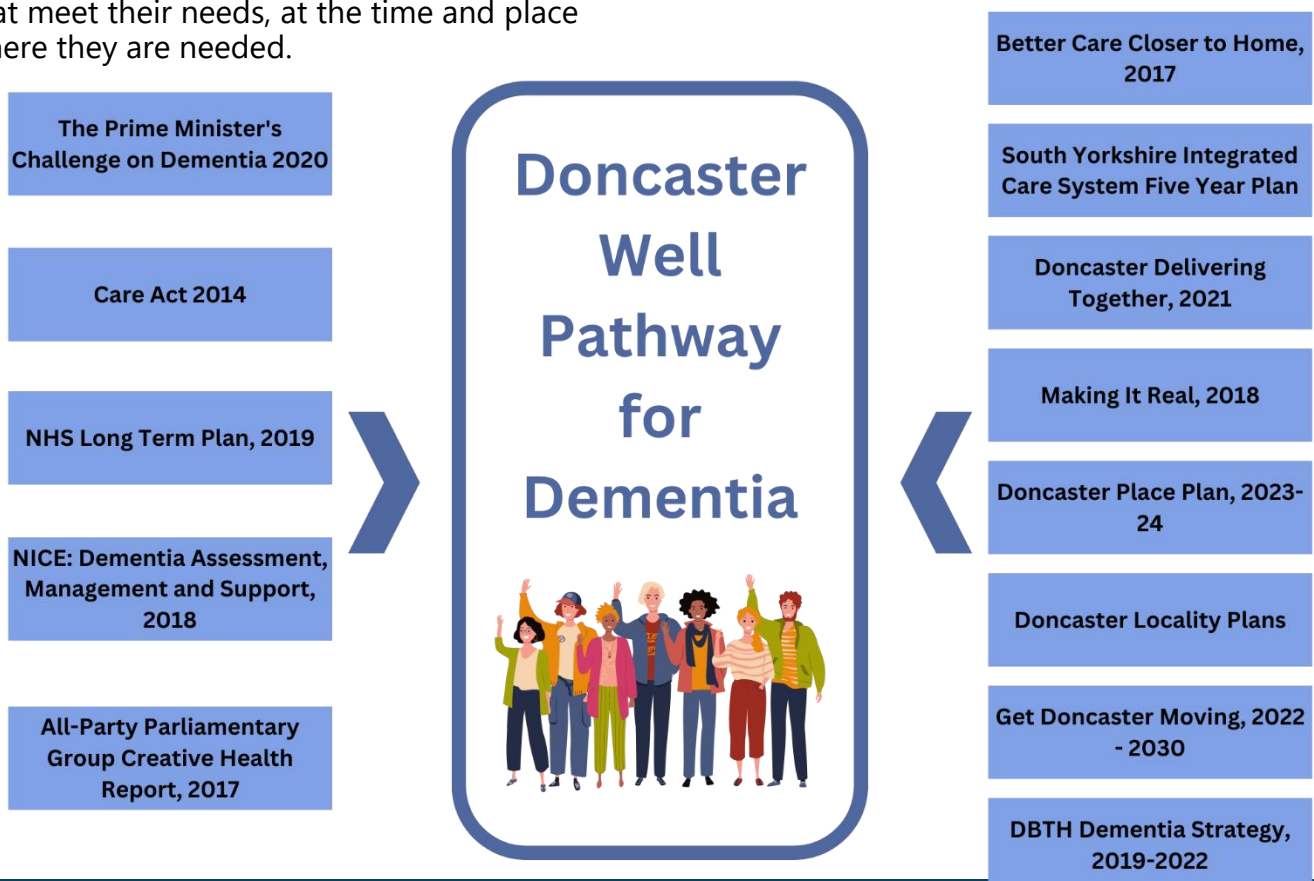
Doncaster and Bassetlaw Teaching Hospital's Dementia Strategy 2019-22 The strategy references the whole delivery of care and would facilitate the seamless transition from primary to secondary care with the goal of reduction in serious incidents, falls and bed days.

