

A S U M E

Volunteering in Dementia



Challenges

In regards to the interactional element of volunteering, dealing with a person exhibiting aggression, bad temper or distress has proved the most commonly cited challenge among volunteers. Some volunteers learnt how to overcome such a challenge by observing staff and carers and how they calmed a situation. Similar to this is the challenge of knowing when to leave alone, perhaps due to the person's needs and disposition at the time. A key challenge that was mentioned was when someone would want to leave the group to go outside, which could present safety issues and be disruptive:

That combination of keeping people safe, trying to help them to calm down, at the same time, you know, addressing their distress in an appropriate way that helps them without saying, no you can't leave. 'Cause you're not allowed to do that. And why should you anyway, you know. And often it would be just a little walk round the village and then come back. And then probably five minutes later they'd want off again. That can be very [challenging]... what can happen then in the group is that other people will then start to get restless. (CVF04, Cumbria)

The challenges can vary by setting, for example between group and one-to-one sessions (e.g. in the home):

*R: When they're in a group [care home setting] it's very difficult. You've got to deal with them individually because of this... There's sex involved, there's jealousies. They're very private. They want you, and if you don't give them exactly 100 per cent, forget it.
I: So that's why you've not found those difficulties in the household level?
Because you've got them one to one?
R: You don't find that. No. (SVM01, Stirlingshire)*

There were also concerns that linked to the stigma that is attached to people living with dementia, or people acting differently in public places in general. Volunteers were concerned about possible responses from other people while out in public:

.....but if you're in a public place, you're aware that other people...that can be challenging. Other people. Because there's so little understanding about dementia that that can be quite challenging. (CVF04, Cumbria)

I think it might be [a challenge] if you're easily embarrassed in public by people who are constantly being repetitive and such, or who don't look quite sort of clean. (SVF02, Stirlingshire)

This was not a concern for themselves but for the people that they volunteered with. Many volunteers described the need to take people out to public places to give them some normalisation (e.g. going to a café, a walk, getting the newspaper) but were aware of the wider reaction to some of the behaviour of the person living with dementia. However, this did not generally intimidate volunteers as they saw it as a challenge worth fighting and felt it was one of their roles to tackle the stigma associated with those living with dementia. However, they often expressed the need for training to help them understand what to do best in these situations and to give them confidence.

The relationship between the family carer and person with dementia could also inhibit involvement or participation in activities. Carers could impact of dynamics of the relationship between the volunteer and the person with dementia:

I think when you take the carer away it's amazing how much more you can sometimes get out of the people, how much more involvement and participation and how they will interact socially with each other without that extra person which I think can be really good. (CVF03, Cumbria)

A challenge for some volunteers was finding something that interested the people they volunteered with. Related to this was a difficulty in developing a connection with the person with dementia. An issue highlighted by a volunteer was a care home bringing residents to a dance activity. It was clear that some of the residents had not been asked if they wanted to go to the activity and the volunteer felt bad about perhaps pushing them too much to get involved in the dancing activity. A further issue raised by one volunteer was that she was being asked to engage in an activity with a person with dementia whose condition had deteriorated to a state that they felt the activity was not appropriate.

The challenges around family members disagreeing on how much involvement their relative is capable of, or how they should be treated was also raised.

However, for some volunteers there had been fewer challenges than they had expected. Volunteering has been much more straightforward than anticipated and one volunteer suggested it was important at the outset to let go of pre-conceived ideas and anxieties {CVF02}.

I think that during my time I didn't come across any, like, big challenges. I think that there are obviously if I was working, like, day and day out, like, for example like my mum does, she will experience a lot more, but no from volunteering yes there wasn't as much. (SVM03, Stirlingshire)

On a personal level, volunteers also had internal challenges to overcome. The need for a volunteer to overcome their own wariness/shyness, particularly in a group setting or activity was a common challenge:

I have mentioned on Tuesdays there is the dancing, I find that fairly awkward. But, you have got to throw yourself into it. So, it is, sort of, activities that...the difficulties and challenges I think are activity centred. (CVM01, Cumbria)

Like the Christmas party I got asked to help with that and I'm not really an outgoing person so I feel that's a bit stressful for me but I get over myself and do it eventually. It's a bit stressful but that's the only part I worry about is trying to keep everybody happy and doing the right thing. (SVF07, Stirlingshire)

A lack of support when starting out volunteering was a rare issue but volunteers emphasised the importance of having that formal support.



For more information visit www.asume.co.uk or contact Dr Vikki McCall, Principal Investigator of the project vikki.mccall@stir.ac.uk / [@vikki_mccall](https://twitter.com/vikki_mccall)