

# Volunteering for the Research Network

Barbara Woodward-Carlton, [Research Network](#) volunteer Yorkshire area, comments on her experience of volunteering for the [Research Network](#) and participating in [Alzheimer's Society's Research programme](#).

## Who can become a Research Network volunteer

In 1999 a small notice appeared in the Alzheimer's Society's newsletter asking that readers consider joining a group to be known as [Quality Research in Dementia \(QRD\)](#) [now known as the [Research Network](#)].

One had either to have [dementia](#), or be a [carer](#) or ex-carer of someone with [dementia](#). As I had looked after my mother who had had [Alzheimer's disease](#) I felt I qualified, particularly as those interested were assured that they did not need specialised knowledge, to be scientifically trained, or to know how to use a computer. Their knowledge and experience of living with the illness or of looking after someone with the illness were what mattered, and still matter. The [Research Network](#) aimed to harness the expertise of the researchers with the expertise of the patients and carers. I duly applied to join and began a journey which has been truly fascinating'

## The work of a Research Network volunteer

'I began the journey by attending two training days which were helpful and interesting. Thereafter, roughly each month I receive a pack of six to eight grant applications, with lay summaries, which I read, consider, grade and comment on. I really appreciate being able



to comment on the projects knowing that all my comments are sent back to the applicants and thus they will always get the carer's perspective. I also appreciate having several weeks to complete the applications!

## **Monitoring dementia research**

'Volunteers are often invited to have further involvement with the [Research Network](#) and so it was I became a monitor on the FITS research project: '[Can enhanced care reduce the severity of behavioural symptoms, improve quality of life and reduce the need for sedative medication in people with severe dementia?](#)' Meetings between the researchers and the monitors took place roughly every six months, sometimes in London and sometimes in Oxford, and were purposeful and friendly. I gained insight into the work of the researchers and an appreciation of the difficulties they faced. They, in their turn, gained an appreciation of what we had to offer a research project. When the results of the trial came through we were all so excited; new ways of providing training and care had been proven to work.'

## **Sitting on Grant Panels**

'Sitting on a grant panel is another process in which [Research Network](#) volunteers can take part. These comprise three consumers together with three experts in the aspects of [dementia](#) relevant to the applicants. There are usually up to six applicants over the course of a day. Each makes a short presentation followed by questions. Again, it's a case of using your common sense while leaving the technical points to be assessed by the experts. But it's a thoroughly worthwhile way of deciding the best recipients for the Alzheimer's Society's all-too-scarce funding for research.'

## **Why join the Research Network?**

'I little expected when I originally asked for more information about the [Research Network](#) how involved I would become, nor how the journey would develop. I am constantly impressed by the quality of the work done by researchers, by their dedication and their passion to make life better for people with [dementia](#) and their carers; likewise by the knowledge, passion and commitment of [Research Network](#) volunteers. It has been a joy to be involved with a group like the [Research Network](#) and to know that finding the cause(s), and finding a cure or cures is nearer and that for many good quality care is already a reality.'

Alzheimer's Society National Dementia Helpline

England, Wales and Northern Ireland: 0300 222 11 22

9.00am-5.00pm Monday-Friday

10.00am-4.00pm Saturday-Sunday

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