

Living well with dementia – a personal experience

It took quite a while for me to realise something was “not right”. It was only when my partner commented that I had done a few “odd things” (such as putting the teapot in the fridge; buying something that I had just bought; forgetting meetings) that I decided to find out more.

I went to see my GP about having a flu jab and mentioned these events to her. She arranged for me to have a brain scan and some blood tests. It took a few months to get an appointment for a scan and then a few more weeks to get invited for a consultation.

I was shown my scan and could see where there was some damage. This damage was the result of a “mini-stroke”. My husband was also consulted and three weeks later I received my diagnosis – the early stages of dementia.

After much consultation and discussion (and much thought by me) the conclusion was that my dementia is possibly linked to the fact that I have Raynauds Disease. With Raynaud's disease, smaller arteries that supply blood to your skin narrow, limiting blood circulation to affected areas. Raynaud's syndrome can be a symptom of an underlying health problem. The ‘link’ to vascular dementia is most likely due to chronic cardiovascular (circulatory) problems that cause impaired blood flow. I have been conscious of this potential link, as my mother and most of her sisters all had the same problem and developed dementia in their late 60s/early 70s.

After my diagnosis I was referred by my GP to the Warneford Hospital, where I and my husband spent a day as part of the European Prevention of Alzheimer's Dementia research project (EPAD)*. This was very interesting and helpful. The consultant spoke to me about what to expect after my diagnosis and he also spoke separately to my husband about how he was feeling.

I have joined the Dementia Friendly Charlbury (DFC) group to which I can contribute my personal experience of dementia and pick up information from other members with experience and knowledge to share. I enjoyed the SMILE sessions provided by Clare Carswell and Rhonda Riachi.

I am still cooking, cleaning and gardening and looking after my allotment. I try to do as much as I can and keep active.

I have neighbours who also have memory and thinking problems and we get together and have a laugh. I am also very lucky to have supportive friends from church and the Charlbury community.

I think it is better to tell people I am having a “senior moment”, if I forget them. It's better to be open and I am happy to contribute whenever I can.

Now I have had my diagnosis, at least I know what is happening and can organise my life to make the best of what the future holds for me. I and my husband also now know where we can get help and support – both medical and practical. I am glad I “took the plunge”.

Written by a DFC member

*EPAD is an inter-disciplinary research project involving public and private sector organisations across Europe. Together they are working towards understanding more about Alzheimer's Dementia and what can be done to prevent and treat it.

DFC Notes:

Sources of support for people with dementia and their carers

Dementia Oxfordshire - Helpline 01865 410210, www.dementiaoxfordshire.org.uk.

Carers Oxfordshire – Helpline 0345 050 7666, www.carersoxfordshire.org.uk

Dementia UK – Helpline 0800 888 6788, www.dementiauk.org

Alzheimer's Society – Helpline 0300 222 1122, www.alzheimers.org.uk

Oxford Dementia and Ageing Research (www.oxdare.ox.ac.uk)

Anyone who is interested in finding out more about dementia and ageing research in Oxford can become a Friend of OxDARE. Friends can choose to receive quarterly newsletters and/or register an interest in taking part in future studies. When new studies get underway, OxDARE researchers will notify Friends by email and invite them to take part. For further information, see the OxDARE website.

Dementia Friendly Charlbury (DFC)

DFC is a local group whose vision is for residents, businesses and organisations in Charlbury who are supportive to people with memory and thinking problems, so that people, families and carers who are affected are able to live well in our town. Contact us on charlburydf@gmail.com or phone 810192