# Sheffield Dementia Strategy 2025-2030















































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# Section One: Our strategic vision

Our strategic vision is for our organisations to work together to make sure people with dementia in Sheffield are supported to live life to their full potential. People with lived experience of dementia will be key partners in this work. We will achieve our strategic vision by implementing the nine Commitments of the Sheffield Dementia Strategy 2025-2030:

#### Commitment 1

Sheffield will become a dementia friendly city – where individuals, communities, organisations and businesses all support people with dementia to live as well as they can.

# Dementia Friendly Sheffield



#### Commitment 2

We will do more in Sheffield to prevent, reduce, and delay, the risk of developing dementia.

# Prevention of developing dementia



#### Commitment 3

We will improve access to dementia diagnosis at the earliest possible stage for the people of Sheffield.

#### **Diagnosis**



#### Commitment 4

For people living with dementia in the early stages of their dementia journey, support in Sheffield will be personalised, local and accessible, to help them to remain independent for as long as possible.

# Early local support



#### Commitment 5

We will provide high quality support to families and carers of people living with dementia in Sheffield to:

- Promote their health and wellbeing
- Enable them to continue their caring role for as long as they want.

Support for Carers of people living with dementia



#### Commitment 6

People living with dementia and their carers will receive Care and Support that recognises and works with them as individuals, so that people living with dementia receive excellent care at the right time and have a good experience in any service across the city.

Care and Support services



#### Commitment 7

We will support families and staff to plan ahead to reduce the likelihood of dementia related crisis. Recognising that not all crisis situations can be avoided, we will raise awareness about help in a crisis and we will make it easier for people to access this support quickly.

Crisis support



#### Commitment 8

We will improve care for people with dementia attending the Emergency Department, those admitted to Sheffield Teaching Hospitals, and those supported in hospital outpatient care. We want to prevent unnecessary admissions to hospital and reduce lengthy stays.

Hospital care



#### Commitment 9

We will ensure that more people with dementia have access to personalised, good quality palliative and end of life care when they need it.

End of life support



# **Section Two:** Background and context for the 2025-2030 Dementia Strategy

# Our partners and approach

In 2019 organisations in Sheffield across the NHS, Sheffield City Council, and voluntary/community sector organisations started working together on actions to improve the lives of people living with dementia – and their (family/informal) carers - as part of our first Sheffield Dementia Strategy (2019-2024). Our vision is to make sure people with dementia are supported to live life to their full potential.

Our plans have been – and continue to be - based on what people with dementia, their carers, and people working with people with dementia, had said was important to them. We have checked our progress regularly to make sure we had been making a difference, including by asking people with dementia and their family carers what their experiences have been. Although there were lots of positive achievements between 2019-2024, we know there is still more to do. There are more details about the achievements from the 2019-2024 Strategy in Section Four of this document.

In 2023/24, as we started to reach the end of the current Strategy, we carried out a period of review and engagement. You can find out more about this engagement in <u>Section</u>

Five of this document.

Through this engagement we have updated and reshaped our Strategy to ensure that it will continue to help us to improve dementia care and support between 2025-2030. Within the 2025-2030 Strategy we have nine commitments that describe how we will do this – these are detailed in Section Three.

The organisations that have been working in partnership include Sheffield City Council, NHS South Yorkshire Integrated Care Board (Sheffield Place), Sheffield Teaching Hospitals NHS Foundation Trust, Sheffield Health and Social Care Foundation Trust, South Yorkshire Housing Association, Sheffield Dementia Action Alliance, Age UK Sheffield, Alzheimer's Society, Sheffield Carers Centre, St Luke's, Sheffield People Keeping Well Organisations, SACHMA (Sheffield African Caribbean Mental Health Association), Sheffield University, Sheffield Hallam University, and Enrichment for the Elderly.

## What is dementia?

Dementia is a syndrome (a group of related symptoms) associated with an ongoing decline of brain functioning.

There are many different causes of dementia, and many different types. Alzheimer's Disease is the most common cause of dementia (around 50%-75% of all cases) and vascular dementia is the second most common type (up to 20% of cases). Other forms of dementia include frontotemporal dementia, dementia with Lewy Bodies, and young onset dementia (those under the age of 65). As outlined on the NHS website<sup>1</sup>:

Dementia symptoms may include problems with:

- memory loss
- thinking speed
- mental sharpness and quickness
- language, such as using words incorrectly, or trouble speaking
- understanding
- judgement
- mood
- movement
- · difficulties doing daily activities

A person with dementia will usually need help from friends or relatives, including help with making decisions. The symptoms of dementia usually become worse over time. In the late stage of dementia, people will not be able to take care of themselves and may lose their ability to communicate.

With the right help and support, many people can, and do, live well with dementia for many years. Although there is currently no cure for dementia, there are medicines and other treatments that can help with some dementia symptoms<sup>2</sup>. A timely diagnosis is also key to ensuring people get the support that they need.

National research tells us that by modifying the dementia risk factors we are able to change, around 4 in 10 cases of dementia could be prevented. Experts agree that what's good for your heart is also good for your brain<sup>3</sup>.

<sup>&</sup>lt;sup>1</sup> What is dementia - NHS (www.nhs.uk)

<sup>&</sup>lt;sup>2</sup> What are the treatments for dementia? - NHS (www.nhs.uk)

<sup>&</sup>lt;sup>3</sup> Can dementia be prevented - NHS (www.nhs.uk)

#### Dementia in Sheffield

There are estimated to be between 6,360<sup>4</sup> and 7,333<sup>5</sup> people aged over 65 currently living with dementia in Sheffield. This is between 6.7% and 7.7% of the 94,820 people aged 65 years and over in the city<sup>6</sup>. There are also approximately 140 people aged under 65 in Sheffield with young onset dementia<sup>7</sup>.

Data suggests that the number of people aged over 65 years in Sheffield could rise to about 7,940 by 2030<sup>8</sup>. Research by the Alzheimer's Society warns that the projected rise in dementia prevalence poses a significant healthcare, social care and economic challenge, with healthcare costs for people with dementia estimated to more than double between 2024 and 2040<sup>9</sup>. The study recommends that keys areas of action to mitigate this are to: improve early and accurate diagnosis; ensure full uptake of NICE (National Institute for Health and Care Excellence) approved medicines; support unpaid care; Improve social care; and improve dementia data capture.

Primary care data highlights that of the 4,670 people with a formal dementia diagnosis in Sheffield, approximately 1,280 are recorded as living in a residential care home and 360 people in a nursing home. This compares to local social care data which indicates that people in receipt of adult social care support include 1,305 people in a residential care home with dementia noted in their records (this will include some people without a formal diagnosis); and 512 people in a nursing home.

We know from national research that vulnerable individuals face increased dementia risk due to lifelong exposure to risk factors, compounded by poverty and ethnicity. Those most affected lack the means to adopt healthier lifestyles<sup>10</sup>. Sheffield is one of the 20% most deprived local authorities in England whilst at the same time having some of the most affluent 1% of areas in the country. Not surprisingly, Sheffield has health outcomes to match these extremes<sup>11</sup>. This includes a gap in healthy life expectancy of 20 years for women between most and least deprived areas. There is a direct correlation between this and the disproportionate impact of dementia on women: Two in three people with dementia (65%) are women, and longer life expectancy alone does not explain this disparity. Women are also more likely to care for a loved one with dementia – making up around two thirds of unpaid carers<sup>12</sup>.

<sup>&</sup>lt;sup>4</sup> Primary Care Dementia Data, August 2024 - NHS England Digital

<sup>&</sup>lt;sup>5</sup> Projecting Older People Population Information System (poppi.org.uk)

<sup>&</sup>lt;sup>6</sup> ONS census, downloaded from NOMIS https://www.nomisweb.co.uk/

<sup>&</sup>lt;sup>7</sup> Projecting Adult Needs and Service Information System (pansi.org.uk)

<sup>&</sup>lt;sup>8</sup> Projecting Older People Population Information System (poppi.org.uk)

<sup>&</sup>lt;sup>9</sup> <u>CF/Pathway Touchpoint (alzheimers.org.uk)</u> - The forecasted increase in dementia prevalence and cost is due to population growth, an aging population, and projected increases in the real-terms unit prices of care

<sup>&</sup>lt;sup>10</sup> Tackling Inequalities in Dementia Risk - Alzheimer's Research UK (alzheimersresearchuk.org)

<sup>11</sup> Shaping-Sheffield-Main-Doc-Final.pdf (sheffieldhcp.org.uk) (page 9)

<sup>12</sup> The Impact of Dementia on Women - Alzheimer's Research UK (alzheimersresearchuk.org)

We know that there are inequalities in people's experiences of getting help, and their outcomes. Access to diagnosis, care and treatment and wider support is felt differently by people who are already disadvantaged. Our plans for the way forward will respond to this with a focus on ensuring gaps and barriers within support networks, and broader awareness of the support available, are addressed through partnerships with communities and voluntary, community and social enterprise (VCSE) groups across the city.

