

A decorative border of small, light blue forget-me-not flowers with yellow centers and green stems runs horizontally across the middle of the page, framing the central text box.

# Derbyshire Dementia Support Service

SUMMER 2021 ISSUE

# Listening to Derbyshire Residents: The Pandemic and Beyond

Earlier this year, the local Alzheimer's Society Team engaged with residents across Derbyshire and Derby City to hear their experiences of local dementia services, particularly during the pandemic.

The research took the form of telephone calls and survey responses. Over 200 people took part, providing views from those with a dementia diagnosis, family and friends, health and social care professionals, and members of the general public.

The questions ranged from the ease to which people were able to access health, social care and other support services during the pandemic, to the physical and mental health impact of lockdown and shielding guidance.

There were also questions about the general level of awareness within society about dementia, and the extent to which people would know how to access support.

Conducted on behalf of the Joined Up Care Derbyshire Dementia Strategy Group, the findings were published in May. As well as providing examples of good practice, the report found that access to information about the services on offer for people with dementia could be improved. In addition, better communication between services would be helpful to families, greater personalised care and increased support for carers.

Alison Clowes, Public Affairs and Campaigns officer at Alzheimer's Society, was involved with the project and said: "It was important to understand how the pandemic has impacted people affected by dementia and the additional support they may require. We also felt it was an important opportunity to get feedback on the wider dementia pathway, and the perceptions people have of dementia services to help us understand what more we can do to demystify dementia."

The report has already generated lots of discussion within Joined Up Care Derbyshire. For more information, please email [alison.clowes@alzheimers.org.uk](mailto:alison.clowes@alzheimers.org.uk).

Some key findings from the report:

- 75% of respondents had seen a deterioration in the physical health of their family member or friend living with dementia.
- The increase in caring roles by family members has led to greater feelings of isolation, anxiety about the future, and concerns about the health of the person with dementia.
- 74% of family carers 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, while 18% said it had stopped the person with dementia accessing the service.
- While 83% of carers were keen for GP appointments to return to face-to-face, most felt that 1-2-1 support and general assessments could take place by phone or online.
- 74% of non-carers felt that people would be scared of a memory assessment because of the outcome. Only 7% thought people were confident to tell others they have dementia.
- 78% of respondents felt that local dementia organisations, medical practitioners and local agencies could do more to raise awareness about dementia and where to seek support.

# Covid-19 Support Provision in Derbyshire

Support we've provided to people living with dementia and carers  
1 April – 30 June 2021

**374**

New referrals / self referrals requesting support (includes people living with dementia and carers)

**157**

People signposted on to our partner agencies

**243**

Referrals received from partner agencies

## Online Group Attendance

**8** New referrals

**37** Singing for the Brain

**145** Memory cafes

Welfare calls are being provided by DSWs where required and we continue to provide companion calls through our volunteers

# Case Study

Our team has continued to support some of society's most vulnerable members as they adjust to a life changing diagnosis of dementia coupled with the restrictions imposed by Covid-19 at a time when they need social support the most.

An example of this is Mrs A who was diagnosed with Alzheimer's Disease shortly before the pandemic forced the UK into lockdown. Mrs A's partner entered our service after her daughter rang us, asking her to help her father who was "at breaking point". When we spoke to Mr A, he admitted finding the situation too overwhelming and was struggling with a full-time job, caring for Mrs A and their home, and having a few hours' sleep each night. During this call, Mr A agreed that he was experiencing severe carer strain and that he had felt like the last few weeks he had been at his lowest and was at a loss as to how to "get through it all". Mr A said that Mrs A's friends had slowly stopped speaking to her and that Mrs A very much missed social interaction. We introduced them to the virtual Zoom dementia cafes that we are hosting during C19 until we return to face-to-face care provision when they could attend and make relationships with others within their locality.