The Palliative and End of Life Care Delivery Group are developing a Team Doncaster approach to be adopted across the city. The vision is for care and support to be tailored to community strengths to help residents maximise their independence, health, and wellbeing. Doncaster residents will have access to excellent community and hospital-based services when needed. When referring to people reaching the end of their life, it is crucial people and their family/carer(s) have access to high quality, responsive services that meet their needs, at the time and place where they are needed.



Housing Lin's '**Housing for people with dementia – are we ready?**' report, **2021**, confirms the need for Dementia Care Pathways to link care and housing together. Health and care assessments, particularly at the post-diagnostic stage, should take into account the extent to which a person's accommodation is dementia-ready.

The report states that people living with dementia and their carer(s) do not always receive sufficient information and advice about housing implications at the point when they suspect or receive a diagnosis. The report provides practice examples to consider.



Workforce and Volunteering

Workforce Development

The new Workforce Strategy for 2023-2026 focuses on values-based recruitment with clear career pathways to provide the many talents the workforce needs to progress and develop. Through delivering the strategy, the changing expectations of people accessing care and support will be met with a strength-based approach focusing on individual outcomes.

Extension of Community Healthcare Outcomes (ECHO) Project

Extension of Community Healthcare Outcomes is an innovative and new way of learning in healthcare via video link, to form an online community, share best practices and support each other. Doncaster and Bassetlaw Teaching Hospitals Trust ECHO hub have recently

launched 'Dementia and me' which explores how Dementia can affect the person, the teams caring for them, and their families. **For more information, please visit:**

[Project ECHO \(stlukeshospice.org.uk\)](http://stlukeshospice.org.uk)

Opportunities for volunteering

There is a wealth of voluntary community-based services and support networks available throughout Doncaster. Raising the profile of Doncaster's many community-based assets, many of which are run by the voluntary sector, will be a key part of achieving this commitment.

To learn of volunteering opportunities across the city, please visit:

<https://www.voluntaryactiondoncaster.org.uk/volunteering>

Communications and Coproduction

Building on our commitment to co-production, a communications and co-production plan will be developed that spans the breadth of work and the communities the plans involve. The plan is building on work that is currently underway, and will make a commitment to the following:



Photo Credit: Home Instead, Dementia Awareness Day, May 2023

1

•Delivering regular updates to the wider community by Newsletter.

2

•Sharing information about ways for more people to get involved at all levels of the strategy development and implementation.

3

•Targeting groups who are currently under-represented to seek views, and keep informed of the work and progress or challenges.

4

•Working with people with lived experience of all ages to make sure that co-production and communications are accessible and meaningful for them.

Research and Innovation

Research

Research is vital to drive forward and evolve dementia services. Research should be embedded as a standard procedure within the Well Pathway (see page 15). People with dementia and their carer(s) should not be excluded from research opportunities.

Work will be undertaken with the Health Determinants Research Collaborative to help identify potential research opportunities.

Innovation

Where required, we will seek to find new ways of working that will serve people better. We will develop new models of support and service delivery through best practice, being creative and working across the health and social care system whilst ensuring a person-centred approach.

Technology

Technology has much to offer to people living with dementia and their carer(s): access to information, advice, and guidance, entertainment, as well as reassurance when a family member or carer(s) doesn't live close by. Used sensitively and thoughtfully, technology enhances rather than replaces human relationships and interactions.

Arts

The Arts have a valuable role to play in enhancing quality of life for people living with dementia and their family carer(s). They have the power to bring people together in the here and now, providing a way to stay connected with loved ones through shared experiences. The Arts can enliven, stimulate and enable people to express themselves creatively beyond words, enabling them to be seen for who they are beyond their diagnosis.



Photo Credit: James Mulkeen, darts

The Arts & Health Board works with key partners from Social Prescribing, Public Health, health professionals, voluntary/community sector, and cultural organisations to develop and deliver academically researched music programmes for adults living with dementia in Doncaster. Our vision is that everyone can access creative activities resulting in them feeling happier, healthier, and more resilient.