Primary Care data from GP records shows that approximately 96% of patients with dementia (aged 65 and over) have a recorded ethnicity of white British, which is broadly in line with the 95% of people aged 65+ in Sheffield identified as being white British in the 2021 census<sup>13</sup>. Data shows 0.6% of patients as mixed ethnic background [census data: 0.3%], 2.8% as Asian [census data 2.7%], 0.2% as Black, African or Caribbean [census data 1.5%], 0.8% as other ethnic group [census 0.6%].

The obvious differences when comparing GP and census data is that mixed and other categories are slightly higher, but also that the 'Black, Black British, Black Welsh, Caribbean or African' patient groups are lower - this may be in part due to recording gaps but it is of particular concern due to national evidence showing that dementia rates are 22% higher among black people in the UK compared to white people, while black and South Asian dementia patients die younger, and sooner after diagnosis<sup>14</sup>. Researchers noted that people in ethnic minority communities may be less likely to seek treatment for memory problems, perhaps due to stigma around dementia, or other barriers to accessing timely and effective care.

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<sup>&</sup>lt;sup>13</sup> Analysis of GP data by dementia diagnosis and ethnicity highlights a number of data quality challenges, including that 18% of patients do not have ethnicity recorded and a further 38% are recorded as "British or mixed British", which is an out of date category that does not differentiate between British people with a mixed ethnic background and people from a white British background - the majority of patients recorded are white British but the category will also include people who are British but not white British.

<sup>&</sup>lt;sup>14</sup> <u>Dementia rates over 20% higher among black adults than UK average | UCL News - UCL – University College London</u>

# **Section Three:** Our nine Commitments in more detail

The following section outlines in detail the nine commitments that are summarised in the Strategic Vision section of this document.

For each commitment we summarise the current context, what people have told us (from our public engagement), and what will be different as a result of the implementation of the strategy.

The 'what will be different' sections of each commitment will form the basis for the implementation plans for the strategy.

#### Commitment 1

Sheffield will become a dementia friendly city – where individuals, communities, organisations and businesses all support people with dementia to live as well as they can.

# Dementia Friendly Sheffield



#### Current context

Sheffield Dementia Action Alliance (SDAA) is a network of organisations who want to help communities, organisations and businesses do more for people affected by dementia: reducing stigma, increasing understanding and making small but significant changes to buildings and environments to make them more accessible for people with dementia. Over the past 5 years SDAA has recruited and supported over 80 members who have made over 200 pledges to make their organisations more dementia friendly. This has included community centres, train operators, places of worship, theatres, libraries, charity shops and pubs.

Progress has been made to increase representation of people from ethnic minority backgrounds in groups such as SHINDIG (Sheffield Dementia Involvement Group); and the Sheffield Memory Hub, SACMHA and Cultural Appropriate Resources have been

working to ensure dementia support is accessible and culturally appropriate; but we still need to do more to celebrate our inclusivity.

A new-build Council Housing Retirement Living and Older Person's Independent Living<sup>15</sup> building has been designed using dementia friendly principles. An intergenerational forum has been set up by volunteers by linking nurseries and schools with care homes, dementia cafés and lunch clubs to reduce the growing isolation.

#### What people have told us

Dementia support and awareness in Sheffield has increased over the last 5 years, however, the growing impact of an aging population on dementia prevalence means the number of people living with dementia is predicted to keep increasing.

Feedback from the Dementia Survey 2023 has informed our ambitions and next steps. People with dementia and their families noted that there has been some progress towards Sheffield being a dementia friendly city through an "Increased awareness of dementia and how it impacts people living with it and their families", and that this progress should be positively celebrated. They felt that the biggest impacts were through "Attitudes", "Being included" and "Patience".

However, people told us there are still gaps and difficulties relating to dementia-friendly transport, community transport, city centre parking, and a lack of awareness and understanding about dementia within the wider community. The survey told us that some communities have different perceptions on dementia and that there is a lack of culturally appropriate services and resources for diverse communities in Sheffield.

This all leads to a lack of support whilst out and about, which in turn increases isolation for those living with dementia, and those caring for them, if they can't go to everyday places. "Taking my dad out has become difficult as no places really cater for people with Dementia - it's difficult". "I feel my father is put off from doing things as he is scared he will forget something or be rushed. This lack of confidence means he gets out of practice from doing day to day things (buying things in shops etc) and this makes him feel more isolated". Some feedback from the 2023 survey suggested people wanting clearer signs to show which businesses which are inclusive for those living with dementia.

#### What will be different

Our ambition is that Sheffield is proud to be a dementia friendly city, where everyone with dementia feels accepted and included when they are out and about. This is not limited to

<sup>&</sup>lt;sup>15</sup> See also Sheffield Older People's Independent Living Housing Strategy (being refreshed in Autumn 2024) older peoples independent living housing strategy 2017 - 2022.pdf (sheffield.gov.uk)

dementia-specific services, but includes their local communities, the city centre and when they are interacting with any organisation or business.

- Led by the Sheffield Dementia Action Alliance (SDAA) at least 100 organisations, business and individuals (including leisure and hospitality), will commit to becoming dementia-friendly; supported by advice, resources and regular workshops by the SDAA.
- The SDAA will be revised, to allow businesses and organisations easier access of support to become dementia friendly. A tiered system of support will encourage more customer-facing organisations to join.
- An accessible toolkit of dementia-friendly resources will be regularly updated and appropriate for the changing demographic and generational transition from paper to technology.
- We will work with transport authorities and businesses to ensure there are dementiafriendly transport options, including active transport.
- In collaboration with housing providers, we will explore creating dementia-friendly housing adaptations.
- As part of the Older Person's Independent Living Housing Strategy, we will increase
  the number and range of mainstream age-friendly and dementia-friendly homes;
  ensure all new major housing developments are designed to be 'lifetime
  neighbourhoods' and dementia-friendly; and improve housing-related support for
  people living with dementia.
- We will work with community leaders to ensure culturally appropriate dementia support services are available and conduct focus groups and feedback sessions within specific communities to better understand their unique needs, concerns, and suggestions regarding dementia care and support.
- We will ensure that everyone has access to correct, culturally appropriate dementia information in a way they can understand, which may include resources translated into multiple languages and made accessible in various formats.
- Training on dementia awareness will be tailored to meet the needs of diverse communities.
- There will be an increase in dementia awareness events both locally and city-wide, focussing on the positive support available for people living with dementia and their carers.
- Regular meetings will be established to bring together stakeholders, people with dementia, and carers to share best practices and address emerging needs.
- As part of fulfilling a priority for Sheffield City Council's Future Sheffield Programme, we will work to enable everyone with dementia to feel valued and supported.

#### Commitment 2

We will do more in Sheffield to prevent, reduce, and delay, the risk of developing dementia.

# Prevention of developing dementia



#### **Current context**

Dementia is not an inevitable part of ageing. The Lancet Commission wrote a report in 2017, updated in 2020 and 2024 entitled *Dementia prevention*, *intervention*, and care<sup>16</sup>.

This report recommended how a life-course model can potentially reduce modifiable risks for dementia.

The model on below summarises possible mechanisms for prevention of developing or delaying the onset of dementia by up to 40%.

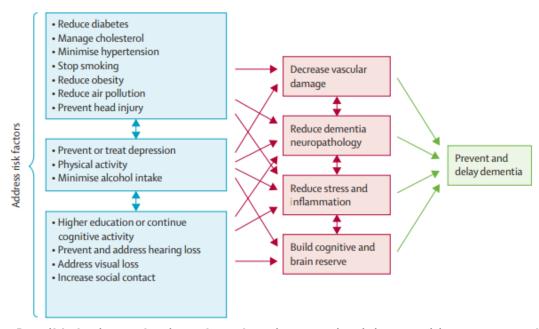


Fig 1. Possible brain mechanisms for enhancing or maintaining cognitive reserve and risk reduction of potentially modifiable risk factors in dementia.