Mr A was advised that it may be possible for carers to visit and ensure that Mrs A was taking medication and eating and agreed to a referral to Adult Social Care to assess how they may be able to help. The referral was made stressing urgency that Mr A was contacted as soon as possible owing to the concern of sleep deprivation, enduring severe carer strain and how overwhelmed Mr A was feeling in coping with his current circumstances. Mr A was referred to the Derbyshire Carer's Association and onto the Citizen's Advice Bureau for a financial assessment, as well as being emailed with a link to the Dementia Talking Point forum where he could communicate online with other carers and read about their experiences of caring for a loved one with dementia as agreed in the original call. Mr A was given our contact details and told that if he found it easier to email than phone then that was fine and to reach out if he had any questions or identified any further support needs.

At the end of the call, Mr A said he was grateful for us calling and for being someone who he felt he could be truly opened and honest with about how he was feeling. He said that he had felt that "there was a light at the end of the tunnel" and that "a weight had been lifted". Mr A was also reminded that we would endeavour to do everything we could to ensure that he and Mrs A got the support that they both deserved.

When we called Mr A a fortnight later, he said that he had gone from having no support lines at all in the last fourteen months to having received contact from several services as a result of our conversations. He felt less isolated by being able to connect using the Talking Point website in talking to other carers online and sharing similar feelings and situations and was happy that he had had financial strain lifted by having him referred to the Citizen's Advice Bureau. He also said that he was appreciative of being able to socialise virtually in our online Dementia Cafes with his wife and having something new to do together.

*"You've done more for me in these last 2 weeks than everyone put together in the last fourteen months! I have been able to open up and talk to you about my feelings and I don't find that very easy to do but you have made it so easy for me".*

“\*\*\*\* has been calling me. I haven't been able to go out and don't really want to go out as I don't feel safe, so it's nice to have someone to talk to”

“I'm happy with the support I get and know I can ring the Alzheimer's Society if I'm worried about anything”

Service

User

Feedback

“Thank you so much, I really appreciate everything you are doing”

“The welfare calls are helpful and I know that someone is going to check on me”

“I have enjoyed having someone to talk to, who understands what is happening. It isn't easy caring for \*\*\*\*, but I do have lots of support and lots of friends so I know I'm more fortunate than most”

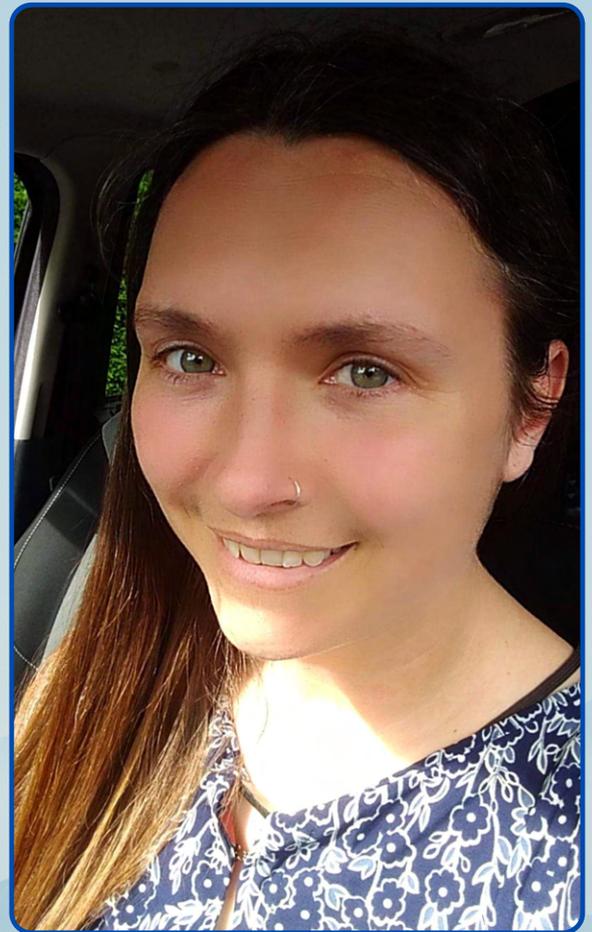
Meet...

## Marie Janes

**Role: Dementia Support Worker**

**Covering: Erewash & Bolsover**

Marie is a new recruit to the Derbyshire Team, starting her role as a DSW in March 2021. She joined after having graduated from her MSc Psychology in Clinical Practice from Nottingham Trent University, part of which included an 8-month placement within the Derby Memory Assessment Service. Marie became interested in neurodegenerative disease during her final year of her undergraduate Psychology degree which made her change her mind from following a career path in Educational Psychology to Clinical Neuropsychology. Marie remains actively involved in dementia research and assists in current research projects at NTU.



