

Local MP learns about effects of early onset dementia

Most people consider dementia – of which Alzheimer’s is probably the most widely known variety – as something that people suffer from almost exclusively in old age. The recent Alzheimer’s Society Awareness Week (3 – 9 July) sought to highlight that many younger people have Early Onset Alzheimer’s. As part of the Awareness Week’s happenings, on 5 July a Parliamentary Tea was held in Westminster, so MPs could meet and learn at first hand the experiences of those struggling to care for younger relatives and partners. The Tea was so well attended by carers that larger rooms than had been planned needed to be used.

Local Member of Parliament Rt. Hon. James Arbuthnot was unable to attend the Tea, but instead offered to visit Bruce Bovill, who lives in Grayshott, to learn about his experiences caring for Jan, his wife of 37 years.

The couple had lived in Grayshott since 1986, and Jan had been involved in amateur dramatics with CADS (Churt Amateur Dramatic Society) and Grayshott Stagers, as well as playing organ at St. John the Evangelist in Churt. Jan is a younger sufferer of dementia, originally showing symptoms aged 50, and now living in a specialist care home, aged 64.



Bruce Bovill and Rt. Hon. James Arbuthnot

The Alzheimer’s Society estimates there are over 18,000 people with an early onset dementia. Even gaining a diagnosis is difficult because Alzheimer’s is usually the last thing doctors consider when a younger patient visits them. Mr Arbuthnot learned that it took eight years and eight hospitals with even more consultants for a firm diagnosis to be made for Jan Bovill, and by then it was only a further three years before her condition was so severe there was no alternative to her being moved to a care home – after being cared for at home by her husband for the previous ten years as the condition progressed.

Bruce explained how difficult it has been for families to receive help as the majority of care services concentrate on the older sufferers. There is little specialist support, including day centres, respite care and care homes. Although there have been service improvements in the past ten years, they are still very patchy across the country. Because of her advanced and challenging condition, Jan lives in a specialist care home in Basingstoke. Losing a wife of any age to dementia and a care home – even one as excellent as the one Jan is at – is dreadful at any age, but when they are young it falls particularly hard.



Jan Bovill at the time her symptoms began

It is a fact of life that one of a younger couple may be in employment when diagnosed, and the other is increasingly likely also to be employed. This means that when caring for a partner, both jobs may be lost, causing the mortgage and thus the family home to be placed in jeopardy. Bruce was fortunate to have been employed by a software company, SAS, that gave him immense leeway in balancing working with his caring role, but even so ultimately he had to stop work.

Where children are involved, there will be additional immense pressures on the partner who is in a caring role, as well as on the children themselves and on the sufferer.

An Alzheimer's patient generally suffers a relatively slow decline, though other dementias are stroke induced and have a different, more stepped pattern. Jan has a combination of dementias that makes life and her future even more difficult to predict. Where a person has Alzheimer's at a young age, it is possible for them to decline over as many as twenty years, many of those years being at an advanced stage.

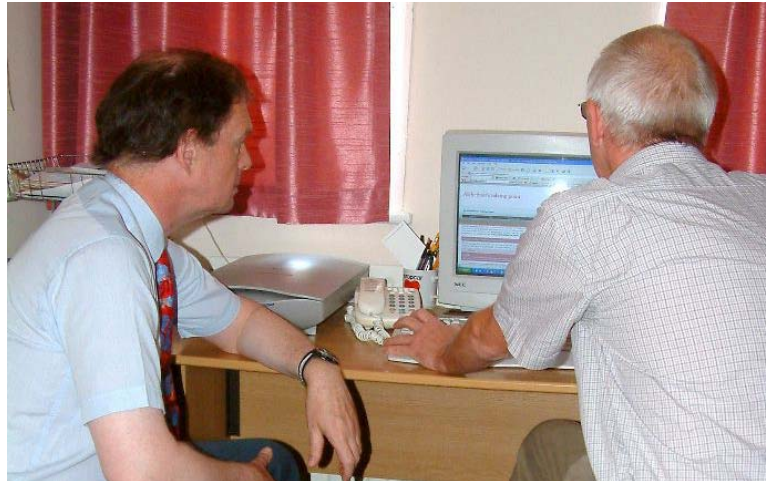
The dementia medications can extend the period when the dementia is less disabling, though NICE (National Institute for Clinical Excellence) recently put cost before benefit in recommending withdrawing medications that enable many people with dementia – and their carers - to keep going.

Mr Arbuthnot was particularly concerned to understand the situation from a carer's perspective. The stresses of caring for a close relative who has dementia are huge, impacting both on a carer's physical and mental health, and of course on their present and a future that is interlinked with that of someone in slow but terminal decline. Very often family and friends drift away, unable to cope even at a distance. One of the most challenging facets is that the person with dementia will, at some stage, cease to recognise their partner.

This may leave a carer very isolated, and one way that the Alzheimer's Society has sought to help in this respect is to host an Internet Web Forum called Talking Point (TP). TP is primarily a means for carers to talk to other carers and it has over 1,100 members. The ability to speak to others in the same position and to have advice from people who have been through the same experiences has often been a life-saver. TP has members of all ages and with experience of almost every angle of dementia. Often the most critical discussions take place

after midnight, often the only time the carer has a few moments to themselves to talk to others in the same boat.

Bruce says "TP has kept me going on many occasions, and it helps me to try and help others. I know this is also the case for many other members."



Rt. Hon. James Arbuthnot learning about "Talking Point"

At present, Jan cannot walk and is losing the ability to crawl, she is registered blind and her speech is gone. Despite this, Bruce sees her smile as he visits her most days, and crawls with her. He is unsure whether or not she knows who he is.

On leaving, Mr Arbuthnot said "I was grateful to Bruce for explaining to me in such a personal and effective way exactly how dementia can take over the lives not just of those who suffer from it but also their carers and others close to them. He took me through the onset of dementia in Jan's early 50s and the way it had progressed to its very advanced stage today. In an odd way I found it uplifting - the story of the battle of a couple against overwhelming odds - but also immensely moving."

This may seem bizarre to anyone who has not been touched by dementia in some way, but having a dearly loved one suffer with dementia, and caring for them, seems to bring out hidden strengths in both. As the Alzheimer's Spring campaign said, "Love Is Forever".

Bruce says "Politicians tend to get a very critical press and it was refreshing to meet Mr Arbuthnot and see his real interest. I think we both learned something today."

Alzheimer's Society web site: <http://www.alzheimers.org.uk>

Talking Point: <http://www.alzheimers.org.uk/talkingpoint/discuss>