<sup>&</sup>lt;sup>16</sup> <u>Dementia prevention, intervention, and care: 2024 report of the Lancet standing Commission</u>

Some mechanisms involve reducing the risk of developing neuropathological damage. This is through interventions to minimise the risk of developing diabetes, hypertension and high cholesterol, preventing head injury, and preventing exposure to air pollution.

Exercise might reduce weight and diabetes risk, improve cardiovascular function, decrease glutamine, or enhance hippocampal neurogenesis. In short, what is good for the heart is good for the brain.

Two in three people with dementia (65%) are women, and longer life expectancy alone does not explain this disparity. One potential lifestyle related factor is that women in the UK are more likely to become less physically active than men earlier in life<sup>17</sup>.

Smoking increases air particulate matter and has vascular and toxic effects. Similarly, air pollution might act via vascular mechanisms potentially leading to neuropathological damage.

The second group of interventions include social interactions and reducing isolation and loneliness, reducing risk of depression and addressing and treating hearing and sight loss.

Early-life factors, such as less education, can affect the resulting cognitive reserve. Midlife and old-age risk factors influence age-related cognitive decline and triggering of neuropathological developments. The preventative measures need to be implemented throughout the life course and requires policy change at a societal level and not just at an individual level.

Culture, poverty, and inequality are important obstacles to, and drivers of, the need for change to cognitive reserve. Those who are most deprived need these changes the most and will derive the highest benefit from them.

#### Specific actions to reduce dementia risk across the life course

The Lancet Commission recommends several specific actions across the 14 risk factors:

- Ensure good quality education is available for all and encourage cognitively stimulating activities in midlife to protect cognition.
- Make hearing aids accessible for people with hearing loss and decrease harmful noise exposure to reduce hearing loss.
- Treat depression effectively.
- Encourage use of helmets and head protection in contact sports and on bicycles.
- Encourage exercise because people who participate in sport and exercise are less likely to develop dementia.<sup>18</sup>
- Reduce cigarette smoking through education, price control, and preventing smoking in public places and make smoking cessation advice accessible.<sup>19</sup>
- Prevent or reduce hypertension and maintain systolic blood pressure of 130 mm Hg or less from age 40 years.

<sup>&</sup>lt;sup>17</sup> PowerPoint Presentation (alzheimersresearchuk.org)

<sup>&</sup>lt;sup>18</sup> Move More Strategy 2021 - 2026 — Move More Sheffield

<sup>&</sup>lt;sup>19</sup> Tobacco Strategy Final 2022-2027 Final Feb 2023.docx (smokefreesheffield.org)

- Detect and treat high cholesterol from midlife.
- Maintain a healthy weight and treat obesity as early as possible, which also helps to prevent diabetes.
- Reduce high alcohol consumption through price control and increased awareness of levels and risks of overconsumption.
- Prioritise age-friendly and supportive community environments and housing and reduce social isolation by facilitating participation in activities and living with others.
- Make screening and treatment for vision loss accessible for all.
- Reduce exposure to air pollution.

#### What will be different

- Local and National government will be lobbied to make policy change around wider determinants of health such as early years provision, education throughout the life course, climate change and commercial determinants of health.
- There will be increased awareness throughout communities about the risk factors for developing dementia. This in turn will mean that there will be increased access to programmes to reduce their risks of developing dementia. This work will recognise the need for more targeted interventions to reduce dementia risks for ethnic minority groups and for women.
- Making Every Contact Count There will be increased awareness in all health and social care staff about the risk factors for developing dementia. This in turn will mean that ALL staff can signpost people to appropriate services to reduce their risks of developing dementia irrespective of the reason for initial contact.
- People with hypertension will be identified and offered appropriate management and treatment.
- People with impaired hearing and vision will be identified and offered appropriate management and treatment.
- Dementia risk awareness will be included in existing health and social care programmes and throughout the dementia pathway.
- People with cognitive impairment waiting for assessment will receive information about keeping well and services available to them.

### Commitment 3

Diagnosis

We will improve access to dementia diagnosis at the earliest possible stage for the people of Sheffield.



#### Current context

Although there is currently no cure for dementia, a timely diagnosis unlocks the door to

appropriate care and treatment. It also gives the person living with dementia the best opportunity to ensure their wishes are taken into account in the development of their care plan and more chance to take part in research if they wish to do so.

National data shows that 65.4% of patients aged 65 or over who are estimated to have dementia had a recorded diagnosis of dementia. In Sheffield we are performing better than the national average and have diagnosed 70.7% of the estimated number of people who are expected to have dementia (as at 31 August 2024). This means we are reaching more people than the national average and are better able to provide them with support.

While we are performing better at diagnosing more people, we are experiencing long waiting times for people to receive a diagnosis. People aged both over and under 65 years old are also currently waiting for up to a year for a dementia diagnosis, following referral from the GP to secondary care.

Mild Cognitive Impairment can be a pre-cursor to dementia in some cases. It should be diagnosed in a timely way so that interventions can be offered to try and reduce progression to dementia.

There is still more work to do to need understand the barriers for, and increase the diagnosis rates for, different groups within our population to ensure there is fair access and assessment. For example:

- People from minority ethnic groups: we need more appropriate cultural adaptations to interventions and services.
- People with a learning disability: The prevalence of dementia in people with learning disabilities is higher than in the general population. However, the early stages are more likely to be missed or misinterpreted, particularly if several professionals are involved in the person's care.
- People who are Deaf: Deaf British Sign Language (BSL) users can face significant barriers to getting a timely dementia diagnosis and accessing inclusive postdiagnostic support.

Research by the Alzheimer's Society warns that the projected rise in dementia prevalence poses a significant healthcare, social care and economic challenge and that a key area of action to mitigate this is to improve early and accurate diagnosis and to ensure full uptake of NICE (National Institute for Health and Care Excellence) approved medicines<sup>20</sup>. These actions are linked as some medication is only appropriate during early or middle stage dementia. Alzheimer's Society research estimates that less than 6% of dementia patients are on NICE-approved medications.

#### What people have told us

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<sup>&</sup>lt;sup>20</sup> <u>CF/Pathway Touchpoint (alzheimers.org.uk)</u> - The forecasted increase in dementia prevalence and cost is due to population growth, an aging population, and projected increases in the real-terms unit prices of care

- The waiting time for a diagnosis is excessive and increases anxiety and stress on carers and patient. The process is sometimes unclear as in what GPs do and which specialist services are involved. Some patients and carers have felt "not listened to" by their GPs.
- Patients from ethnic minority groups have increased barriers to diagnosis due to a lack of culturally appropriate information and diagnostic tests.
- There were a number of people who described being "dumped" following diagnosis to just cope on their own.
- Some people said they would be happy to receive their dementia diagnosis from their GP, especially if this meant a shorter wait, but some people also asked for assurance on things like if this would affect their ability to claim dementia related benefits and if it would work with GPs who didn't have dementia as their special interest area.

#### What will be different

- Patients presenting with concerns over cognition will still be offered further
  investigation and assessment. GPs will continue to make referrals into specialist
  memory services but also to make more community pragmatic diagnoses of
  advanced dementia (for older adults) where this is most appropriate. Patients
  diagnosed in primary care will still have access to post diagnostic services.
- More hospital doctors (older adult geriatricians doctors who specialise in treating older people) will make a diagnosis of advanced dementia where this is most appropriate. If there is a need for later reassessment (due to possible delirium) then investigations will be started or requested while the person is still in hospital, to enable that process after discharge. Patients diagnosed in Sheffield Teaching Hospitals will still have access to post diagnostic services.
- To support the increase in primary care/hospital diagnosis of advanced dementia, there will be clear pathways between in primary care/hospital and specialist memory services to enable people to be diagnosed and treated in the most appropriate place.
- We will develop and enhance the service provided through the Memory Service at Sheffield Health and Social Care NHS Trust. This will support broader involvement of the wider workforce in Sheffield in providing assessments, better access to support from VCSE partners and a move towards an approach that is better placed to help patients access the new treatment options which are in the pipeline in research or developing approaches to clinical care.
- There will be improved waiting times for patients waiting for a specialist memory service assessment (for both those aged under 65 who are referred to Sheffield Teaching Hospitals and those over 65, referred to Sheffield Health and Social Care).
- To support improved waiting times. we will improve access to scanning services as part of the patient pathway.
- There will be a timely offer of medication if appropriate.
- We will review the uptake of NICE approved dementia medicines in Sheffield

