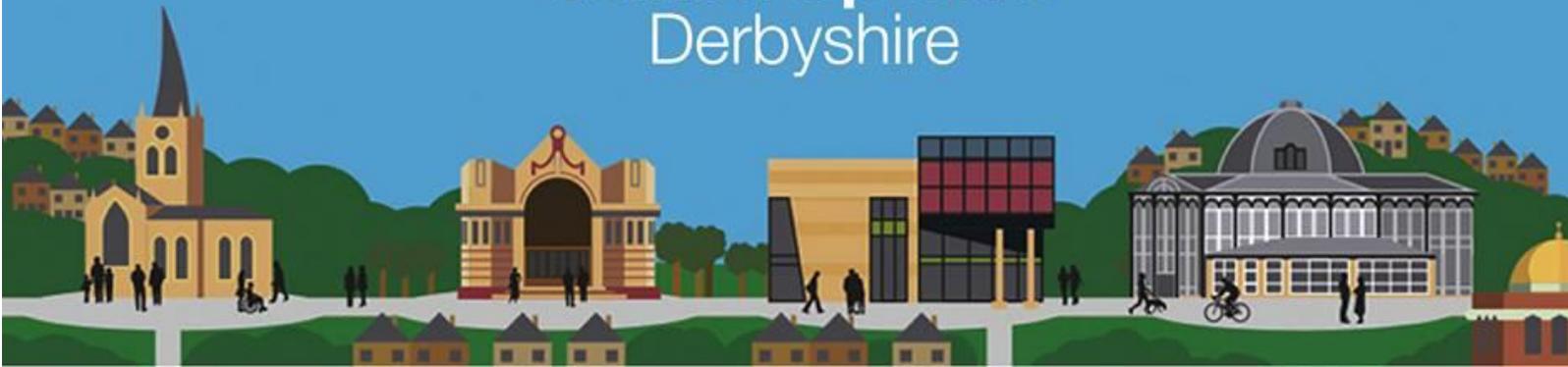


# Joined Up Care Derbyshire



## Joined up Care Derbyshire: Well Pathway for Dementia

Engagement April-July 2019

---

### Joined Up Care Derbyshire

Planning future services together  
so people can be healthy,  
live well and stay well.



## Overview

The Dementia workstream of Joined Up Care Derbyshire (JUCD) aims to provide the best care and support for people in Derbyshire living with dementia, their carers and those close to them. An important part of the workstream activity is to ensure that people using, and involved with services contribute to how the local Derbyshire pathway of services and strategic overview develops.

At National level, following extensive consultation, a Well Pathway for Dementia was established (see below) and in Derbyshire we have been using this as the framework for developing our services for several years. In order to refresh the Derbyshire Pathway a period of engagement was undertaken with the aim of gathering the views of local people who access or provide dementia services. Co-producing this pathway will ensure these views contribute to building and improving services and support for people to live well with dementia in Derbyshire over the next 5-10 years.

## 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"

**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"

**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"

**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"

**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"

## The Engagement

People were asked to comment on key issues identified as important to the work of the dementia workstream over the next 5-10 years. These have been expressed as 8 priorities:

### 8 Priorities

- Ensure the people of Derbyshire have information about dementia and are aware of ways in which they can reduce their risk of developing dementia
- Deliver services that diagnose early so that people can access support and plan for living with dementia
- 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
- Tailor services to meet the needs of different, and diverse community groups
- Improve access to, and quality of, treatment and support following diagnosis, for people living with dementia and their carers
- Ensure care for people living with dementia is well co-ordinated and integrated
- Continue to build communities where dementia is understood and people living with dementia are included, respected and supported
- Ensure more people with dementia have an advance plan of care that describes their wishes for the future

#### What:

People were invited to comment on 8 priorities, and on any other aspects of dementia provision people felt had been omitted, or was important.

