Derbyshire Well Pathway for Dementia

Joined Up Care Derbyshire - Strategic Vision 2020 - 2025

NHS

DERBYSHIRE County Council

Derby City Council

Introduction

The Derbyshire Sustainability and Transformation Partnership (STP) is known as Joined Up Care Derbyshire (JUCD)

JUCD involves health, care and voluntary sector organisations across Derbyshire and Derby City working together to provide the best care possible for the people of Derbyshire. Derbyshire is a big county, covering some 2,625 square kilometres and comprising over 30 towns, a busy city, and a population of more than one million and the needs of populations in different parts of the area can vary. In order to further understand and be responsive to local populations the county has been divided into eight areas called ‘Place Alliances’ and further into primary care networks (PCNs). This will help to make sure that care and support best meets the needs of local people, within their local Place.

The **Derbyshire Well Pathway for Dementia** aims to provide the best care possible for people living with dementia, their carers and those important to them. It has been produced by a strategy development group comprising health, social care and voluntary sector representatives and mirrors the NHS England Well Pathway for Dementia (next slide). The Pathway sets out our vision and ambitions for the next five years in order to achieve further integration of support, good quality care, better outcomes and a system that is simpler to navigate for those in need of support. The dementia workstream includes goals aimed at tackling delirium in dementia, as it is recognised that people living with dementia are at a higher risk of developing delirium, both conditions share many symptoms and delirium can have a significant impact on an individual’s health and life expectancy.

The Well Pathway for Dementia

Services and support for people living with Dementia and their carers in Derbyshire will be mapped against this pathway to ensure consistency and clarity of support available at all stages of the condition.

NHS ENGLAND TRANSFORMATION FRAMEWORK – THE WELL PATHWAY FOR DEMENTIA

PREVENTING WELL

Risk of people developing dementia is minimised

"I was given information about reducing my personal risk of getting dementia"

STANDARDS:

- Prevention[1]
- Risk Reduction[5]
- Health Information[4]
- Supporting research[5]

DIAGNOSING WELL

Timely accurate diagnosis, care plan, and review within first year

"I was diagnosed in a timely way"

"I am able to make decisions and know what to do to help myself and who else can help"

STANDARDS:

- Diagnosis[1][5]
- Memory Assessment[1][2]
- Concerns Discussed[3]
- Investigation[4]
- Provide Information[4]
- Integrated & Advanced Care Planning[1][2][3][5]

SUPPORTING WELL

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

"I am treated with dignity & respect"

"I get treatment and support, which are best for my dementia and my life"

STANDARDS:

- Choice[2][3][4], BPSD[6][2]
- Liaison[2], Advocates[3]
- Housing[3]
- Hospital Treatments[4]
- Technology[5]
- Health & Social Services[5]
- Hard to Reach Groups[3][5]

LIVING WELL

People with dementia can live normally in safe and accepting communities

"I know that those around me and looking after me are supported"

"I feel included as part of society"

STANDARDS:

- Integrated Services[1][3][5]
- Supporting Carers[2][4][5]
- Carers Respite[2],
- Co-ordinated Care[1][5]
- Promote independence[1][4]
- Relationships[3], Leisure[3]
- Safe Communities[3][5]

DYING WELL

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

"I am confident my end of life wishes will be respected"

"I can expect a good death"

STANDARDS:

- Palliative care and pain[1][2]
- End of Life[4]
- Preferred Place of Death[5]

References: (1) NICE Guideline. (2) NICE Quality Standard 2010. (3) NICE Quality Standard 2013. (4) NICE Pathway. (5) Organisation for Economic Co-operation and Development (OECD) Dementia Pathway. (6) BPSD – Behavioural and Psychological Symptoms of dementia.

What is Dementia?

Dementia is a syndrome in which there is deterioration in memory, thinking, behaviour and the ability to perform everyday activities.

Dementia has a physical, psychological, social, and economic impact, not only on people with dementia, but also on their carers, families and society at large.