- Following diagnosis, Memory Service, Neurology, and GPs should refer people where they can to access post diagnostic support – including Sheffield's Dementia Advice Service; Sheffield Carers Centre; and support from young onset dementia services.
- We will increase the diagnosis rates for people with a learning disability, using appropriate resources and diagnosis tools. Better liaison between the Community Learning Disability Team and Neurology will fast track diagnosis wherever possible via multi-disciplinary team meetings (MDTs).
- We will increase the diagnosis rates for people across ethnic minority groups, working with communities to develop and use more culturally and linguistically appropriate resources and diagnosis tools.
- We will explore ways to make diagnosis more accessible for Deaf people in Sheffield.
- There will be greater use of new technologies to support the diagnostic pathway.
- Carers' voices will be heard during the assessment process. There will be an offer of carer support before, during and after diagnosis and also at ongoing reviews.
- People diagnosed with Mild Cognitive Impairment will be offered information on helping reduce progression to dementia and will be reassessed to diagnose dementia if it occurs.
- Where possible patients will be offered to be involved in research opportunities. We will particularly encourage uptake of people who tend to be under-represented in research opportunities (people from ethnic minority backgrounds and women).
- Sheffield will work with regional and national leads to explore the opportunities for new dementia drugs, that can slow down memory and thinking decline in early Alzheimer's disease.

### Commitment 4

For people living with dementia in the early stages of their dementia journey, support in Sheffield will be personalised, local and accessible, to help them to remain independent for as long as possible.



#### Current context

Since the launch of our 2019-24 Dementia Strategy, we have commissioned<sup>21</sup> and established services and referral routes to support people living with dementia and their families during the early stages of their dementia journey:

<sup>&</sup>lt;sup>21</sup> See **Commissioning Plan: Community Dementia Support 2021-2027** for more details - 4 Commissioning Plan - Community Dementia Support 2021-2027 FINAL v08.07.2021.pdf (sheffield.gov.uk)

- Dementia Advice Sheffield: A new one-stop shop for dementia advice for people with dementia, their families (400 enquiries per year) and professionals (500 enquiries per year).
- Direct referrals (30 per month) from the Memory Service of those newly diagnosed with dementia into local support and dementia groups.
- People Keeping Well Dementia Support: Dementia Link Workers support 1500
  people living with dementia with an initial call and then ongoing 6-monthly
  wellbeing check-in calls as appropriate, to provide information, signposting and a
  trusted ear.
- People Keeping Well Dementia Support: In 2019 there were only 4 commissioned Dementia Cafés; now almost 1,000 people attend the 40 different commissioned dementia groups (Memory Cafés, gardening and animal, musical, social, creative, sporting and some culturally specific groups) that run each month across all areas of Sheffield. Groups are based around ideas and suggestions from people living with dementia and adapt according to local demand.
- Young Onset Dementia Hub: Young Onset Dementia workers, age-appropriate groups and peer-support assists people under 65 living with young onset dementia, and their families, in this service which started in 2020.

Dementia Reviews completed by Primary Care have been updated using templates to ensure a more holistic approach, including addressing carer needs. Pilot projects have combined health care professionals with community-based dementia specialist workers to support people into accessing local support systems and provide patient and carers with point contact. Projects have trialled taking Dementia Reviews outside of GP surgeries and into community centres and dementia cafés.

#### What people have told us

47% of the overall respondents in the 2023 Dementia Survey said these early-stage services are currently having a positive benefit to helping them live well with dementia. They were described in the survey as a "Lifeline", helping people to "Feel less alone and have a place where they feel safe and supported to talk about their daily challenges without judgement". The Dementia Link Workers were praised for being the "Go-to person" and giving people with dementia "Confidence" to live their lives.

Many people living with dementia, their unpaid carers and dementia professionals told us that they appreciated having "Good, clear sources of information in one place". However, others told us they are struggling to find all of the relevant information and it is difficult "If you are a sole carer you basically don't have a lot of time or patience to read stuff or search the internet for an answer".

The other main themes for what people found difficult about local dementia support were: a lack of effective links between services; a desire for an even greater variety of

dementia groups; a lack of culturally appropriate support; a lack of services for those with higher Young Onset Dementia needs; and a lack of befriending support.

#### What will be different

Based on the themes in the 2023 survey:

- Local community dementia support and advice services will be easily accessible, clear, and better publicised (including online and in print), so that everyone in Sheffield can easily find relevant dementia information and support when they need it.
- Support will be offered via a variety of methods, including telephone, online and face-to-to-face, in culturally appropriate and language-accessible ways.
- The Memory Service and Neurology Service will consistently offer everyone who is newly diagnosed, a referral into local community dementia support, so that noone feels unsupported.
- Dementia services will link up more collaboratively and establish clearer referral routes, so that all professionals and volunteers (including those involved in hospital discharge) are aware of all the services available and can ensure that every contact counts.
- Local community dementia support services will be developed to provide:
  - Greater capacity for Dementia Link Workers, to ensure information, guidance, advocacy and support to people with dementia and their carers is personalised, consistent, and that they know who to turn to.
  - An even wider variety of local dementia groups (including those which help people to stay active), based on what people with dementia and their carers want, which meet more regularly, at a mix of different times, and at appropriate and accessible venues.
  - Culturally appropriate support to meet the needs of diverse communities, by partnering with a range of community leaders and organisations, so that dementia information is effectively distributed, and support is suitable and meaningful.
- Support for people with Young Onset Dementia will be reviewed, to ensure that the needs of those Under 65s are being met at all stages of their dementia journey.
- A review will be undertaken to investigate options for more befriending services, for those for whom local dementia groups are not suitable.

 Primary Care will be encouraged to continue to improve Dementia Reviews to include wherever possible Advanced Care Planning plus 'contingency planning', and working alongside social prescriber roles and community dementia workers in local community settings.

#### Commitment 5

We will provide high quality support to families and carers of people living with dementia in Sheffield to:

- Promote their health and wellbeing
- Enable them to continue their caring role for as long as they want.

Support for Carers of people living with dementia



#### Current context

The Young Carer, Parent and Adult Carer Strategy<sup>22</sup> defines a carer as 'someone of any age who provides unpaid support to family or friends to enable them to cope and carry on with their day-to-day life as they could not manage without this help. This could be caring for a relative, partner or friend who is ill, frail, disabled or suffers with mental ill-health or substance misuse'.

It is estimated that in England, there are 676,000 people with dementia and around 540,000 carers who support them (NHS England). In Sheffield where there are about 7,000 people with dementia, this equates to approximately 5,600 carers. 30% of carers on the Sheffield Carers Centre's register care for people living with dementia.

The majority of carers of people living with dementia will be adults, but some may be young carers under 18, caring for a grandparent with dementia or a parent under 65 with Young Onset Dementia.

NHS England says that one in three people will care for somebody with dementia in their lifetime and that it takes an average of 2 years for someone to realise they're a carer. A survey by Dementia Carers Count in 2023<sup>23</sup> found that 39% of unpaid carers of people living with dementia provide care 24/7 and 29% have been caring for over five years. 25% described their physical health as poor and a third described their mental health as poor or very poor. 89% had reached crisis point at least once, with over a quarter trying to manage crises often.

<sup>&</sup>lt;sup>22</sup> See Sheffield Young Carer, Parent and Adult Carer Strategy Carers' Strategy | Sheffield City Council

<sup>&</sup>lt;sup>23</sup> https://dementiacarers.org.uk/wp-content/uploads/2022/05/Invisible-2023-Report.pdf

Research by the Alzheimer's Society<sup>24</sup> warns the largest cost associated with dementia is the cost of unpaid care (accounting for 50% of the total in 2024) and that unpaid carers are a critical part of supporting people with dementia. The research estimates that 70% of carers will be seeking more support by 2040 and that an important way to mitigate this is to increase funding for respite, support and carer training.

Since 2019 Sheffield Carers Centre has increased the overall numbers of carers they are supporting and expanded the number of carers' groups and activities they offer, including running support groups, events and workshops for those caring for people with dementia. Sheffield Teaching Hospitals has implemented a 'Carers Passport'<sup>25</sup> which helps identify carers, and have a webpage for 'When someone you support is in hospital'<sup>26</sup>.