#### When:

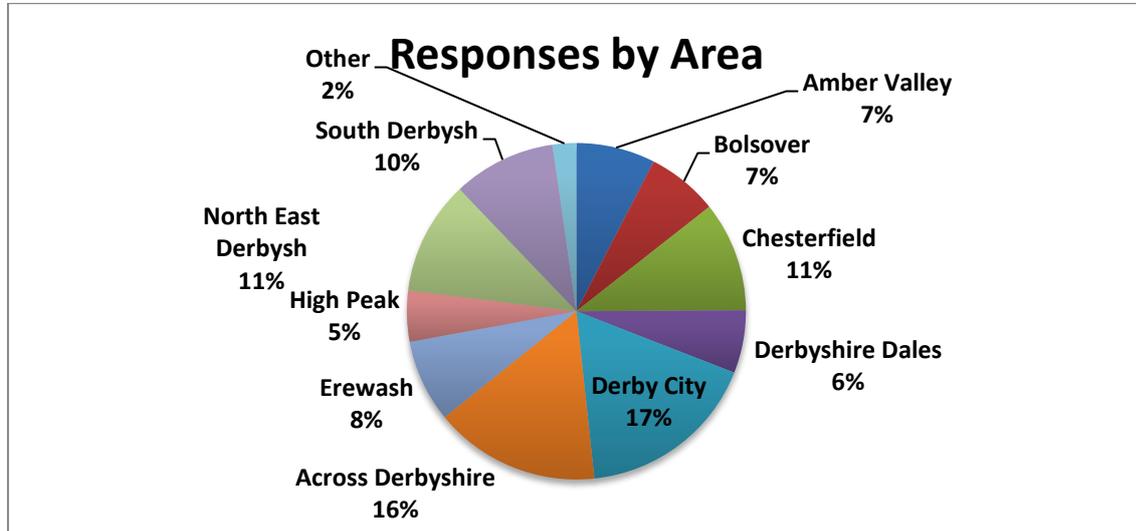
The engagement was open from 8th April to 5th July 2019.

#### How:

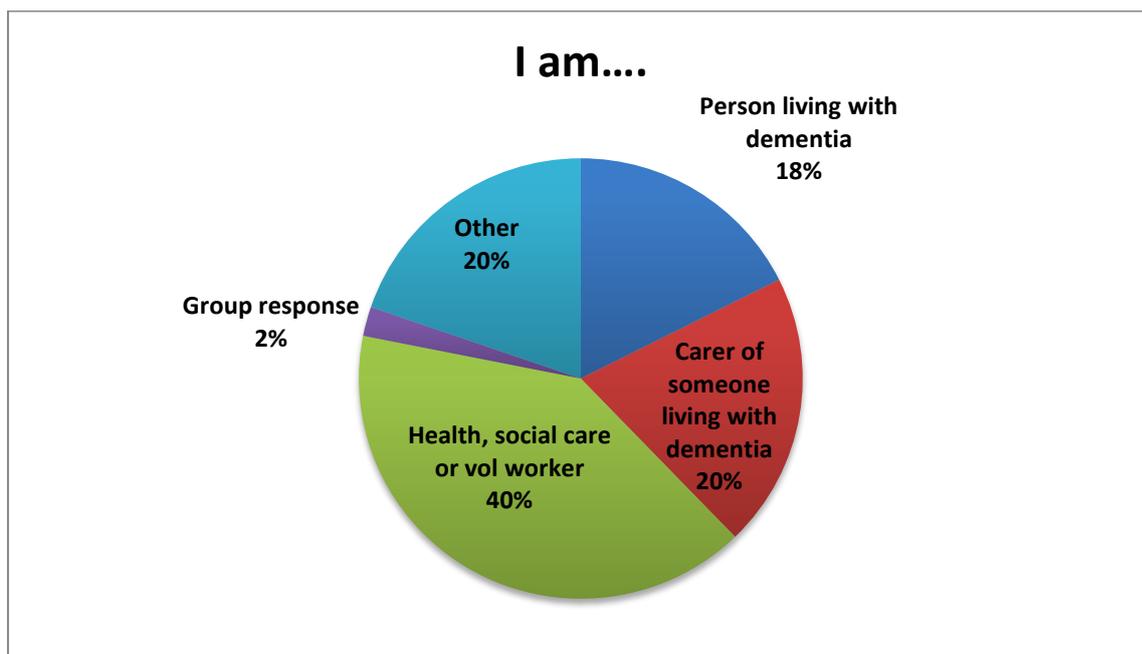
An online and paper surveys, together with face to face meetings held by representatives of various organisations facilitated the engagement.