Keeping Active

With any type of dementia, keeping active both physically and mentally has a huge number of benefits. It can improve the health of your heart and blood vessels, help keep your bones strong (reducing the risk of osteoporosis) and prevent falls. In addition to this, keeping active can also improve sleep health.

Best Practice

Best practices are health practices, methods, interventions, procedures, or techniques based on high-quality evidence to obtain improved patient and health outcomes. By working with the Yorkshire and Humber Clinical Dementia Network, we will strive to adopt best practice where possible.

Action Plan

Cross-cutting Themes

1.1	Doncaster will work to strengthen co-production for dementia to ensure services and strategies are driven by people with dementia and their carer(s).
1.2	Ensure that dementia services are inclusive of everybody including people with protected characteristics, people experiencing significant poverty (core20 population), people from ethnic minority communities and inclusion health groups.
1.3	<p>Promotion of courses for people with dementia, unpaid carer(s), family members, care and support staff, professionals and the wider public.</p> <p>Training provision in Doncaster will be co-produced with people with dementia and their carer(s)'s and evaluated to ensure training and development is of a high standard.</p>
1.4	Develop health and social care Dementia Reporting Dashboards in line with the strategy and service implementation.
1.5	Ensure people with dementia are treated with dignity, respect and compassion , at service level with health, social care and support staff but also on a wider awareness-raising level with communities across Doncaster.

Information, Advice and Guidance

2.1	Information, advice and guidance will be of a good quality, written in simple to read language accessible to anyone who needs it.
2.2	Advice on reducing the risk of dementia will be available and stakeholders will promote this messaging.
2.3	Access to information digitally will be available in one place (Your Life Doncaster). Access to information will also be available across locality hubs.

Receiving a Diagnosis

3.1	Doncaster will maintain their diagnosis rate above the national average of 66.7% and work to improve this target to 75% in line with other South Yorkshire authorities.
3.2	Reduce the delay from the point of raising concerns to receiving a diagnosis , by working with health partners (GP Access, Clinics and Health Provision).
3.3	Ensure the timely start of treatment and services for people diagnosed with dementia.