Dementia Advice Sheffield has been commissioned to include a single-point-of-access for anyone in Sheffield wanting advice, information and support about dementia. 60% of enquiries to Dementia Advice Sheffield are from carers of, and people living with, dementia. The People Keeping Well dementia support organisations across the city offer dementia groups and memory cafes which provide peer support for carers, and dementia-specific carer support groups in some areas. The Dementia Short Term Intervention Service has prevented 60% of carers referred to them from reaching crisis point, by offering intense support in complex situations for a defined period.

#### What people have told us

There were 183 responses to Sheffield Dementia Survey in summer 2023, of which 54 were from unpaid carers and family members. From the responses, it was clear that being connected to information, advice, training, support and guidance was helpful; conversely, when this did not happen, it made things more difficult for the carer.

"As a professional I often find carers and service users are unaware of what help is available". A carer wrote that there is "Difficulty in getting information and advice. It seems like a constant battle". However, where carers are linked to support, they can get what they need, with one carer commenting that it was useful "Meeting people in the same situation as myself. Groups share information which is very helpful".

Other main themes from the survey of what was making life more difficult for carers of people living with dementia were: lack of 'training' for unpaid carers, lack of understanding, logistics and practicalities, a lack of joined-up services and the health and wellbeing of the carers themselves (isolation and physical, mental and emotional demands). "Many families feel guilty about accepting help from services - they believe they should be able to help their loved one by themselves. This attitude needs to change".

<sup>&</sup>lt;sup>24</sup> <u>CF/Pathway Touchpoint (alzheimers.org.uk)</u> - The forecasted increase in dementia prevalence and cost is due to population growth, an aging population, and projected increases in the real-terms unit prices of care

<sup>&</sup>lt;sup>25</sup> https://www.sth.nhs.uk/clientfiles/File/STH Carer's Passport.pdf

<sup>&</sup>lt;sup>26</sup> https://www.sth.nhs.uk/visitors/when-someone-you-support-is-in-hospital

#### What will be different

Our vision for carers of those living with dementia, is that:

- Sheffield is a 'City where Carers are valued and have the right support to continue to care for as long as they want to' (Young Carer, Parent and Adult Carer Strategy).
- 'Unpaid carers are recognised for their expertise and supported to make the right choices for them and their family' (Sheffield Adult Social Care Strategy<sup>27</sup>).
- We will respect the six carer principles of the Sheffield Carer's Strategy, which are that every carer, including those caring for people living with dementia, should have appropriate opportunities to:
  - 1. Access at the right time, the right type of information and advice for them, their family and the person they care for
  - 2. Understand their rights and have access to an assessment
  - 3. Have a voice for themselves and the person they care for
  - 4. Have regular and sufficient breaks
  - 5. Continue to learn and develop, train or work (if they wish to)
  - 6. Look after their own health
- The Dementia Strategy Implementation Group and the Carer's Strategy Implementation Group will work together to help people caring for individuals with dementia to recognise themselves as carers. This will ensure that their needs are identified, and that they are supported to continue in their caring role - for example through support groups and personalised support, information and advice - for as long as they wish to.
- Carers of people living with dementia will be supported holistically to live as well as they can this includes having a prevention-focused approach and access to mental health support e.g. talking therapies.
- Organisations will work together to ensure that carers of people living with dementia from diverse communities are supported with understanding dementia and accessing appropriate, equitable and culturally competent support.
- GPs, health partners, social care, and the voluntary sector will collaborate to ensure they connect carers into the information, advice and support that they need, for example through appropriate referrals not simply signposting.
- We will publicise dementia awareness, understanding and education sessions for carers of people living with dementia across the city.
- We will review the resources and information for carers of people living with dementia to help people feel better connected, and will ensure the resources are inclusive in language and imagery, and are widely and regularly promoted.
- Service planning and care provision will take into account the needs of people caring for those living with dementia to access planned and emergency respite.

<sup>&</sup>lt;sup>27</sup> Sheffield Adult Social Care Strategy <u>Our adult social care vision and strategy | Sheffield City Council</u>

- Services in the city will recognise carers, to enable a personalised approach to the delivery of services, for example flexibility on appointments, carers leave, reasonable adjustments and flexible working.
- Services will support former carers with transitions after their caring role ends.

#### Commitment 6

People living with dementia and their carers will receive Care and Support that recognises and works with them as individuals, so that people living with dementia receive excellent care at the right time and have a good experience in any service across the city.

Care and Support services



#### Current context

Our vision for Adult Social Care is that 'Everyone in Sheffield lives in a place they can call home, in communities that care, doing things that matter to them, celebrated for who they are - and when they need it, they receive care and support that prioritises independence, choice, and recovery'28.

Our aim is to enable people to live as independently as possible in their own home, in their communities for as long as possible. For those that move into a residential or nursing care setting we want to ensure they receive high quality person-centred support from staff who understand what matters to the person in their care.

There are a range of services to support people living with dementia in this ambition.

#### What people have told us

The dementia survey completed in 2023 for those living with dementia, their careers and organisations that support them, highlighted things that are working well. These included having dementia trained staff taking a person-centred approach, support that enabled a person to remain connected to their community, good access to information and advice, and aids and adaptations supporting the person to be able to do the things that are important to them. "I know my mother-in-law feels safe and she is safe".

The survey also highlighted a key theme for the Strategy is consistency and connectivity. Many areas that are working well for some people, are not working well for others. People

<sup>&</sup>lt;sup>28</sup> Sheffield Adult Social Care Strategy <u>Our adult social care vision and strategy</u> | <u>Sheffield City Council</u>

told us they feel disconnected from sources of support, there is a lack of continuity in the support they receive, there is a lack of trained staff in some services, there is a need for increased wrap-around support in all settings, and a lack of support to meet the needs of people from diverse ethnic communities. For example, feedback from SACHMA (Sheffield African Caribbean Mental Health Association) highlighted that "Care staff need to have cultural awareness training- for domiciliary carers, and those in care homes, so basic needs, such as food choices, skin care and hair care is appropriate to meet the needs of the African Caribbean community".

Respondents also highlighted the need to promote not only the services but the benefits of accessing support, highlighting a feeling of guilt about seeking support - and this needs to be addressed thorough talking about dementia, its impacts and how we enable people to live as independently as possible and be cared for with compassion and understanding.

#### What will be different

We are committed to working with people living with dementia and their carers across all the communities in Sheffield to promote sources of **information**, **advice and support**. We will do this through a variety of mediums including the wider promotion of information on the Sheffield Directory<sup>29</sup>, and its availability in multiple languages via the 'recite me' function.

The **technology transformation** will see the deployment of digitally enabled equipment supporting people both in their own homes and in the community. The Devices for Dignity initiative will focus on ensuring that all Technology Enabled Care (TEC) is equally accessible, at the same time preventing digital poverty and supporting digital inclusion as we aim to address health inequalities.

More broadly across all the Commitments we will explore how digital innovations can help us provide quicker access to support, the provision of information, screening within primary care, the timeliness of diagnosis and aids to support people live well in their home.

We are committed to ensuring that our social work, occupational therapy and wider social care workforce working in either home care, day services or residential / nursing care receive the training they require to deliver person centred care this includes culturally competent approach to care and support and ongoing specialist dementia training to provide them with them with the knowledge, skills and understanding to care and support people living with Dementia. This will be supported by effective liaison and a shared care approach with NHS community dementia services. There are clear opportunities to upskill care home staff in caring for people with dementia and provide individualised care plans to support residents with complex needs.

<sup>&</sup>lt;sup>29</sup> www.SheffieldDirectory.org.uk/dementia

Our **Occupational Therapy** service can help to identify changes within a home environment or find a different way to do things, safely and as independently as possible, enabling people to do the things that matter to them. Our aim is that dementia friendly resources relating to falls and home environment will be available to all those living with and supporting those living with dementia.

People will have choice and control over how they access support to meet their eligible needs including through a **Direct Payment** whereby a person (or someone acting on their behalf) can choose to receive a personal budget so they can arrange and manage their own support.

Our aim in Sheffield is to expand and develop the **Personal Assistants** (PA) workforce to ensure that there are PAs available who can be employed to support people from diverse communities living with dementia. We will also shape a vibrant and innovative market of support providers/agencies that can be purchased by people who self-direct their own support to meet their needs and outcomes.