World Health Organisation

Background: The estimated prevalence of dementia in Derbyshire (City and County)

Late Onset Dementia (over 65)

People diagnosed over 65, and particularly over 85, are at increased risk of having additional health conditions, frailty and of experiencing complex needs as a result.

2020
16,100

2025
18,800

2030
21,900

Young Onset Dementia (under 65)

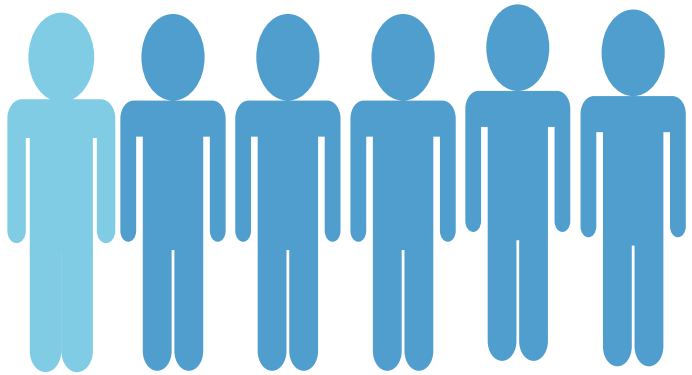
People diagnosed under 65 have different needs and commitments; they often follow a different clinical pathway, and may also need different forms of support.

2020
805

2025
889

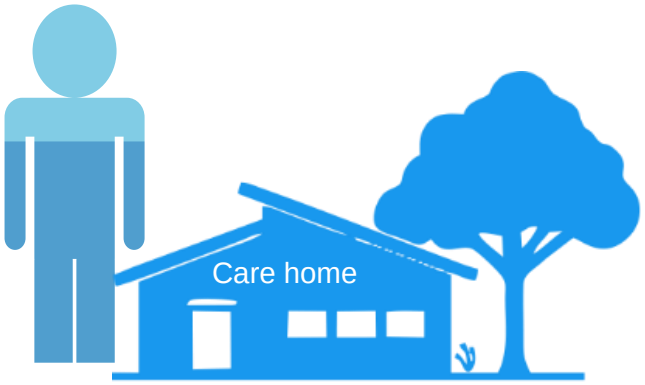
2030
872

People with dementia aged 80+



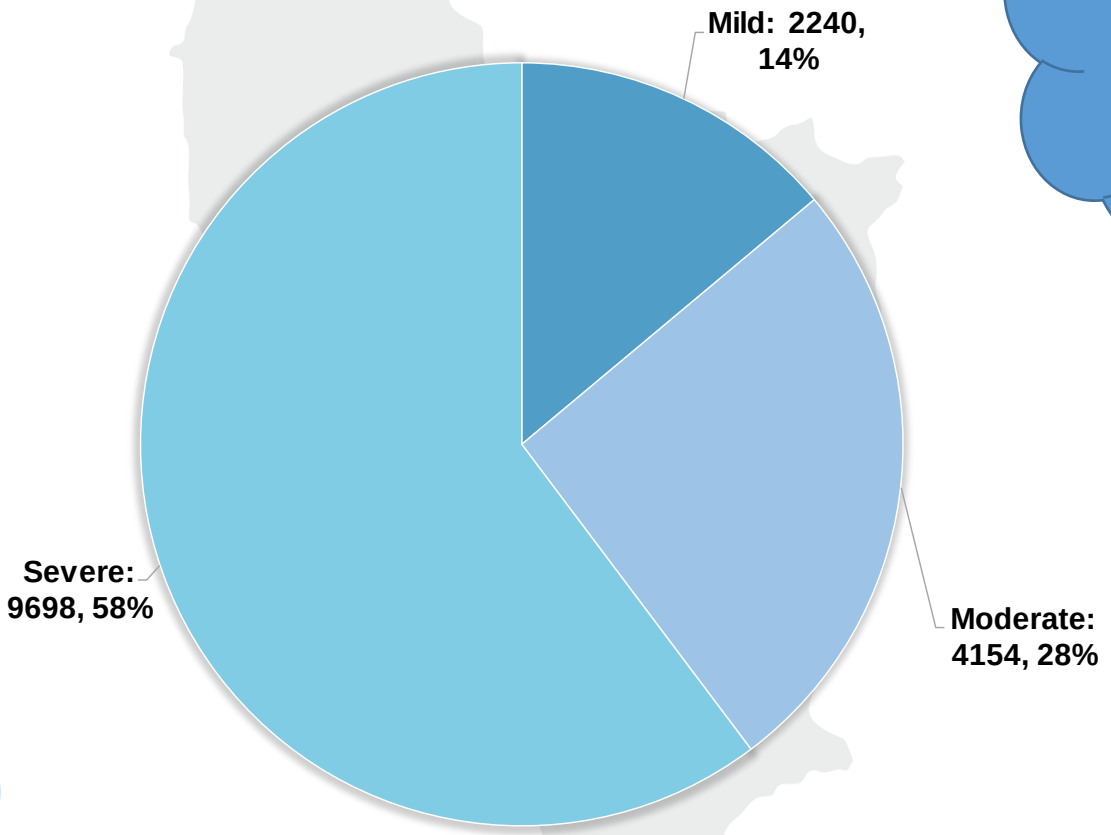
The greatest risk factor for dementia is age, **1 in 6 people over the age of 80 have dementia**.

