

ASUME

Volunteering in Dementia



Impact on carer

Volunteers were often as much focused on supporting the carers as well as the person with dementia. This was a central theme from the findings. Many of the volunteers believed their volunteering had a positive impact on carers:

Just [for the people that attend the group] to have an enjoyable time, and particularly for the carers that come. I think they're just as important, in fact if not more so. (CVF13, Cumbria)

But it shows you this is where you can do as much as you can for the person with dementia, but it's the carer that's the one, that's the target, type of thing. (SVM01, Stirlingshire)

The impact on the carer was mostly described as providing them with the chance to take a break from having sole responsibility over the person with dementia. However, it was also described as a positive impact where interactions with the group could support the carer through their day and give them something to look forward too.

Some people come as couples, so they've got their own personalised carer if you like. But again having more people there means they can relax a little bit, you know. The responsible person in that partnership can relax and enjoy it, because they're well supported within the group. And I think the group is as important for the carer as it is for the person with dementia. (CVF16, Cumbria)

In Dancing Recall I think you're there and you're supporting the participant but you're also supporting the family. I think it's a release for them to come and offload a little bit on to you as a volunteer and also just maybe take the lead with sometimes it was the husband or the wife or a friend just to give them a break. Yes, so I think you're supporting the carer or the partner as much as the candidate (CVF02, Cumbria)

Certainly we've got some very eloquent carers who have said some excellent things about how the group helps them. One lady in particular who said at a forum that I was at recently, she said, how long the days are caring for someone with dementia which is something I can empathise with. She said, on Tuesdays and Wednesdays when we have the group I wake up in the morning and those days are not as long because there's something good in there and there's a time that I can focus on. (CVF03, Cumbria)

Furthermore, the impact and support received by the carer was linked to the idea that volunteers could create a 'safe space' for carers to relax in, free from judgement and stigma that can be experienced in the outside world.

Also I think for the carers, yes, they can talk about how they feel and they can talk about how they feel without being judged with each other and with you. I think it helps if they know you've been there a bit really because some of the things people think and feel they're maybe slightly ashamed of and I think they're happy to talk to you. So I think that's quite helpful. So I think it's about a 50/50 role really so I would say our use is we're there for as much for the carers as for the people with dementia. It's the same thing, really. (CVF03, Cumbria)

Importantly here, volunteering with those with dementia and the carers is clearly seen as a package, with CVF03 noting here that 'it's the same thing really'.

The view among many volunteers was that they were helping to share the load or to give carers a break. The activities themselves were also linked to the potential impact. Here it was not only having a break from caring responsibilities but also being able to participate in the activities being facilitated by volunteers.

I think it's just nice that they know there are other people there. 'Cause they have a lot on their plate. And just...I think for them, it's respite, you know, because singing...and a lot have had backgrounds [audio appears to distort]...so, but you can tell they're enjoying it as well and they can share the load, if you like, with others for that hour or whatnot. (CVF01, Cumbria)

The networks that are formed are particularly important, as noted by this carer:

So it just gives me a wee break, you know, it's good that way.....Yes, it takes a lot of pressure off of me, and it's good for [name] to get out with other folk, I think. You know, instead of just being together, the two of us, though. (SCM01, Stirlingshire)

The activities therefore provided respite, enjoyment and social links that would perhaps not have been available without volunteers. The impact that volunteers had on carers was also acknowledged by those with dementia. One carer's partner enjoyed attending group sessions and meeting up with other volunteers:

Jonah loves it. He loves it and I think that does him good being with [other carers and volunteers]...and the lasses, well, he's just one of them. (CDF07, Cumbria)

The impact on carers is not restricted to sharing the load allowing the carer some personal time. The interaction of the person with dementia with the volunteer can impact positively on the carer.

He was quite cognitively aware, but the part that had gone was his speech, and he could only say dance, [name] and something else. His daughter used to come with him..... He took a liking to me for some reason. His daughter said that I looked like her mum when she was younger.....and he came over and he was like dance, dance, dance, and then he was going like me, dance, and apparently that was the first time that he'd got up and done...and he was doing all this jiving and stuff. I couldn't keep up with him. But he was really jiving and his daughter was really happy to see him come out. (CVF09, Cumbria)



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