For people considering arranging and managing their own support, including employing their own Personal Assistants (PAs), we will continue to develop our support offer. The Direct Payment Support Service will work with people providing advice and information to help people get the right support for them. We are committed to enabling people to be in control of their support, being informed about their options and supporting them throughout.

All our commissioned provision is supported by a strong quality assurance process which provide support and accountability to ensure all those providing care and support deliver excellence. We will work in partnership to develop and implement a dementia quality assurance framework.

Our new care and well-being service for home care provision will provide a wide range of vital care and support in people's own homes to enable people to live well with dementia. This includes personal care, support to administer medication, support with the activities that are part of normal daily living – including accessing the community. Moving forward our focus is on moving away from a task-based service to delivering high quality care, by carers who are trained in understanding dementia. Our ambition is to ensure we deliver the outcomes that are important for the individual to achieve "what matters to me" and their carer.

Working in partnership with each person living with dementia, our providers and our social work teams are all geographically located around in the primary care networks facilitating the opportunity for **wrap-around support** from health, social care and voluntary sector organisations in each community. We will strengthen our working partnerships in each community to deliver co-ordinated wrap around support.

Dementia and cognitive impairment are estimated to affect over 85% of the people living in **residential / nursing care homes.** We will work with partners including people with lived experience, providers, and housing colleagues to develop and implement a new specification for all those living in a residential / nursing care setting. We will deliver a residential and nursing provision offer that supports those living with dementia who require residential and nursing support in both a crisis and in delivering high quality short-term and long-term personalised care.

#### Commitment 7

We will support families and staff to plan ahead to reduce the likelihood of dementia related crisis. Recognising that not all crisis situations can be avoided, we will raise awareness about help in a crisis and we will make it easier for people to access this support quickly.

Crisis support



#### Current context

Dementia related crisis will mean different things to different people. It can include:

- Occasions when people can no longer stay in their own home and need to receive
  care in a different setting. This can be for many reasons, for example a short period of
  respite, an assessment of needs following an emergency admission to hospital,
  rehabilitation following a physical health problem or palliative care at the end of life.
- Sometimes people with dementia may need specialist support with dementia related behavioural or psychological symptoms. This support could be in their own home or sometimes in a hospital.
- When someone's carer can no longer provide care for them (either temporarily or permanently).
- People with dementia can sometimes want to explore. This might only be into the garden or street for a short time, but sometimes people get lost and go missing.
- People living with dementia usually have a range of complex health conditions as well
  the dementia, which contributes to their frailty. People with dementia who become
  acutely physically unwell and need to be admitted to hospital deteriorate faster
  cognitively than others without dementia. It is important to protect physical health
  and ensure that people have help if needed to ensure that they eat and drink enough
  and can take medication.

Support that is available in Sheffield for a dementia related crisis includes:

- People living with dementia and their carers can access support via their GP with
  physical or mental health needs and during evenings and weekends care is accessed
  via 111 or the GP "Out of Hours service". GPs can access support from Older Adult's
  Mental Health Team for people with dementia related behavioural or psychological
  symptoms. Advice for when someone is in hospital is from the Psychiatric Liaison
  Service.
- Sheffield Health and Social Care Foundation Trust also provides a specialist ward for people who have complex dementia and associated highly distressed behaviour.
- The "Acute Deterioration Pathway" is guidance that was created in 2023 with engagement and agreement from South Yorkshire Police, Yorkshire Ambulance Service, Out of Hours GP Service, Older Adult's Mental Health Team, Psychiatric Liaison Service and primary care. The pathway aims to enable patients in crisis to be managed where possible to stay at home or where needed to be transported safely to hospital.
- The Alzheimer's Society in Sheffield provides a "Dementia Short Term Intervention Service" that can provide support for up-to 6-week service to patients and families with higher dementia needs who are struggling to cope. The service will ensure access to the right support for them by coordinating wraparound support from health and social care services, providing support to avoid a crisis.

# There is more about Support for Carers and Adult Social Care in other parts of this Strategy.

#### What people have told us

- Feedback from families and carers was that help and care from community mental
  health services and from adult social care services isn't available quickly enough and
  they feel confused by the services and how to access that help.
- People working with dementia also expressed concerns about what are often considerable waiting times for these services (particularly for people new to a service).
- People don't always know where to go in crisis and aren't always able to connect people to services in times of crisis.
- Carers (supporters) of people living with dementia talked about the lack of information and support that was available to them, for example one carer described how there was "No available information forthcoming from GP, social worker or any other services... [I was] left adrift until breaking point" and another noted there was "No easily accessible help, struggled for 8 years on our own until had to put mum in a care home, it's terrible the lack of help for willing carers".
- Carers talked about how their cared for person often experienced multiple health conditions as well as dementia (for example cancer and respiratory infections) and how this impacted not only on their physical health but also led to a deterioration in their dementia symptoms, for example "My husband recently had a chest infection and everything nose-dived. The huge change in behaviour was nearly my undoing but we had some extra respite in place".
- Carers also often had numerous health conditions themselves and felt exhausted and isolated, for example saying how "Nobody appreciates that I am a sick person too with physical limitations, yet I am expected to shoulder everything".

• People recognised the need for "More work in areas of diversity to reach out to those people not accessing support".

#### What will be different

- People living with dementia and their carers will know who to contact in a crisis (whatever time and whatever day of the week regardless of the type of need physical health, mental health, social care etc.).
- Post diagnosis people living with dementia and their carers will be supported through
  education and information about the factors that can lead to crisis and how to prevent
  a crisis from happening. For example, good hydration and nutrition to reduce UTIs and
  constipation, thinking about how over time dietary likes and way of eating changes so
  how to adapt and ensure good nutrition and hydration is maintained.
- Health and care professionals will be aware of the best pathways (and which services they need to work with to ensure joined up responses when people are in crisis or at risk of becoming in crisis).
- Carers and people living with dementia will be supported, as part of care planning processes, to complete and maintain emergency (or contingency) plans to help them if they are at risk of crisis. This will be linked into existing citywide care plans such as 'OK to Stay'.
- There will be better identification of carer stress and offers of support to try and prevent crisis.
- There will be better identification of people with dementia who are alone and do not have someone caring for them, and how this may increase the risk of crisis.
- There will be an effective and timely response to requests to older adults mental health services for urgent dementia assessments and treatment in the community to support people and their carers when in crisis to help prevent admission to a mental health hospital ward.
- Adult Care and Wellbeing will work with those living with dementia and their carers to develop contingency plans and if there is a crisis will support the person and their carer as a matter of urgency.
- We will better understand and meet need regarding respite, emergency bed placements, and assessment beds.
- Care homes will receive better support to help them support their residents to avoid or manage dementia crisis.
- There will be reduced unnecessary admissions to hospital and care homes for people
  with dementia, due to increasing awareness and application of the Acute
  Deterioration Pathway within the Yorkshire Ambulance service, out of hours GPs, with
  South Yorkshire Police and other providers.
- We will review and monitor the use of antipsychotic drugs for treating people with dementia who are experiencing severe agitation, aggression or distress from psychotic symptoms (such as hallucinations and delusions). These should only be used as a last resort (for example when the person, or those around them, are at immediate risk of harm) and should be reviewed regularly.
- Heath and social care workers will be aware of the "Herbert Protocol" and support patients and carers to use this where appropriate.

- Organisations will recognise the importance of ensuring that crisis responses are culturally competent and that information and guidance on avoiding crisis targeted equitably across communities.
- We will work to reduce health and wellbeing risks for people with dementia. This will include promoting appropriate referrals to allied health services e.g. hearing, sight, podiatry, OT, physios, community nurses, and to fall reduction pathways, as well as protect physical health and ensure that people have help if needed to ensure that they eat and drink enough and can take medication.

#### Commitment 8

We will improve care for people with dementia attending the Emergency Department, those admitted to Sheffield Teaching Hospitals, and those supported in hospital outpatient care. We want to prevent unnecessary admissions to hospital and reduce lengthy stays.