## Responses

233 people from across Derbyshire responded to the engagement.



The oldest person who responded to the engagement was 95, the youngest 23. A range of people responded including a large number of people living with dementia and their carers and people who work or volunteer in dementia services. It was noticeable that some people responding as professionals were also carers, or with close family members or friends living with or affected by dementia. A large proportion of people describing themselves as 'other' were relatives or friends of those in a caring role, or were bereaved carers.



We asked people three questions about the priorities:

1. Please mark your top 3 priorities, and tell us why they are important
2. Please tell us about any other priority you think we should add to the list above?
3. Do you have any other comments?

## 1. Please mark your top 3 priorities, and tell us why they are important

There were three key areas that people identified as most important which were the same across all groups of respondents:

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

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

Deliver services that diagnose early so that people can access support and plan for living with dementia

One respondent highlighted what many agreed with when they said:

*“All these priorities are clearly very important.” Carer*

People responding to the engagement had plenty to say about each priority, a selection of comments appears below.

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

*“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 (PLWD)*

**Deliver services that diagnose early so that people can access support and plan for 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." PLWD*

*"Early diagnosis allows people to live their lives as fully as possible for as long as possible." Carer*

**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**

*"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." Professional*

*"All people with dementia are different depending on the stage of the dementia, the type and the age and health of the person with dementia and so services need to be able to cater for differing needs in order for dementia patients to remain at home as long as possible. Staff need to be able to respond to these differences in an appropriate way for the individual concerned." Carer*

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

*"We live in a diverse society therefore services should not be one size fits all." Professional*

*"Sensory Impairments should be taken into account more often when communicating." PLWD*

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

*"My belief is that access to treatment and support is crisis led and pretty shambolic." Carer*

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

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

*"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*

*"When I know our GP and Social Worker are in touch and sharing information, I know the response we have received is better." Carer*

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

*"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 more awareness across the board, schools could teach children as many Grandparents get Dementia." Carer*

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

*"Advance plan of care - I have written down my funeral arrangements and also how I want to be looked after in a care home so my family are clear on this." PLWD*

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

## 2. Please tell us about any other priority you think we should add to the list above?

People living with dementia were clear that there should be more activities they can participate in, and that the people in the role of carer should have more support.

*"If you help my wife you also help me." Carer*

*"More about activities available - the programme Dementia Choir on BBC is an excellent example." Carer*

Carers also reflected that their role is often not taken into consideration enough.

*"I believe 'Caring Well' is such an important element and is being over looked."*

*"It is often left to the person closest to the person with dementia to get things done, this is so hard at times and not always effective."*

There was a level of concern expressed across respondents about support given to carers and how well (or otherwise) they were prioritised as having expert experience in the individual, their needs and how best to provide care.

This is summarised well by two respondents;

*"When someone with dementia goes into hospital for whatever reason please listen to the family members or primary carer of that person. They are the people who are focussed on the wellbeing of their loved one who is currently in the care of the medical staff. They know what they are talking about when it comes to how their loved one responds best in situations. Never, ever, ever disregard anything that family member or carer says; it might just help the person with dementia AND the staff looking after them. A better experience for the person with dementia invariably means a better experience for those looking after them." Carer*

*“More support needs to be given to carers - until you have lived with someone with dementia that gets up 5 times every night, you have no idea what dementia is all about. It’s not just keeping an eye on someone during day light hours - for a carer it never stops – ever” Carer*

Several respondents also highlighted the particular needs of younger people living with dementia, and the need for targeted services for people of working age living with dementia, and their family.