Support Following Diagnosis

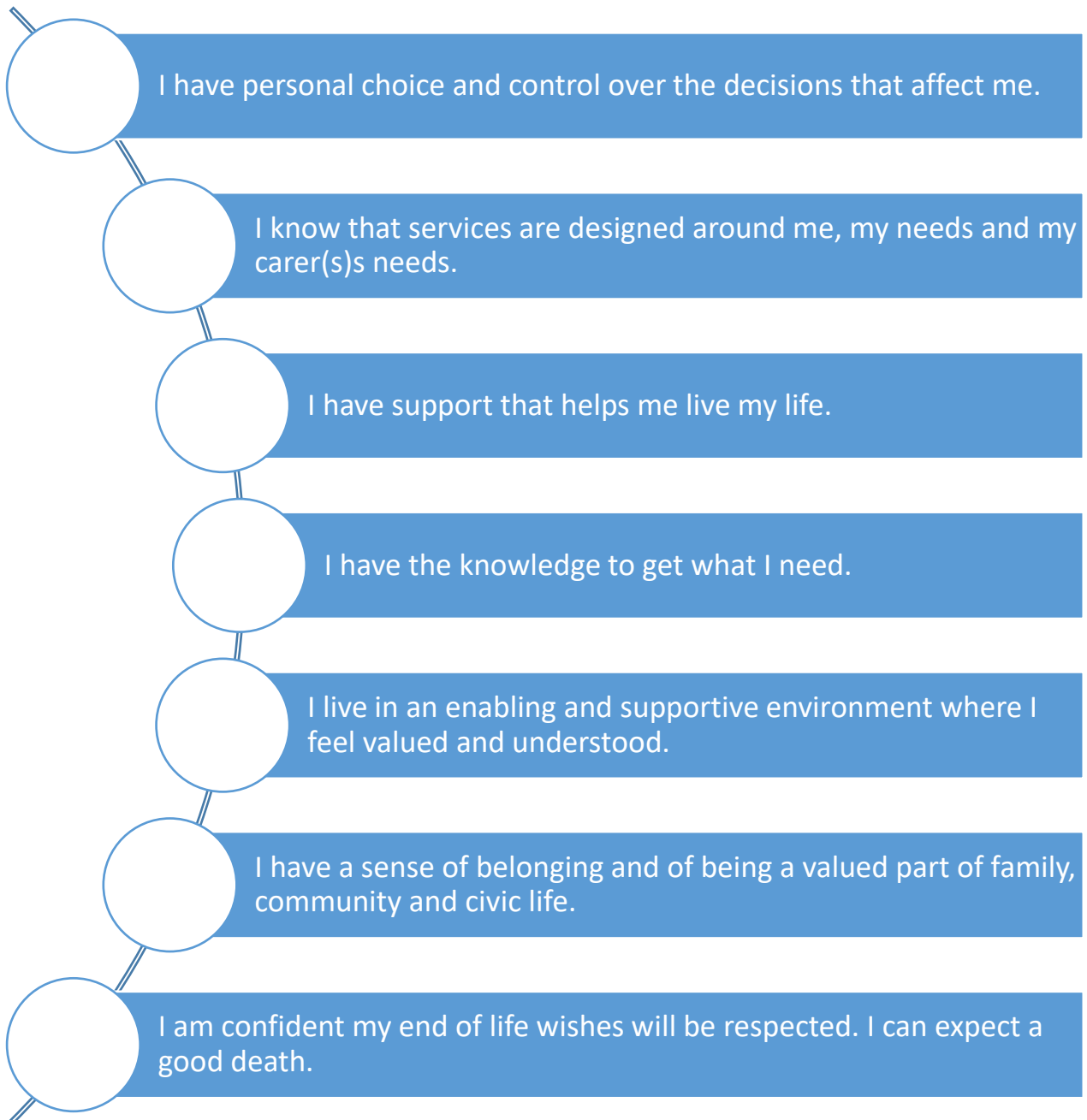
4.1	People will have access to one point of contact for ongoing navigation to ensure they feel continually supported throughout their journey. This support will be available to people with dementia, people in the pre diagnosis pathway and their carer(s)/supporters.
4.2	Strengthen transport links in Doncaster for people with dementia to increase accessibility of services.
4.3	A multi-agency approach will be taken towards people with dementia that live alone to coordinate and ensure they have the same quality of care and support as people with an informal support network.
4.4	Align services/support with the locality way of working to ensure support is built on assets within Doncaster Communities and gaps identified and addressed.
4.5	Support will be based on needs rather than a one-size-fits-all approach. People with dementia will receive support that they wish to receive aimed at their own level of need and interests.
4.6	People with dementia and their carer(s) will be fully supported to make informed decisions in relation to future care and support options.
4.7	Consider the impact of social isolation on people living with dementia or memory concerns.

Support for Carer(s)

5.1	In line with the Doncaster Carer(s)'s Strategy, carer(s) will be identified at the earliest opportunity to enable them to connect with support.
5.2	Carer(s) and family members will be fully prepared for the signs, symptoms and emotional effects of dementia on them and the person with dementia.
5.3	Carer(s) and family members will have the skills and knowledge to be proactive when supporting the person with dementia.