#### Current context

- At any one time 1 in 4 hospital beds are occupied by people living with dementia.
   These admissions can trigger distress, confusion and delirium, and subsequently lead to a decline in function and reduced ability to return to independent living.
- Local data shows that significant numbers of people with dementia in Sheffield
  experience emergency hospital inpatient stays. In 2022/23 there were an estimated
  6100 people aged over 65 with dementia in Sheffield. 1195 patients with a recorded
  dementia diagnosis had a total of 1990 spells in hospital, though actual figures will be
  higher as only 70% of people with dementia in Sheffield have a formal diagnosis.
- Based on figures captured by Sheffield Teaching Hospitals (STH) between September 2023 August 2024, there were 3,730 episodes of confirmed dementia admissions (this figure also captures multiple admissions by the same patient) for patients who were aged 70+, compared with the total admissions for 70+ (36,694). This means that for the time period ,10.2% of these admissions were dementia episodes.
- The average length of stay for those with a recorded diagnosis of dementia was 4.1 days higher than for those aged 70+ without a recorded dementia diagnosis (11.8 days compared to 7.7 days). A dementia patient aged 70+ with a confirmed diagnosis on average spends an additional 11.9 days in the trust once they are medically fit for discharge. This is 6.6 days higher than the Trust average for 70+ patients (11.9 days compared to 5.3 days). In addition to this an average of 67.5 patients with Dementia are readmitted to Sheffield Teaching Hospitals within 30 days following discharge

(based on 810 readmissions during the time period of September 2023 to August 2024).

#### What people have told us

Following feedback from the survey we understand the importance of providing personalised care in Dementia friendly environment which focuses on patients with Dementia living well during the time they are under our care, ensuring relatives and carers are supported along the journey.

#### Key themes included:

- The importance of having meaningful 1:1 activities as well as group activities
- The value of introducing Admiral Nurse roles
- The need for dementia friendly transport to/from care homes/nursing homes
- Carers support
- Personalised care
- Communication cards in different languages with simple questions
- Dementia friendly environments
- The importance of focusing in preventing deconditioning when people are in hospital.

#### What will be different

#### We will:

- Continue to work with voluntary organisations to identify and refer those with less complex needs who still require additional support on discharge.
- Identify patients with dementia who would benefit from early discharge with support from the Virtual Ward for ongoing management in the community.
- Improve recognition and treatment of delirium through the introduction of the "4AT" delirium test with the new electronic patient record as well as a Confusion Care Plan.
- Utilise the new electronic patient record to improve identification and recording of people with dementia, including robust care planning utilising the All About Me booklet and ensuring a culturally competent approach to meeting people's needs.
- Promote the role of Carers within the Trust as outlined in the STH Carers Policy.
- Ensure our workforce has the relevant level of training for their role through our mandatory and bespoke training modules as needed.
- Continue to expand and develop Dementia Champions throughout the Trust through targeted recruitment and regular training days.
- Improve links between Sheffield Teaching Hospitals and Sheffield Health and Social Care to include Older People's Liaison Psychiatry working within STH and communication with Memory Clinic.
- Utilise Dementia Care Mapping and our Dementia Dashboard to identify areas for improvement and formulate appropriate action plans based on the patient experience.

- Continue to ensure that when a person with dementia visits hospital, attends as an outpatient or has an inpatient stay, they will be cared for in a physical environment that meets their needs.
- Continue to develop and expand our programme of support, stimulation and activity to enhance the inpatient experience.
- Continue to work closely with the Sheffield Hospital's Charity to support innovation in the field of dementia.
- Continue work around meaningful support to patients who need enhanced care.
- Develop better ways of communicating with our patients through the roll out of communication cards, ensuring they are simple and available in different languages.
- We have appointed two Dementia Transitions of Care Admiral Nurses. They will
  provide intensive clinical case management for people with complex dementia needs
  from the point of referral in the hospital to a post discharge period of up to 6 weeks,
  promoting a 'home first' approach and reducing lengthy stays and unnecessary readmissions to hospital.

#### Commitment 9

We will ensure that more people with dementia have access to personalised, good quality palliative and end of life care when they need it.



#### Current context

Each person with a diagnosis of dementia is unique. It is therefore key that the wishes of the person, as far as it is possible to do so, are understood and carried out, allowing them to die with dignity, free from pain and in the place of their choice.

The Sheffield Dementia Strategy Commitments will align with national guidance on dementia and palliative care and with the South Yorkshire Integrated Care Board All Age Palliative and End of Life Care Strategy<sup>30</sup>.

#### What people have told us

A Sheffield Healthwatch survey (published January 2024)<sup>31</sup> asked for on people's views and experiences of end of life and palliative care. Responses reflected how important it is

<sup>&</sup>lt;sup>30</sup> (Public Pack)Palliative and End of Life Care Presentation Agenda Supplement for Health Scrutiny Sub-Committee, 25/01/2024 10:00 (sheffield.gov.uk)

<sup>&</sup>lt;sup>31</sup> FINALPeople's experiences of palliative and end of life care.pdf (healthwatchsheffield.co.uk)

for health professionals to have timely open and honest conversations about the future with people living with dementia and their carers to find out about peoples' preferences for care and to inform them about how they may be supported in the future, taking into account, 'what matters to me' including any cultural and religious considerations.

The importance of including any cultural and religious considerations was also reflected in Dementia Strategy survey feedback from SACHMA (Sheffield African Caribbean Mental Health Association): "It is important to continue to value the things that were of value to the person living with dementia, prior to their illness; for example, their presentation, their personal care, their choice in music, smells and tastes they recognise and like".

#### What will be different

We will consider initiatives to increase skills, knowledge, and confidence of those caring for a person close to them with dementia who is seriously ill and nearing the end of life.

We will do this through supporting the SY ICB All Age Palliative and End of Life Care Strategy workforce training and development plan to ensure that plans (for specialist, primary care, and generalist workforces, along with wider health and social care professionals and those working within communities including the voluntary sector) meet the needs of people with dementia in Sheffield.

We will recognise that the voluntary and faith sector workforce, communities, and volunteers have a key role in the integrated system. We will continue to support community and faith-based networks in responding to the needs of people with dementia who are dying, and for those caring for a person with dementia and grieving.

We will prioritise and promote recognition of dementia as a life-limiting condition by ensuring that people with dementia and their carers are aware of and able to engage in advance care planning to support their needs going forward.

We will ensuring equitable access to integrated palliative dementia care and support through collaboration with health and care services, communities and the voluntary and community sector.

We will promote initiatives to engage views, increase skills, knowledge, and confidence for those caring for persons with end stage dementia nearing the end of life.

We will ensure that the workforce, voluntary and community sector and public are educated and confident in advance care planning and care of people with dementia towards end of life, including in relation to any cultural and religious considerations.

We will promote the role of, and engagement in, research in palliative dementia care.

# **Section Four:** What did the 2019-2024 Dementia Strategy achieve?

Here are some more examples of differences that the implementation of the Sheffield Dementia Strategy made to people's lives:

# Dementia support groups

The development of community dementia services and dementia link workers services have meant that there are more friendly and fun dementia-specific and dementia-friendly groups in local areas and across the city. In 2019 there were 4 monthly dementia cafés, but there are now 40+ dementia groups meeting monthly, fortnightly and weekly. 1019 people with dementia attended their local dementia group in the first 3 months of 2024-25, including:

- Dementia and Memory Cafés, social dining groups and coffee mornings
- Walking groups, exercise and chairobics classes
- Music and singing sessions
- Carer support groups and pampering sessions
- Culturally appropriate groups for men and groups for women
- Gardening, allotment and farming projects and much more

There are now new services that provide high quality, personalised dementia daytime opportunities in Sheffield. These support adults of all ages with dementia to continue to remain independent within their community, and to support their family carers in their caring roles. We have told lots of people (including health and care staff) about what support is available.

# Support for carers of people with dementia

We have helped more people who look after a loved one with dementia to think of themselves as carers and told them about the support they can have. We made a video with six family carers in Sheffield to help raise awareness, and over 2,000 people have watched this video. More family carers of people with dementia have been supported by Sheffield Carers Centre to get the help they need with their own health and wellbeing. We have also raised awareness with hospital staff, doctor's surgeries and other health and care staff about the importance of recognising and supporting family carers. We have run training and support sessions for family carers, to help them understand more about

caring for someone with dementia, how to look after their own wellbeing better, and to meet other carers in similar situations.

We have raised awareness about dementia diagnosis and support for carers within different communities in Sheffield. This included focused work and information videos produced with local communities in Urdu and Arabic (with subtitles).

#### Information and Advice

We have improved the information and advice that is available to people living with dementia and their families. Dementia Advice Sheffield, which started in 2019 for professionals and volunteers, was opened to the public in 2022. People with dementia and their families can now contact Dementia Advice Sheffield via telephone or email with any non-medical dementia-related query. We have told lots of people (including health and care staff) about this new service, which in 2023-24 dealt with 937 enquiries for dementia advice, and 1028 referrals.

