

# A S U M E

## Volunteering in Dementia



### Home

The comparison of the housing setting was one of the driving interests of this project and we talked to those people who had dementia who resided independently in their home, in care homes, and extra care settings. The setting of the volunteering activity did affect the experience and had an impact on those volunteering and those living with dementia.

*Here we are in a totally different setting, they're not in their own home, and I thought, wow. I mean, it was a wonderful care home, absolutely wonderful, and they looked very happy, but it's a difference (CVF08, Cumbria).*

One to one volunteering activity was much more likely to be conducted in a home-setting with those living independently.

*Well it would be and certainly one of the ladies whom I take out to lunch, for about a year I used to go on a Monday to her house. She now lives in a home. I'd take my own lunch because she didn't eat her lunch. The carers came in and made her a disgusting looking ham sandwich - a horrible looking thing - and so in order to get her to eat at least on a Monday I'd pop in and we'd have lunch together; I'd eat mine and she'd eat hers, so that would be a household thing (CVF10, Cumbria).*

Volunteers often reported very positive outcomes in relation to home settings, where they generally had more freedom to shape the activities and interactions with those they visited. They often described it as rewarding. The qualitative and networking data also show and emphasize the ability of volunteers to move between settings. Often volunteers would follow the person they volunteered with if they moved to another setting e.g. from home to care home.

A caveat to the positivity around home-settings was the reticence and protectiveness of respondents to their home setting. Those that we spoke to that were accessed through housing associations (i.e. not connected to a volunteer organisation) were much more likely to report limited involvement with volunteers. When asked if they would like involvement of volunteers there was hesitation in regards to people coming into their home setting. There was a link between volunteers and institutional interference. Therefore the home-setting of volunteer activity was both an opportunity but also a key risk that had to be managed sensitively. There was clearly scope for more links to those living at home, but this would have to be done sympathetically without challenging independence.

There were some good practice elements seen from the housing associations in some of these cases. In one situation, the person living with dementia and their carer lived two minutes away from each other. When the mother had been diagnosed with dementia the housing association had been able to move her closer to her family network, increasing her ability to live independently for much longer due to the family network. However, there was very little feedback from housing associations in the organisational survey, which shows there may be scope for housing associations to link to volunteers to support their tenants in this area.

Volunteers were less likely to talk about care home settings as 'home'. There were certain perceptions that were linked to care homes in particular, and some organisations in the survey had pointed out this affected recruitment in this area:

*Q: In your experience, what are the key challenges in recruiting people to volunteer in dementia-related activities?  
A: Retention, and with older volunteers it's the stereotype 'bad' care home and fear of dementia (Organisational survey)*

Therefore, the survey noted that although home-settings and community settings together are more prevalent in regards to volunteering activity settings, the perceptions and stigma attached to care homes is still a clear element that affects volunteer's perceptions in the area of dementia care.

*And also I visited a lot of care homes where people sat around. You'll have seen them, you know. And you, kind of...you know, I'm getting older myself. I'm 67 and I think, Jesus Christ, I don't want to end up like that. You know, so there wasn't a lot of choices for people, I didn't feel. To end up sat in a circle and there are lots of people with dementia, you know...and quite horrendous really. So that was always with me. (CVF04, Cumbria)*

Volunteers liked a one to one home-setting because it gave them freedom of choice over their support for those with dementia, which they felt was more constrained in a care home setting. Some volunteers noted that the professional staff were a key element in encouraging volunteering activities or dissuading them:

*Maybe people think there isn't as much of a need in residential homes because you've got professional staff but I think those professional staff are only individuals at the end of the day with their own insecurities about things. it's quite a...it's in front of people if you're not comfortable with that whereas I think if you come voluntarily to a group you're there willingly and more likely to engage whereas the residents in the residential home obviously were keen to engage but you can't just assume that the staff are. (CV02, Cumbria)*

The findings suggest that if staff are involved in the volunteering activity it can have more successful impacts for residents. Therefore there is also scope for reassessing volunteer activities and recruitment in home settings as the impact we saw earlier was very positive in this setting as well.



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