Before doing her undergraduate degree as a mature student, Marie worked with children and young people and uses the skills she acquired in those roles to engage with the younger generation to enable understanding of dementia, build relationships between the young and the old, and is passionate about stamping out the stigma that a diagnosis of dementia often brings.

When not at work, Marie volunteers for a food charity, redistributing food to those who need it and runs a children's liturgy group and a baptism course at her local cathedral. She enjoys long walks in the Derbyshire countryside with her husband, teenage son and dog and, pre-Covid, was well travelled. Marie describes learning languages as one of her hobbies and is currently learning Welsh, to add to those which she currently speaks which are Icelandic, French and Italian.

In May, the incredible Fraser Lamont, a DSW in the Derbyshire team undertook the NC500 challenge, cycling and trekking through Scotland, raising funds and awareness for the Alzheimer's Society. The NC500 is 516 miles around the North Coast of Scotland, starting in Lochcarron, on the West coast of Scotland. Journeying clockwise, Fraser ventured for 23 days through the rugged and breathtakingly beautiful landscapes, updating his team back in Derbyshire at various stages and treating them to some stunning photos and sharing some stunning scenes. Fraser's challenge included cycling around the Isles of Skye and Arran and climbing and hiking through the Hidden Valley and Glencoe. The weather meant that Fraser was unable to climb Ben Nevis as had planned, however, he is going back in a couple of weeks to finish the challenge and complete the climb by traversing the largest mountain in the UK standing at 1,345m/4,413ft. From his home in Derbyshire, Fraser has travelled well over 2,000 miles. Fraser's marvellous efforts can still be sponsored through his sponsorship page:  
<https://www.justgiving.com/fundraising/nc500>  
trek



# Dementia Action Week



Marie delivered a live virtual lesson to 850 students at Trent College, Long Eaton, in Derbyshire where she talked about dementia, the power children and young people have in destigmatising dementia and the roles everyone can have in developing a better future for dementia. Marie also spoke about the work that the Alzheimer's Society does within Derbyshire and the purpose of Dementia Action Week. Much positive feedback was received from both staff and students, and the school are keen to make relationships with the Derbyshire team to recur the delivered lesson annually plus inviting us into school more frequently going forward.

Marie had some emails from Sixth Form students in the days that followed to say that they had really enjoyed the lesson and that it had sparked an interest in them to learn more about dementia and asking as to what they can do within their local community. Marie found it an encouraging sign of confidence in a changed landscape of dementia for the future by supporting a sustained relationship with these children who will be our future clinicians, policy makers and more roles besides. The success of the event has made Marie keen to facilitate further sessions with the school and schools in her area.

## Groups

In addition to the virtual groups offered, we are working towards the reintroduction of several face-to-face Dementia cafés across the Derbyshire area in late July. The dementia cafés will be based on the current Covid restriction, venue suitability and availability.

### Dementia Support Service

Face to face Dementia Support appointments are available for anyone wishing to have their support provided safely within their own home. Alternatively phone appointments will continue should this be the preferred option of support.

## Virtual Groups Dates and Times

### **Mondays**

Singing for the Brain

11.30am to 12.45pm

Memory Café

14:45 to 16:15

### **Tuesdays**

Wellbeing

10:30-11:30

Sessions alternate between 'Reading for Wellbeing' and 'Armchair Art Gallery'

### **Wednesdays**

Memory Café

9.45am to 11.00am

## Other News....

A patient & carer expert programme has been launched within the Derbyshire Healthcare NHS Foundation Trust where individuals with personal experience of memory impairment or caring for someone with dementia are being invited to be part of a teaching programme where medical students can improve their understanding of how it feels to be living with dementia through supervised interviews. Participants can be as involved with the programme as they wish to be. This innovation is headed by Tracey Barker and further details can be obtained by emailing: [tracey.barker1@nhs.net](mailto:tracey.barker1@nhs.net) or calling 01332 623937/ 623932