70 per cent of people in care homes are estimated to have dementia or severe memory problems.



Severity of condition

It is estimated that 58% of people living with dementia will have a mild condition, 28% will be moderately affected and 14% will have severe dementia.



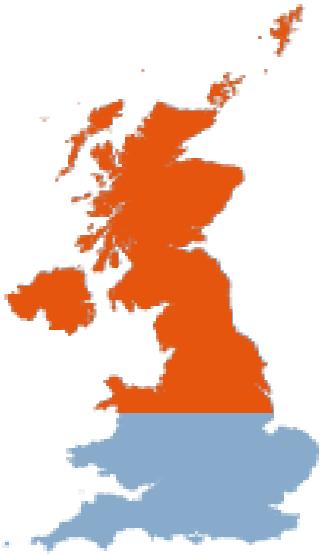
Estimated number of people with late onset dementia by severity of condition, 2020, Derbyshire and Derby

The total number of people over 65 potentially living with severe dementia across Derbyshire increases from 9,698 to 14,190 by 2030.

Further information about dementia population projections is available **here**

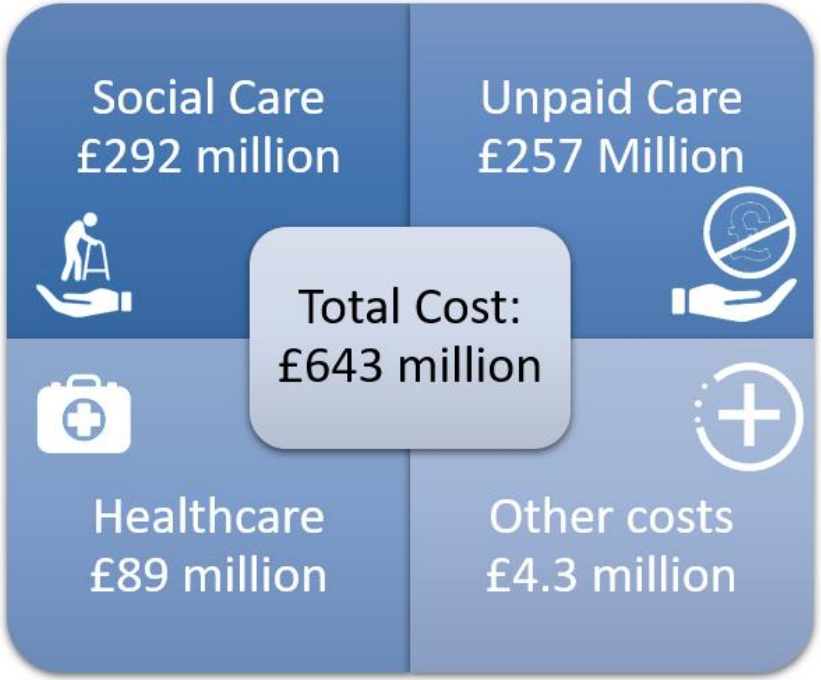
Background: the cost of dementia

Dementia costs £29.5 billion in the UK, with 40% of this funded through unpaid care.