### 3. Do you have any other comments?

Throughout the engagement respondents were concerned about the level and availability of training for all involved in delivering care and services for people living with dementia, one respondent had a suggestion;

*“To provide generic training for Health, social care and volunteers and carers of people living with dementia, as this will lead to a better understanding and awareness into the progression of dementia.”  
Professional*

It was pointed out by several respondents that given the growth in the population of older people, and growth also in people living longer with both physical health conditions and dementia that the way in which different health and social care services work together needs urgent consideration.

Some pointed out accessing services was easier in larger urban areas than in small villages, although some also pointed to very good examples of activities available in more rural areas.

There were comments about people who lived alone, and were housebound living with dementia and how accessible any services were for them.

Finances and resourcing were frequently mentioned by respondents. Whilst there was understanding that the health and care system had a level of funding, it was clear that respondents felt this wasn’t at the level required to meet the needs of individuals living with dementia, or those trying very hard to care and support them at home, whether home was the family home or a care home.

## Key Themes Summary

- 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
- Younger people 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
- One size does not fit all, people are individual
- The importance of dementia aware communities
- Midlife health promotion of how to reduce risk of dementia

## Complementary Local Engagement

We are mindful that engagement takes place in many ways and at different forums. In addition to these engagement findings, the development of the Derbyshire Dementia Pathway will also take into account the following programmes of engagement:

In 2018 Healthwatch Derbyshire gathered valuable information, through their Derbyshire Dementia Engagement Report, on the experiences of people living with dementia and those close to them, on health and social care services in County areas. The recommendations from this engagement will be incorporated into the Dementia Well Pathway – Strategic Overview.

In May 2019 the Creative Carers group, together with Making Space and Age UK, produced a report (*Strength Project: carers of people with dementia*) based on engagement with carers in Derby City. They are also now working with Derbyshire County Council, Healthwatch Derbyshire and Derbyshire Carers Association to engage further with carers in Derbyshire County regarding their experiences. Initial findings suggest the need for more support groups, concerns about the quality of information

available for carers and general support available. The report also called for decision makers to work more collaboratively with carer led organisations as a proactive way to increase co-production. This report, and findings will also be taken into consideration.

A research project undertaken by Dr Fiona Marshall from the University of Nottingham, in the Derbyshire Peak District national park area (*A summary report for families and care givers about rural dementia May 2019*) considers the specific difficulties experienced when living with dementia in rural communities. This report highlighted the need for improved transport systems, targeted services for younger people living with dementia, timely information when people really need it and improved end of life care. The report also highlighted that whilst there is a growing reliance on a digital response generally across the country, this isn't of use where connections are poor. The report called for a bold and innovative approach to development of services in rural areas. This report, and findings will also be taken into consideration.

Qualitative feedback for this engagement was also received from Derby City Race Equality Forum and Derbyshire Black, Minority, Ethnic (BME) Forum. Particular issues for some cultural communities centred around the fact that dementia is not being acknowledged per se, and that the language used around dementia isn't accessible for many in diverse communities, the use of jargon being an example. Views were also forthcoming from Derby City Disability Equality Forum, again echoing the need to support carers and people living with dementia as a whole family approach. These comments, and feedback will be considered when developing the Strategic Vision, and the follow on delivery plan.

## Next Steps

The Joined up Care Derbyshire Dementia Workstream partnership are extremely grateful to everyone who provided feedback, through whatever forum. All feedback will be considered when revising the local dementia pathway / strategic overview priorities and the voices represented in the feedback will be instrumental in defining this.

After revising the Strategic Overview: Derbyshire Dementia pathway, 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.