

**Joined Up Care**  
Derbyshire

# Derby & Derbyshire Dementia Strategy 2025 -2030 ENGAGEMENT SUMMARY



# Overview

The Joined up Care Derbyshire Dementia & Delirium Partnership carried out engagement from April – July 2024 to understand what people in Derby & Derbyshire think is important for dementia care.

A survey was designed by the JUCD Dementia & Delirium Partnership that covered all areas of the National Framework – the Well Pathway for Dementia:

## We use the National Framework to guide the services we offer

### Preventing well

Helping people to reduce their risk of developing dementia.

### Diagnosing Well

People are accurately diagnosed in a timely manner.

### Supporting Well

People living with dementia, and their carers, have access to high quality health & care services.

### Living Well

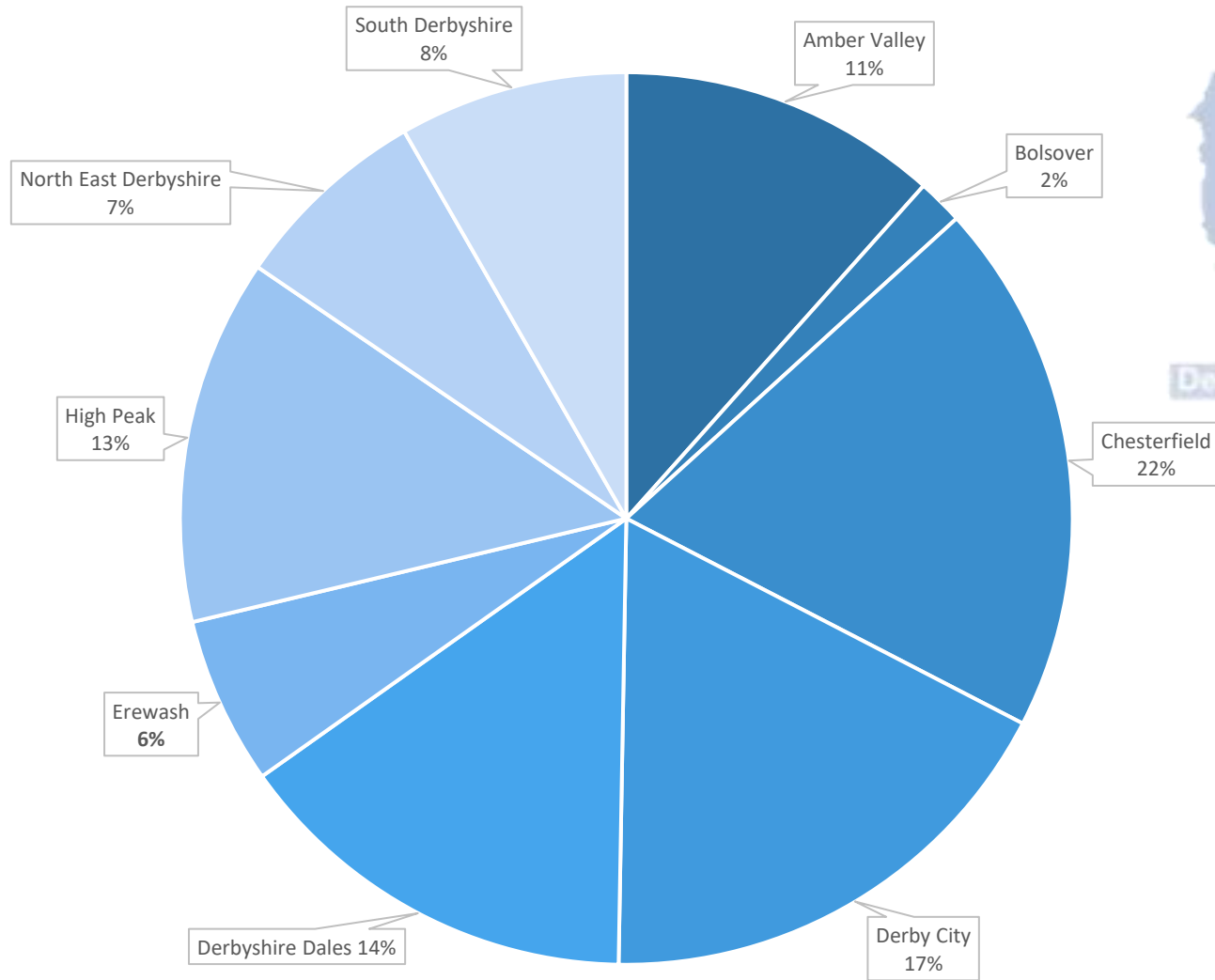
People living with dementia can live normally in safe & accepting communities.