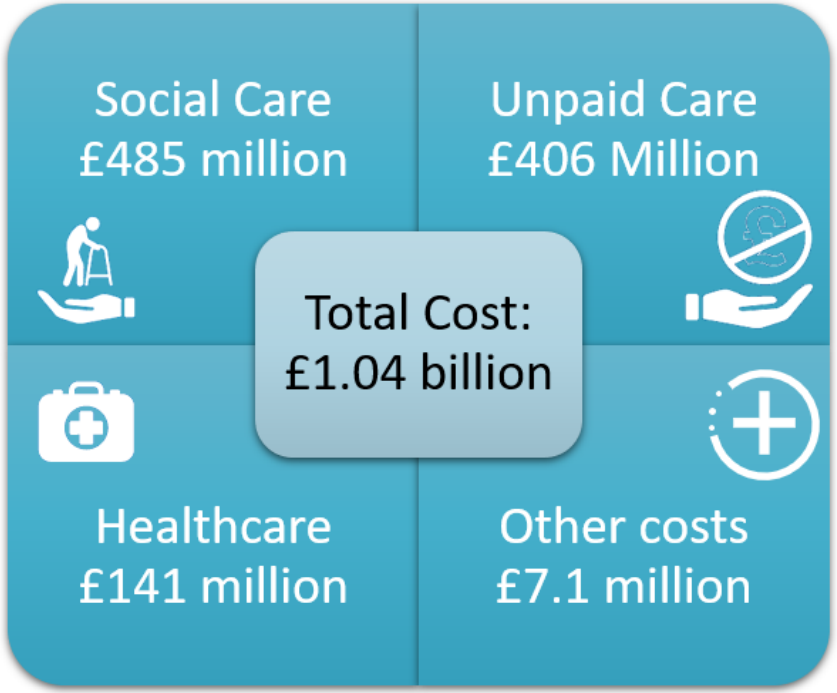


Estimated cost of dementia to Joined Up Care Derbyshire

2020



2030

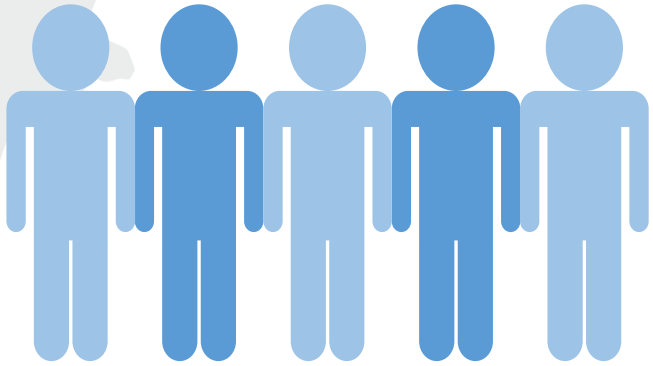


Local engagement

The Derbyshire Well Pathway for Dementia has been informed by undertaking engagement at various levels and in a range of places with people living with dementia, carers, those important to them and organisations providing statutory and voluntary services.

We received a range of feedback about what is important to people which has helped to shape the local pathway. The full report is available here.

Complementary engagement and research undertaken by key partners has also been taken into account.



What people said

"I want my family to know how they can do things to reduce the risk of developing Dementia as I would not want them to get it." Person living with dementia

"An early diagnosis is important for a person living with dementia as at the beginning it is quite frightening and frustrating and if we understand and are informed about the condition it would give the person the support they need."

