

Downham Dementia Cafe

Interview with Jacqueline Westrop



The Project

Downham Dementia Café works to support people diagnosed with dementia and their caregivers in the small Norfolk town of Downham. It started off as a monthly café for people to meet and talk and this grew until they were providing four cafés a month before Covid. Meetings take place in the Methodist Church Hall. They were seeing up to 200 people a month before the pandemic, and were about to begin fundraising for an advocate to help with carers' assessments. They were also considering raising money for counsellors for the carers, due to the issues arising around grief and bereavement - the loss of the person that they once knew.

Impact of the pandemic

When the pandemic hit, it became clear that the cafés could no longer continue. Most of their members were highly vulnerable and shielding, so they had to switch to telephone support. Few were technically equipped or had the knowledge to manage online meetings, but they did manage to use Skype with some. So, the main impacts of the pandemic were social isolation and depression and, for many, there was a deterioration in people's dementia.

One of the key differences that she has seen as they come back to meeting people again, is that they have younger people diagnosed with dementia. They also have their first gay couple attending the café.

Side by Side Fund

At the time that they saw this announced, they had used up much of their funding and were struggling so it was good timing, an 'excellent opportunity'. The important thing was to see that we were doing 'good work with user-led organisations. For us in the dementia support association, that is critical'...

"...because at the end of the day, all our people are actually fitted into boxes, that is actually provided by statutory providers, and you know, you cannot manage care through ticking boxes. Basically, you can only manage care through understanding the individual."

She said that it was important to find an organisation that shared their values of equality and respect. She feels that some of the larger organisations 'leave people behind' through focusing their efforts on fundraising for a cure. They don't do the same level of face to face work locally.

The money is being used to kick-start the cafés. When they were allowed to meet in groups of six outside, they would bring together two couples with two volunteers to go out for afternoon tea. This might be about £10 for the tea and cakes. Then, when they were allowed back into the venue, some of the money was used for the rent of rooms. They have had four cafés so far; the first two were not well attended but the last one had 12 couples attend. Those in the morning have a subsidised lunch and those in the afternoon have a subsidised tea. They were planning a garden tea party for the bank holiday, with music from a dementia musician. The most frequently requested song is Lily the Pink!

Impact of the fund

The mental health of carers has also been affected by the social isolation; some people were in tears at being able to come out and meet people. There was sheer relief. It meant so much to them. They are running quite small groups at the moment, as there is still some nervousness amongst people about coming out. Some people are fearful and almost agoraphobic.

"It doesn't need huge amounts [of money] to kick-start something really, because we'd got to the stage where we had probably five pounds in our current account, we still had a little bit of money in reserves basically. So that, when we got the grant, it was 'Yes!' kind of thing, ring up the Methodist Hall, book the hall..."

She gave an example of a couple, a man with dementia and his wife who also emerged from lockdown with a diagnosis of dementia. She was the first one back to the café, and 'it was like the light switched on'. She hadn't talked to anyone for six months. She was suddenly in a place where she could talk.

"I can't overemphasise the fact that, as we've brought people back, the common factor is 'Thank God, I'm back. I can talk to people now. And that's the impact you're having basically.'"

Grant application process

It was straightforward, although there were a couple of glitches on the IT links. The person she spoke to on the phone, was a 'lovely person'; she found all her dealings with the organisation to be 'lovely'.

Ways NSUN could support groups

Interested to explore taking the advocacy work forward. The two things that interest her are the user voice - organisations that promote the user voice and advocacy. She feels that something good can be grown out of that. Her mantra for dementia is 'You can live well with dementia - but you have to live with it'. She gave an example of her uncle who continues to beat people at chess despite his dementia. Every individual experiences it differently.