### Dying Well

People living with dementia die with dignity in a place of their choosing.

# Overview

## District wide response:



**301** people from across Derbyshire responded to the engagement:

**193** completed the online survey.

**39** people attended an event at the Postmill Centre

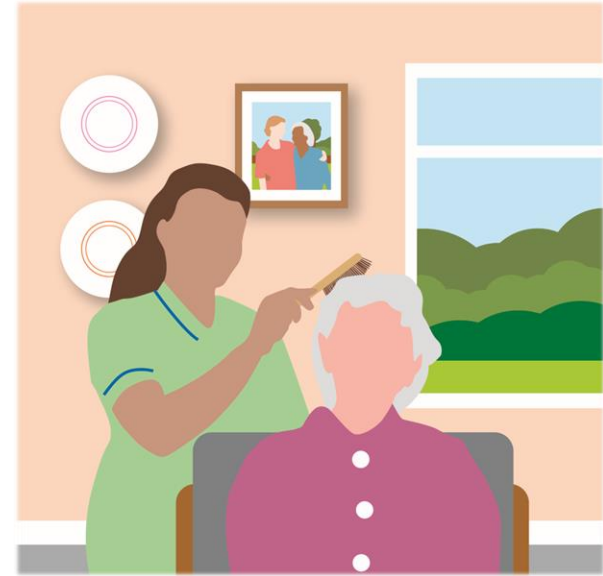
**40** people attended a Derbyshire Dialogue online forum

**30** people provided feedback to Healthwatch Derbyshire.



# Strategic Priorities

- 1 Ensure all staff that work in the health and social care sector have the information, knowledge and skills required to meet the needs of people living with dementia wherever they receive care
- 2 Improve access to, and quality of, treatment and support following diagnosis, for people living with dementia and their carers
- 3 Deliver services that diagnose early so that people can access support and plan for living with dementia
- 4 Ensure more people with dementia have an advance plan of care that describes their wishes for the future
- 5 Ensure care for people living with dementia is well coordinated and integrated
- 6 Tailor services to meet the needs of different, and diverse community groups
- 7 Ensure the people of Derbyshire have information about dementia and are aware of ways in which they can reduce their risk of developing dementia
- 8 Continue to build communities where dementia is understood and people living with dementia are included, respected and supported