Person living with dementia

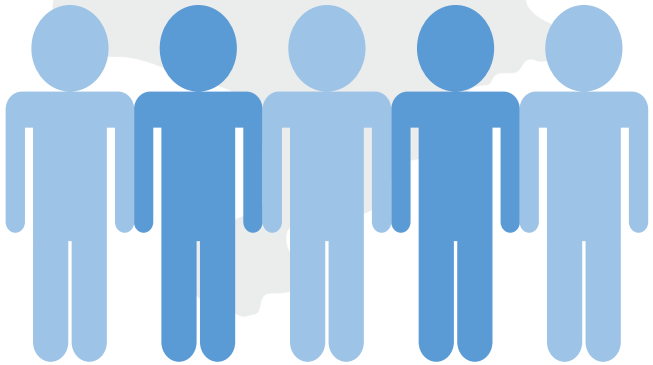
"It is still a minefield for people often not knowing where to go for support. Care needs to be coordinated so everyone is aware what is available and support needs to be on going." Carer

"We live in a diverse society therefore services should not be one size fits all." Health / Social Care worker

"People with dementia use a wide number of services across the health and social care arena. All staff should be equipped to treat and care for these people." Health / Social Care worker

"We go to a garden centre where the staff know us and know she has Dementia - the way they speak to us puts me at ease and makes me want to go back again and again." Carer

"There needs to be much more for younger people to access." Carer



"It's important for wishes for the future to be known whilst I still have capacity."

Person living with dementia

Engagement: Key themes

- The importance of Early Diagnosis to enable informed early decision making, and facilitate advance care planning
- The importance of post diagnosis support and timely information on an ongoing basis
- Carers don’t feel supported practically, and they aren’t prioritised for support or as experts
- People under 65 living with dementia require targeted support
- Health and Social Care need to integrate, to reduce fragmentation, improve communication and reduce repetition and confusion for carers and people living with dementia
- Good training for staff is essential, sharing specialist skills and acknowledging that people with dementia may have complex physical health needs and people with complex physical health needs may have dementia
- Advance Care Plans are important and should be discussed more often
- Prevention and Risk Reduction should be promoted more, particularly for those in midlife
- One size does not fit all, people are individual
- The importance of dementia aware communities

National and Local Drivers

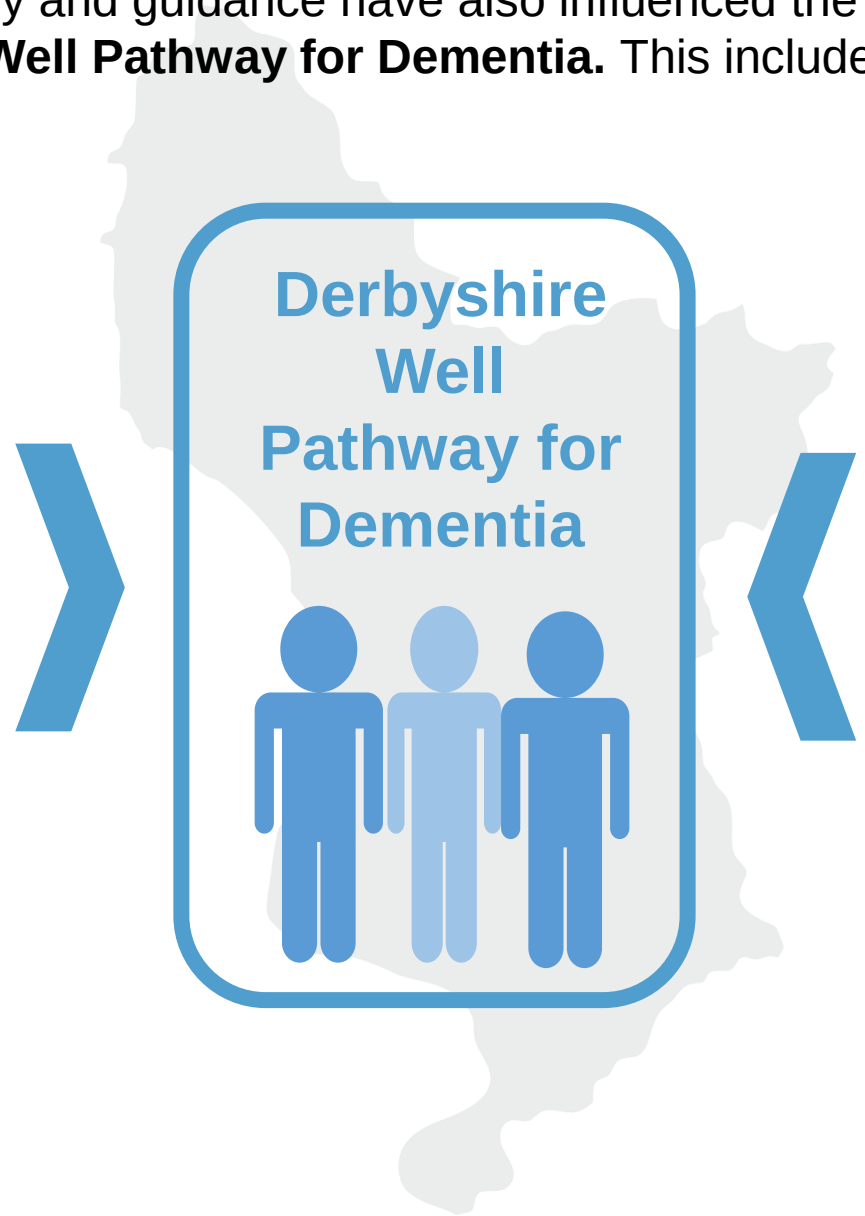
National and Local strategy and guidance have also influenced the direction of the **Derbyshire Well Pathway for Dementia.** This includes:

The Prime Minister's Challenge on Dementia (2016)

Care Act (2014)

NHS Long Term Plan (2019)

NICE: Dementia: assessment, management and support (2018)



Better Care Closer to Home (2017)

Derbyshire Frailty Pathway

Delirium Pathway

Derbyshire County Council Plan

Derby City Council Plan

JUCD pathway workstreams

Achievements in Derbyshire over the last five years

A Memory Assessment Service that supports earlier identification and diagnosis of dementia

A Dementia Support Service to provide key information, advice and peer support

A Dementia Rapid Response Team to provide enhanced support and treatment for times of escalating need

A Dementia Reablement Service in the county focussed on stabilising support at home for people living with dementia

New Extra Care and Community Care Centres built in the county specifically designed for people living with dementia

Changes to day hospital services to ensure people are offered programmes of specialist education and advice as soon as they receive their diagnosis

Programmes of education for our Acute Care Hospitals: Chesterfield and Derby have provided staff training, promoted dementia friendly ward design and increased the number of dementia specialists working on physical care wards

Dementia Friends initiatives promoting the inclusion of people living with dementia in everyday life and activities

Improved approaches to integrating care for people living with dementia and their carers

A commitment, and practical approaches to ensure health, social care and voluntary sector organisations work better together to benefit people living with dementia, their carers and those close to them

A programme of delirium awareness made available across all health, social care and voluntary staff

Delirium in dementia

Delirium is a physical health condition which people living with dementia are highly susceptible to developing and delirium can exacerbate dementia symptoms.

People living with dementia can experience extremely poor outcomes as a result of having delirium. The Derbyshire Well Pathway for Dementia incorporates delirium in dementia education and prevention strategies, because it is recognised that better approaches to managing delirium will have a positive impact and enable people living with dementia to live better.

Approaches such as the online **Delirium Awareness e-learning** (available here) and the **Delirium Animation Video** (available here) have helped to improve staff knowledge and skills. **Over 2,000 people have completed the e-learning to date**. This is part of our commitment to enable the health and care community to work well together to integrate care for people living with delirium and dementia.

Our strategic vision

- To inform our Strategic Vision we have developed **eight key strategic priorities**.
- We based our local engagement on these priorities so that a range of people could have their say on how these were important and could be achieved.
- To ensure that these priorities cover all stages of the NHS Well Pathway for Dementia, we have mapped these priorities against the different stages**:**

- On the following slides we set out our vision over the next five years of how we will collectively use these priorities to guide service development.
- This is what we commit to and call the **Derbyshire Well Pathway for Dementia**.