#### **Dementia Care Reviews**

We have provided information and resources to doctors' surgeries to help improve the quality and number of annual Dementia Care Reviews that they provide. Fewer of these reviews happened during the covid pandemic and lockdowns but doctor's surgeries are now carrying out more again (84% of people diagnosed with dementia had their review in 2023-24).

# **Memory Service**

Effective relationships have been established across the Memory Service and the Dementia Advisory Service as they have established and developed their service. This has ensured that a joint approach is being taken to coordinate how advice and support is being provided to people with dementia and their carers and relatives.

We have undertaken an external review of our Memory Service to ensure our plans for the way forward are shaped and informed by best practice, and this will be a key feature of our work as part of the updated Strategy and Commitment 3.

## Dementia research

We have been actively involved in dementia research to shape future practice and ensure we are adopting the latest best practice as it emerges. Examples of this are: CognoSpeak an automated cognitive assessment tool based on language that uses automated speech recognition and machine learning, and trials for memantine and cholinesterase inhibitors

in Lewy body dementia (COBALT). We are also a partner in the <u>Dementia Platform UK</u> providing us with wider opportunities to access new research and innovation.

# **Training**

We have improved the information and training that is available to health and care staff on important areas such as preventing falls for people with dementia, advanced care planning, and supporting people well at the end of their life.

# Support to prevent a crisis

The Alzheimer's Society Dementia Short Term Intervention Service is now available to help people who are starting to struggle with their situation and need help to make plans that address their immediate difficulties. Doctors' surgeries and other health and care staff refer people into this service. About 90 people are supported every three months.

# Hospital support

Sheffield Teaching Hospitals NHS Foundation Trust have been making improvements to how people living with dementia are looked after when they go into hospital – for example, through better designed wards, more staff training, and new dementia specific activities for people on wards. Approximately 150 staff members are now "Dementia Champions".

In summer 2024, we recruited two new Admiral Nurses to support timely hospital discharge and help prevent readmission.

# Crisis support

We have worked with Yorkshire Ambulance Service, out of hours doctors, the Police and other organisations to start to improve the help people with advanced dementia get if they are in a dementia related crisis, for example due to their dementia symptoms suddenly getting much worse.

# Working towards a Dementia Friendly Sheffield

Work through the Sheffield Dementia Action Alliance is aiming to make Sheffield a more "Dementia Friendly" city.

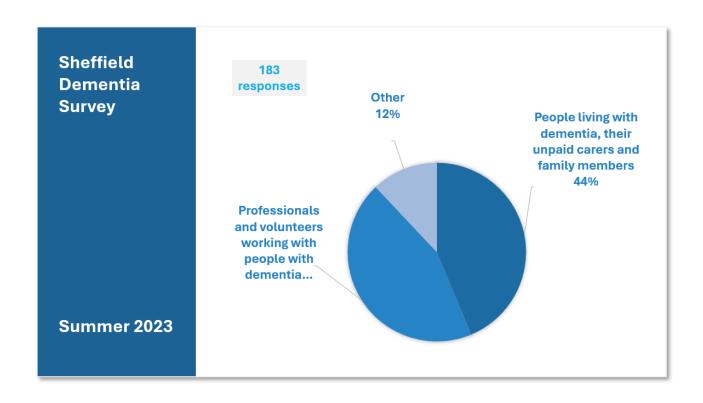
# Section Five: Our engagement process

# How we engaged with people

In summer 2023, we started the process of reviewing the current Strategy to enable us to update and then relaunch a refreshed Strategy to run from 2025-2030. Engagement with people living with dementia, their families, and the organisations working to support them was a key part of this review. We talked to people to find out what is working well for people living with dementia in Sheffield, and what else needs to happen to build on this.

To help with the review, in the summer of 2023, the Dementia Strategy Implementation Group (DSIG) (a cross-organisational Group which oversees the Strategy) launched a short survey to help us gain people's views on what is working well and what else needs to happen. We also updated people about the progress we had made on the Strategy so far.

An online survey was produced (with plain language paper copies available) to support all partners to engage with the public in a consistent manner. This was distributed through various networks to reach a wider audience, including the Dementia Strategy partners (with a focus on supporting people living with dementia and their carers to complete the survey); GPA1 Primary Care Network dementia group, and SHINDIG Sheffield Dementia Involvement Group (SHINDIG). See details below:



We tested out and added to the feedback with further detailed discussions with:

- The People Keeping Well Dementia Link Workers
- Dementia Strategy Partner Organisations
- A focus group of care home staff
- Feedback from the Sheffield Dementia Involvement Group (SHINDIG) in July 2023 and again in August 2024. Sheffield Dementia Involvement Group is hosted by Sheffield Health and Social Care NHS Trust and is a forum for people living with dementia to have their voices heard. It also offers opportunities for people to get involved in research, advise on new products and educate health care staff and students. The full reports, and other SHINDIG reports are available online<sup>32</sup>
- The GPA1 Primary Care Network Dementia Partnership
- Organisations representing Sheffield's diverse communities, including Sheffield
  African Caribbean Mental Health Association (SACMHA), Firvale Hub and Aspiring
  Communities Together (ACT).

# Summary of what people told us

#### Sheffield Dementia Survey



- Community voluntary services eg dementia cafes, dementia friendlygroups, day activities
- Availability of dementia information and advice
- Support from family and friends
- Good support in some care homes – eg dementia friendly activities, trips out



- Negative attitudes and lack of understanding about dementia
- · Lack of access to dementia information
- Inadequate support for unpaid/informal/family carers
- Some poor experiences of health care and care services
- Need to do more to meet needs of diverse communities
- Diagnosis waiting times
- Transport barriers
- · Costs of services/support

**Summer 2023** 

A full report will be available to view on Sheffield City Council's website.

<sup>32</sup> https://www.shsc.nhs.uk/get-involved/service-user-groups/sheffield-dementia-involvement-group-shindig

#### What we did with the feedback

Each commitment within the revised Strategy has an identified lead organisation, and organisational leads ensured that the detailed feedback from the engagement was reflected in the "What will be different?" narrative under each commitment. We have also summarised what people told us as part of the engagement relating to each commitment.

We also identified some **cross cutting themes** that relate across all the Commitments:

We recognise the importance of the following considerations across all the Commitments

- 1. Involving and listening to people with lived experience and their family carers, to ensure that their expertise and experiences influence the work that we do.
- Increasing our understanding of the needs of all our communities in Sheffield, and of working more closely with individuals and organisations representing diverse communities.
- 3. Reducing wider health and wellbeing risks for people with mild cognitive impairment and/or dementia. This will include promoting appropriate referrals to allied health services e.g. hearing, sight, podiatry, Occupational Therapists, community nurses, physios, and to fall reduction pathways.
- 4. Understanding that **poor health and wellbeing are inequitably distributed** across our city. We also know that most of the solutions are not to be found within NHS and social care services alone.

# How we will feedback to people who contributed to the engagement

The majority of engagement participants supplied feedback anonymously and can't feedback to them directly. However when we have carried out dementia surveys previously, we developed a short public "open letter" following the engagement that we circulated through the same channels as we circulated the invitations for people to take part in the engagement.

We will follow the same approach and share another "open letter" as part of the communications leading up to and launching the refreshed Dementia Strategy.

#### This will:

• Thank people who contributed to the survey and/or the wider engagement.

- Share examples of how the themes that came out of the engagement directly influenced what we included in the refreshed Strategy ("You said, We did").
- Include examples of where partners have already started to work on these improvement areas.
- Include information about how people can access support in their community to live well with dementia or receive support as a carer (including if they are struggling).
- Also include information about access to training/non-clinical advice or signposting for people working in a paid role supporting people with dementia.

# **Section Six:** How we will monitor our Dementia Strategy

#### Involve

 We will continue to involve people with lived experience in the ongoing delivery of the strategy, its implementation plans, and our assurance of the strategy. We plan to formalise and strengthen this approach in 2025.

### Review

 The Dementia Strategy Partner organisations will meet regularly to review and assure progress against the detailed implementation plans that will sit under each Commitment in the Strategy.

### **Monitor**

• Where appropriate, lead organisations will monitor elements of their plans through their own internal governance processes.

# Report

• We will report into the citywide *Mental Health, Learning Disability, Dementia and Autism* Delivery Group (which reports into the Health and Care Partnership structures).