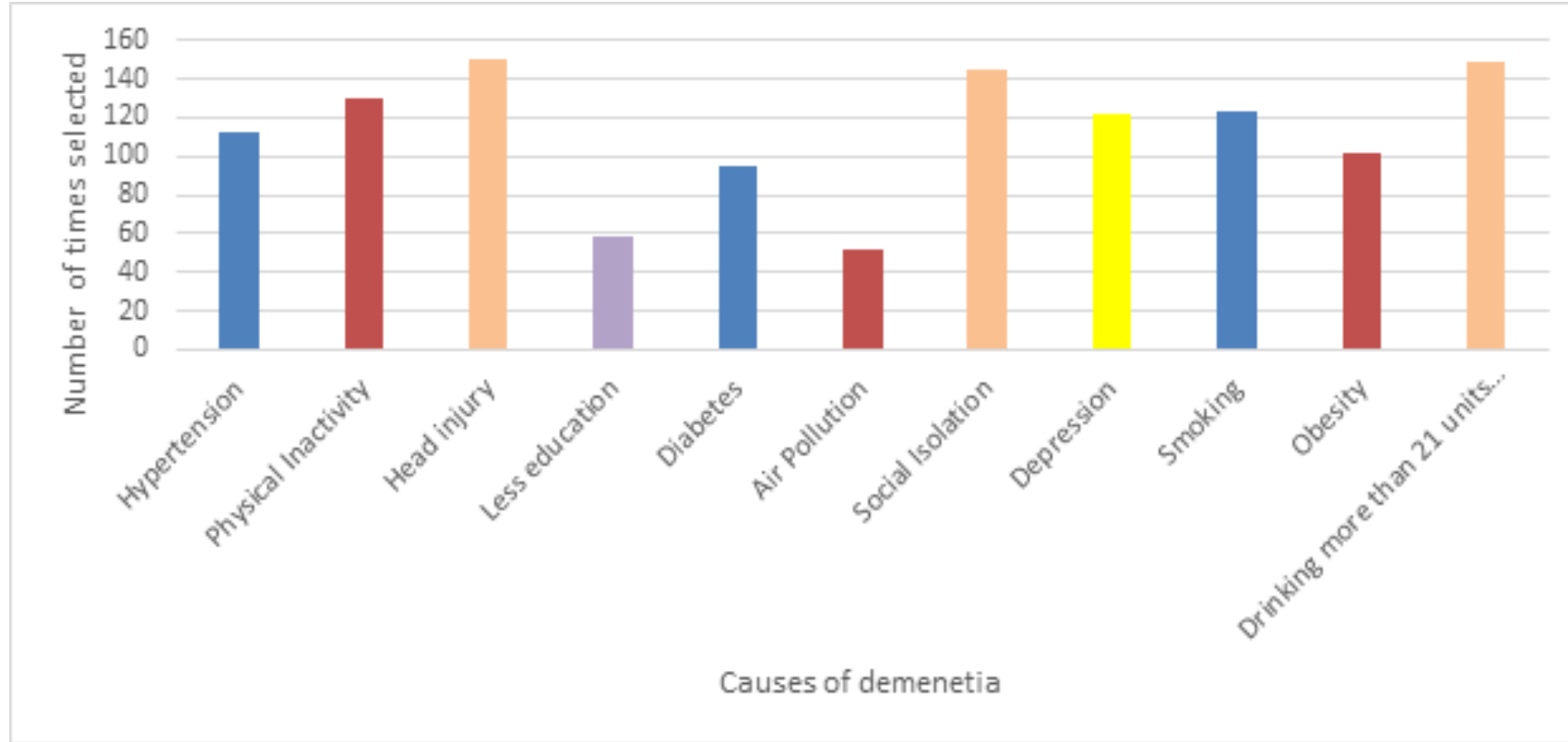
## What did we want to find out?

We wanted to know if the current priorities in the Dementia Strategy are still important and if there are any new priorities we need to consider.

We asked people to order the current priorities in order of importance and this is what they said.

# Preventing Well

People were asked which factors they were aware of that could increase the risk of dementia.



Many commented that they felt more needed to be done to educate people on the preventable risks of dementia whilst introducing activities to help people achieve a healthier lifestyle.

“Public Health strategies to tackle the things that are known to cause Dementia”.

“Raise awareness of the risks that cause Dementia to help people to identify the areas where they are more vulnerable or are even increasing their own risk”.

# Diagnosing Well

We asked people to prioritise what was most important to them for the diagnosis process.

- 1 Not having to wait too long for an assessment and diagnosis
- 2 Understanding the benefit of an assessment and diagnosis
- 3 Knowing how or where to get an assessment or diagnosis
- 4 Understanding what support is available whilst waiting for an assessment or diagnosis
- 5 Being offered information and advice at the assessment
- 6 Who you receive an assessment or diagnosis from
- 7 Understanding what happens at an assessment
- 8 Not having to travel far for an assessment

“Provide ongoing support, communication and contact with the patient and their family to avoid isolation & deterioration in Dementia and subsequent carers stress.”

“Ascertain early on what difficulties they’re experiencing and if they require formal support or their carer requires support”.

# Supporting Well

We asked people to prioritise what was most important to them for dementia care and support.

- 1 Education sessions about living with dementia
- 2 Consistency of support
- 3 Wellbeing support for carers, including a carer support plan
- 4 Telephone and/or face to face information, advice and signposting to other local support
- 5 Peer support
- 6 Financial assessment or support
- 7 Easy to use and up to date website with local support options
- 8 Information on housing adaptations or accommodation options

“Greater awareness of Dementia and the way it affects daily routines across all services. Too often we have had to explain the challenges the disease bring when accessing healthcare services.

“Respite / breaks which give you the confidence your loved one is still being cared for well, with respect and dignity”.

# Living Well

We asked people to prioritise what would be most helpful for people to live well with dementia.