The Vision: Preventing Well

Priority

Ensure the people of Derbyshire have information about dementia and are aware of ways in which they can minimise their risk of developing dementia

We will implement a broader dementia awareness and information programme
We will work in partnership across Derbyshire to spread risk reduction messages
We will ensure risk reduction messages are accessible to everyone living in Derbyshire

The Vision: Diagnosing Well

Priority

Deliver services that diagnose in a timely manner so that people can access support, make decisions and plan for living with dementia

We will maintain the dementia diagnosis rate above the national target of 66% and in line with national aspiration we will aim to improve this target to 75% by 2025
We will strive to increase the number of people diagnosed with dementia and starting treatment within 6 weeks of referral, in line with the national aspiration
We will provide services, from the point of diagnosis that deliver access to timely support and focus on planning for the future
We will continue to promote involvement in research, and increase the numbers of people diagnosed in Derbyshire participating in research

The Vision: Supporting Well

Priority

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

We will build on education and training programmes to improve the knowledge and skills of everyone working with people at every stage of living with dementia
We will improve the way health and social care staff share their specialist skills and knowledge to support best practice
We will work across organisations and with all stakeholders to improve palliative care for people living, and dying with dementia and their carers

The Vision: Supporting Well

Priority

Ensure care for people living with dementia is well co-ordinated and integrated

We will improve the way health and care staff work together to meet the needs of people living with dementia, particularly where the person also has other health conditions
We will improve the way health and care staff share information and decision making with people living with dementia, their carers and with each other
We will make systems easier to navigate, and support people living with dementia and their carers to understand their options for health, care and support
We will listen more to family carers, and promote and respect their role within the care and support process

The Vision: Supporting Well

Priority

Improve access to, and quality of, treatment and support following diagnosis, for people living with dementia and their carers

We will provide dementia education and information programmes for people diagnosed with dementia and their carers to access
We will improve the offer and uptake of assistive technology for people living with dementia to support their independence
We will maintain and design services delivering evidence based, quality treatment at the point of need for people living with dementia
We will improve equity and availability of services

The Vision: Living Well

Priority

Continue to build communities where dementia is understood and people living with dementia are included, respected and supported

We will continue to build community resilience and to foster inclusivity for people living with dementia, and awareness of dementia
We will increase co-production of services, ensuring people living with dementia, and their carers are involved in designing, developing, and reviewing services
We will proactively develop housing and accommodation options for the increasing number of people living with dementia

The Vision: Dying Well

Priority

Ensure more people with dementia have an advance plan of care that describes their wishes for the future

We will work across organisations and with all stakeholders to improve care for people dying with dementia
We will improve and embed advance care planning for people living with dementia
We will empower carers to feel confident, and supported in their role
We will increase the number of people dying with dementia doing so in the place of their choice and with an advance plan of care

The Vision: Whole Pathway

Priority

Tailor services to meet the needs of different, and diverse community groups

We will analyse the gap and barriers to under-represented groups including BAME communities, people with learning disabilities, people of working age and those with a sensory impairment accessing the dementia pathway
We will work to ensure services are accessible and sensitive to the needs of specific under-represented groups

Joint Implementation Plan

Implementation Action	Lead	2019-20	2020-21	2021-22	2023-24	2024-25
Implement a broader dementia **risk reduction** information programme.	All Partners					
Maintain and improve the **dementia diagnosis** rate in Derbyshire to 75%.	DHCFT					
Improve people with dementia and carer's confidence in **navigating the health and social care system** and understanding support options available.	All Partners					
Continue to improve the **in-patient experience** and develop **hospital discharge pathways** that improve outcomes and quality of care.	Acute Hospitals, DHCFT, DCHSFT, Hospice Care					
Embed **end of life care** planning and improve quality of **advance care plans** undertaken by professionals supporting people living with dementia.	DHCFT, DCHS and Acute Hospitals, CCG					
Improve and integrate training to improve **staff skills and knowledge** about dementia and delirium across the statutory, voluntary and private sector.	All Partners					
Work with partners, particularly District and Borough Councils to develop new **extra care accommodation** options for people living with dementia.	Derbyshire CC, Derby CC					
Work closer with **BME communities** to improve understanding and access to services and support for people living with dementia.	DHCFT, Derbyshire CC, Derby CC					
Improved and focus the offer and uptake of **assistive technology** for people living with dementia to increase their independence.	Derbyshire CC Derby CC					
Increased **co-production of services** and support involving people living with dementia and their carers in a more meaningful way.	All partners					