Outcomes

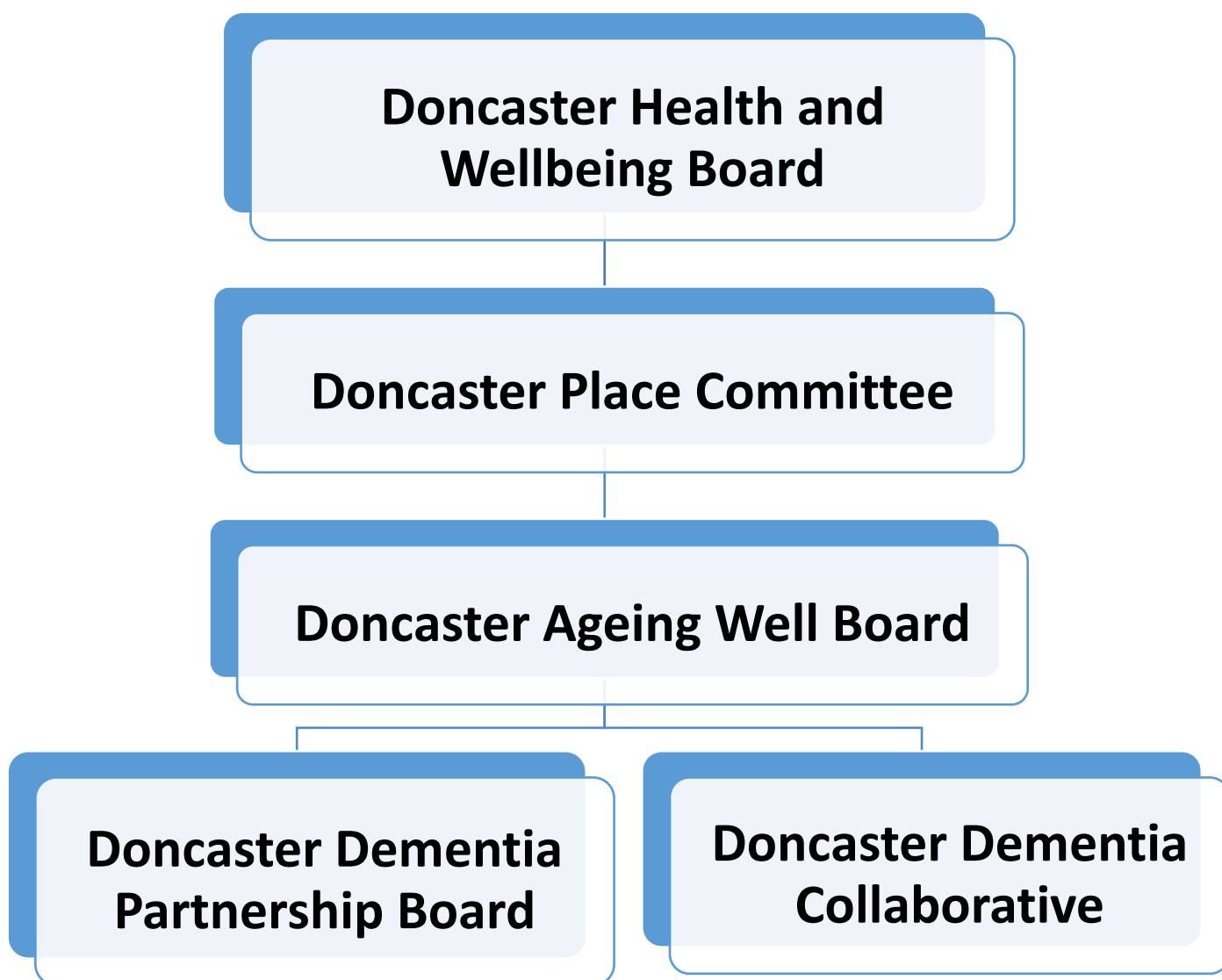
The following 'I' statements taken from the Care Act, 2014, will underpin this dementia strategy.



Governance

During the implementation of this strategy, appropriate leads will be identified through the Strategy Group and for each priority area to drive related actions forward.

The Doncaster Dementia Strategy Group will transform into the Dementia Partnership Board that will meet quarterly to discuss the strategy delivery plan and the delivery of strategy actions will be accountable to the below governance structure:



Acknowledgements

We would like to take the opportunity to express our gratitude to the people living with dementia, their carer(s), families/friends and the Doncaster Dementia Collaborative for sharing their experiences with Team Doncaster in order to shape Doncaster’s Dementia Strategy.

And also, the organisations below who have contributed to the development of this strategy:



City of Doncaster Council