- 1 Person-centred approach
- 2 Flexibility of when you want to access support
- 3 Well trained/ well informed staff
- 4 Joined up approach of services
- 5 Consistency of where care and/ or support is received from
- 6 Signposting to other local support

“Support local businesses to become Dementia friendly and to have information that is accessible for people living with Dementia.”

“Things like the Memory Market Place, where people can go and meet all support organisations in one place.”



# Dying Well

We asked people to prioritise what would be most important for end of life care for people living with Dementia.

- 1 Support with Advance Care Planning  
(Planning for care and support needs towards the end of life)
- 2 Support to get the right treatment
- 3 Flexible care and support at home
- 4 Choice and control over provision
- 5 Bereavement support for carers
- 6 Support on resuscitation options
- 7 Support on choice of the place of death

“Have conversations about end of life care planning earlier and by all services to ensure all are aware of the person’s wishes.”

“The conversation about end of life care needs to be provided consistently and reviewed regularly.”

# Engagement Event

In addition to the survey feedback, we held an engagement event at the Postmill Centre in South Normanton on 24<sup>th</sup> July 2024. 38 people attended this event including 2 people living with Dementia and 4 carers.

At the event we presented the survey feedback and asked some further questions with the following responses:

## What are your priorities? Are we missing anything?

“We need more peer support”

“We need help to navigate services”

“We need more information on how to cope with day-to-day life”

“Waiting well support is important”

“Tackle stigma that leaves carers feeling they have failed”

“Access to respite care and day care is difficult”

“No care home provision for under 65s”

# Engagement Event

## What could be better? What works well?

“Creative activities work well and need to be more widely available.”

“Better information sharing between services.”

“More brain health awareness raising.”

“Delirium awareness training works well.”

“The Dementia Palliative Care Team works well.”

## What do Carers need?

“More flexible options for respite.”

“To be shown more respect and recognised as experts.”

“Support to understand benefits and allowances.”

“Education on physical care tasks as well as on Dementia.”

“Not having to re-tell their story over and over.”

# Engagement Event

## What one thing you would tell those who design Dementia services?

“There should be more focus on co-morbid conditions and how Dementia impacts these.”

“Listen to the carer and people who access services, they are the experts on what they need.”

“Access to Activity groups and support to participate is vital.”

“Make it easier to access services.”

## What worries you about Dementia Services?

“There are few opportunities for peer support people living with Dementia or carers.”

“There is a lack of knowledge and training for GPs in rarer Dementias.”

“Respite care is getting more difficult to access and the mental health needs of carers aren't recognised.”

“Unsafe discharges from Acute Hospitals are a concern.”

# Feedback gathered by Healthwatch

During the engagement period, **Healthwatch Derbyshire** gathered some additional feedback when attending events where they were able to talk to people with lived experience of Dementia. The following findings will be taken into account when developing the new Strategy:

*Reports of difficulty obtaining blister packs for medication.*

*The importance of Carer Health was highlighted - who will support if the carer is not able to.*

*Difficulties persuading loved ones to attend Memory Assessment and then received cold, clinical response.*

*Some GPs not aware of Dementia Diagnosis Pathway.*

*Lack of Dignity and Respect by some Hospital staff treating Dementia patients.*

*Living Well with Dementia programme seen as an excellent resource.*

*Excellent practical support options provided by the Voluntary Sector.*

# Key Themes

The following key themes came up several times within the engagement and will be addressed within the new Strategy:

More education sessions about living with Dementia and a range of topics are needed for all

More support is needed for carers including; peer support, wellbeing support and respite.

Dementia care and support needs to be more joined up and accessible to all residents (particularly younger people and those from BAME backgrounds).

People should not have to wait long for assessment and diagnosis.

There needs to be more education about Brain health in Derbyshire.

Support Pre-Diagnosis is important so people can help and prepare themselves.

More support and consideration is needed of end of life care choices.

# Next Steps

The Joined up Care Derbyshire Dementia & Delirium partnership are extremely grateful to everyone who provided feedback. All feedback will be considered when updating the new strategy and the voices represented in the feedback will be instrumental in defining this.

After reviewing the strategy, the next step will be to share this with key stakeholders. We then hope to commence work on building and improving opportunities and services for people to live well with dementia in Derbyshire.