Priority actions in progress are highlighted in darker blue

Outcomes

By 2025, people living with dementia and their carers in Derbyshire will:

- Have access to information to improve awareness of ways in which they can minimise their risk of developing dementia
- Have access to proactive dementia diagnosis and post diagnosis support to help them to understand their condition and plan how they can live well with dementia
- Be cared for and supported by a workforce that is constantly improving their knowledge and skills to support people living with dementia and their carers
- Receive dementia care and support that is both integrated and coordinated around themselves and their carers
- Have access to good quality post dementia diagnosis, treatment and support
- Live in communities where understanding of dementia is growing, and people living with dementia and their carers are respected, included and supported
- Have support to describe and share future preferences and improved end of life care and support
- Have access to dementia care and support that strives to meet the needs of different and diverse groups across the community

Next steps

- We will **review the joint implementation plan annually** to ensure we are working towards our overall ambition to provide the best quality care possible for people living with dementia in Derbyshire.

- We will ensure that all implementation partners involved in the **Derbyshire Well Pathway for Dementia** commit their own organisational implementation plan.

- We will **monitor population changes** covering the numbers of people predicted to develop dementia in Derbyshire over the next ten years.

- We will **track the impact, demand and capacity** within our pathway to identify further resources required to support our shared priorities.

Integrating with other pathways

The **Derbyshire Well Pathway for Dementia** prioritises the needs and wishes of people living with dementia and their carers. However there are many other pathways of care that at any point in living with dementia the person may need support from. Therefore it is **important that we take into account other care pathways** and share learning with them. For example, a person living with dementia may also be physically frail, so it is important that people caring know how to support both of these conditions.

The other care pathways that are particularly important include the **end of life pathway** and the **frailty pathway**, where work is already underway to ensure that the specific needs of people living with dementia are considered. It is very important for our strategic vision that services **respond to the person's range of needs and circumstances** rather than providing a prescriptive one size fits all approach. We will continue to build on cross-partnership programmes of education and awareness raising to share skills and knowledge across our pathways of care.

This Strategic Vision has been developed in partnership by:

NHS
Derbyshire Healthcare
NHS Foundation Trust

Alzheimer's Society
United Against Dementia

NHS
Derbyshire Community Health Services
NHS Foundation Trust

healthwatch
Derbyshire

DERBYSHIRE CARERS ASSOCIATION

Derby City Council

NHS
Derby and Derbyshire
Clinical Commissioning Group

Derby & Derbyshire
age UK

DERBYSHIRE
County Council

NHS
University Hospitals of
Derby and Burton
NHS Foundation Trust

Ashgate Hospicecare
Every Person Matters

MakingSpace

NHS
Chesterfield
Royal Hospital
NHS Foundation Trust

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Office for National Statistics (2018). 2016-based subnational population projections for local authorities and higher administrative areas in England [online]. *Office for National Statistics* [viewed Oct 2018]. Available from: https://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationprojections/datasets/localauthoritiesinenglandtable2

https://www.carersinderbyshire.org.uk/caring-for-someone-with-dementia

https://www.livelifebetterderbyshire.org.uk/

Partner websites

www.derbyshire.gov.uk
www.derbyandderbyshireccg.nhs.uk
www.derbyshirehealthcareft.nhs.uk
www.uhdb.nhs.uk
www.dchs.nhs.uk
www.derby.gov.uk
www.healthwatchderbyshire.co.uk
www.alzheimers.org.uk
www.makingspace.co.uk
www.chesterfieldroyal.nhs.uk