



Supporting people affected by dementia in Derbyshire during the pandemic and beyond

People with dementia and those with an un-diagnosed memory concern have been hardest hit by the pandemic. Nationally, they account for over a quarter of all Covid-19 deaths¹, while tens of thousands more have seen their condition deteriorate at an increased pace due to limited support and social isolation brought on by repeated lockdowns. In addition, over 40% of family carers have spent more than 100 hours per week caring for a loved one living with dementia².

The local picture

Derbyshire residents are no different. Research³ conducted by the Derbyshire Alzheimer's Society on behalf of the Joined Up Care Derbyshire Dementia Strategy Group found that 75% of respondents had seen a deterioration in the physical health of their family member or friend living with dementia. In addition, 78% had seen a deterioration in the individuals mental health and almost a third (63%) reported that dementia symptoms had become a lot worse.

Family members who took on a greater caring role during the pandemic felt this was mainly because of national lockdown and shielding requirements. The suspension of face-to-face support groups and access to respite care also had an impact, as did personal decisions to cancel home care support. Many local residents said these increased caring roles led them to have greater feelings of isolation, anxiety about the future, and concerns about the health of the person living with dementia.

Local services during the pandemic

As expected, the research found that some primary care services such as GPs, were difficult to access, particularly at the beginning of the pandemic. But most people said they found it “okay” or “easy” to access other services including adult social care and telephone support services.

However, it was concerning to find that a significant number of respondents were either not aware of a service or didn't think they would be entitled to it. This included financial and group/individual support services and indicates the need to reassess how information about dementia services is circulated.

Accessing services: face-to-face or remote?

Almost three quarters of carers (74%) said their usual face-to-face services had been replaced with telephone calls or online services during 2020. Of these, 43% found this change to be okay, 21% found it difficult. Significantly, 18% said this change had stopped the person with dementia from being able to access their service.

¹ González, Livingston et al. Impact and mortality of COVID-19 on people living with dementia: cross-country report. 2020. International Long Term Care Policy Network, Care Policy and Evaluation Centre, London School of Economics.

<https://ltccovid.org/wp-content/uploads/2020/08/International-report-on-the-impact-of-COVID-19-on-people-living-with-dementia-19-August-2020.pdf>.

² Alzheimer's Society. 'Exhausted' family and friends spent 92 million extra hours caring for loved ones with dementia since lockdown. 2020. <https://www.alzheimers.org.uk/news/2020-10-05/exhausted-family-and-friends-spent-92-million-extra-hours-caring-loved-ones>.

³ 219 people from across Derbyshire County and Derby City engaged with the research, which took place between January – February 2021. The subsequent report, “Engagement Project: Understanding how people affected by dementia in Derbyshire have been supported during the pandemic” was released in May 2021.

While some preferred having a virtual appointment because they could attend it from home, 83% of carers were keen for post-pandemic GP appointments to take place in-person and 72% thought informal group sessions would be better face-to-face, particularly for the person with dementia. However, the majority of respondents felt that 1-2-1 support and general assessments could take place by phone or online.

The biggest concern raised was for those who do not have access to technology as they have been missing out during the pandemic and should be able to have the same rights as others in the future.

Normalising dementia

The research shows there is still a stigma attached to dementia. Only 47% of respondents agreed that people understand dementia is a medical condition. More than half that number (18%) felt that people know where to go for information about dementia. Even more concerning was that 74% felt that people may be choosing not to get a memory assessment because they are “scared” of the outcome; and only 7% thought people were confident to tell others they have dementia.

Over three quarters (78%) of respondents thought that local dementia organisations, medical practitioners and local agencies could do more to raise awareness about dementia and where to seek support. Suggestions included more community-level information, greater local visibility by dementia organisations, greater integration between health and social care so that dementia isn't overlooked.

Post-pandemic life

The findings showed a great deal of hesitancy about post-pandemic life. In terms of local dementia service provision, the following suggestions were put forward by carers:

- Contact with professionals: Increased contact, earlier follow-up calls and regular check-ups/assessments were all mentioned. Having professionals reach out to families rather than rely on people knowing who to contact was also high on the list, along with a care coordinator.
- Greater personalised support: More support for informal carers and more support for people with dementia living on their own.
- Group services and activities: A number of comments mentioned an increase in the number of peer groups and a wider range of activities – both in the community and activities people could do in the home, including physical activity.
- Joined up services: Shared services (particularly community-based) across the City and County to help people to access the nearest service rather than the one in their 'area'.

The above is a brief overview of the research findings. Many other areas of the dementia pathway were discussed, along with the experiences of those with family or friends in hospital, or in a care home. The Joined Up Care Derbyshire Dementia Strategy Group will be evaluating the findings and fully exploring the issues raised by respondents. The Group is committed to taking any possible action that will improve services for people affected by dementia.

To read the full report, “Understanding how people affected by dementia in Derbyshire have been supported during the pandemic”, please email derbyshire@alzheimers.org.uk.