

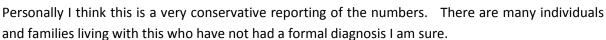
Before I forget

The Dementia Awareness Project

Many community areas and Area Boards across the county signed up to become dementia aware at the last round of "What matters to you" planning events. Most recently, some have set up dementia aware working groups

using Wiltshire Councils <u>Your community dementia tool kit</u> and the Before I forget newsletter.

Why does it matter? There are currently 6,512 people living with dementia predicted to grow by almost 30% by 2020 – (source Wiltshire Councils community dementia toolkit).

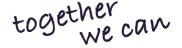


We all know someone who is living with this debilitating disease and it effects more than just the person living with it. With this in mind our communities are being encouraged to become more dementia aware. But what does that mean? The word "aware" can translate to being alert, mindful, attentive, responsive or conscious of. All of these are relevant. How many of us have been behind someone elderly in a queue at a shop or bank, who seemed a little confused or forgetful? How did you respond? Were you frustrated at being held up? Or did you move forward to reassure and support? And bear in mind this disease targets younger people too.

I am reminded of a tagline "one small thing" can make such a difference. So if your "one small thing" is being more patient in that situation, then make it a personal pledge. You never know 20 or 50 years from now it could be you learning to live with dementia!

I will not regurgitate more of the aims and objectives from the tool kit here, nor will I repeat the information about clubs and support groups. As for working with surgeries and advisors, well let's just say that staff numbers are low and time is precious so don't expect too much, however responses differ greatly across the county. So one of the things you could do is visit each surgery in your area and see what information they have in response to initial enquires. Give constructive feedback and work together to improve the offer if necessary.

Another area is providing local businesses with useful information to help train staff. It could be a showing of the <u>Wiltshire Voices</u> Film which is 25 minutes long or The film "<u>A day to remember</u>" made by the NHS which is much shorter at just over 3 minutes. I also found this one from the BBC in 2005, "<u>Living by post it note</u>" which is interesting and 55 minutes. Use these to encourage and inform staff, friends and relations to attend a <u>Dementia Friends</u> workshop or to become a <u>Dementia Friends Champion</u> and learn how to deliver the workshops. The <u>Altzhiemers</u> website has lots of information about becoming a dementia friendly community. Just to prove social media has its uses, Colin Parish tweeted this to me "Something you don't see every day - a song/animation about dementia by Massive Dog. When You Were Superman. Please RT. <u>youtu.be/-p7kgXAC2w0</u>". Really great way to reach out to young people.



What I find most frustrating when I ask the question about what information and resources available, is the number of times the standard response is "we signpost people on to..." in response to a query. Signpost to what? What are the outcomes? Do people become disengaged before they reach the "destination"?

At our group we are reminded that there are many forms of dementia. It affects all ages. It affects the wider family, friends and carers. What information and resources are readily available to give real help? How easy is it to access an art group or memory club?

So *resources*: <u>Wiltshire Council</u> has a page that covers fact sheets in libraries to carer training for friends and family, e-learning and the SCIE Open Dementia e-learning Programme is aimed at anyone who comes into contact with someone with dementia and provides a general introduction to the disease and the experience of living with dementia. It is worth a visit.

Many living with dementia remember the past much more easily. Memory books are one way to engage that involves the person living with dementia. From the Alzheimer's Forum there is this <u>link</u> about them I also found a link to the <u>Activities to Share</u> website that sells the books ready to use and has other ideas for engaging activities. Have a browse as there are ideas for different senses and levels of motor skills. The Dementia UK website also has information on <u>Life Story Books</u> and a free MS Word template to download (copyright is with Dementia UK). It looks easy to use for the computer savvy, alternatively printed off as hard copy to complete, it is 15 pages long.

During my browsing I also came across "<u>Blue Sky White Clouds</u>" a book for memory challenged adults. The link takes you to Amazon for the blurb. I don't advocate buying from Amazon but it you look at the "customers also bought" section there are other similar books to browse. You could also have a look at <u>enjoy-able living</u> which is another website selling user-friendly activities for those with memory issues. Please note I am not recommending these sites only making you aware of them to give you some ideas.

Finally there is another project that links into being dementia aware. The "<u>Safe Places</u>" project aims to identify locations within a town or village where vulnerable people can seek help if they are feeling overwhelmed and need a little help. The link will take you to details about this project.

Aggression — whilst most campaigns focus on those living with dementia as being confused but calm there are others who become loud and/or aggressive as the disease progresses. It seems almost taboo to speak about these instances but I will do so here if only to reassure anyone looking after a loved one who exhibits this behaviour that they are not alone. "Mid-to-late stage dementia and Alzheimer's patients often present challenging behaviour problems for their caregivers. The anger, sadness, paranoia, confusion and fear they're experiencing can result in oppositional, aggressive and sometimes violent speech or actions." (source http://www.aplaceformom.com/blog/2013-02-08-dealing-with-dementia-behavior/) The Alzhiemers Society has information and advice on dealing with dementia and aggressive behaviour.

The Care Act 2014. The Act strengthens the rights and recognition of carers in the social care system, including, for the first time, giving carers a clear right to receive services. These are by far the strongest rights for carers yet. More information and support for carers at CarersUK.

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Other websites:

Age UK has a section on dementia with links to other resources

Alzheimer's

Alzheimers Wiltshire for Wiltshire based support

<u>Dementia.com</u> aims to provide patients with dementia, their carers and family members with helpful resources and information.

At Dementia information about assistive technology

<u>Culture Dementia UK</u> previously known as Friends of African/Caribbean Carers and Sufferers of Dementia (FACCSD).

The <u>Day Clock</u> is designed for use in Care Homes by <u>Designability</u> a charity that research and design assistive technologies. They have also just launched the <u>analogue one button radio</u>. They already have one button digital radios and <u>The Wander Reminder</u>. The Wander reminder system uses personalised messages to help people with dementia maintain their daily routine. A familiar voice message can remind people with memory problems not to go out of their homes at inappropriate times of the day.

Dementia UK

Dementia OK offer advice around the needs of people with dementia, their care givers and families.

<u>Health Talk</u> is a charity website that shares people's experiences of caring for those living with dementia.

Innovations in Dementia a Community Interest Company

NHS Choices

Telephones for living with dementia – there are several models such as <u>Ownfone</u> or the Photophone and other assistive technology from <u>AlzProducts</u>

UCL Dementia Research Centre

<u>Young dementia UK</u> is the first national source of information and support to focus specifically on young onset dementia; created with and for younger people, families, friends and supporters.

<u>SCIE Dementia Gateway</u> a website is for anyone who wants to understand dementia better: what it is, what it means for daily life, and what we can do to better support those living with dementia, including family and friends.

Talking Products for independent living

<u>The Dementia Action Alliance</u> is a movement with one simple aim: to bring about a society-wide response to dementia. It encourages and supports communities and organisations across England to

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take practical actions to enable people to live well with dementia and reduce the risk of intervention.

<u>The Reader Organisation</u> – for reading clubs

WSUN – for Memory Clubs

BBC has programs on Living with dementia such as – Oct 13th 7-30pm -

http://www.bbc.co.uk/programmes/b04lcrg8 and the

http://www.bbc.co.uk/blogs/5live/posts/Diagnosed-with-dementia-when-young blog post

