

Alzheimer's Disease: a personal journey



There is little worse than someone telling you that they know what it's like to be in your shoes, when you know they have no idea at all. On the other hand, finding someone who genuinely understands is like discovering lost treasure. This is how I have felt on the journey I have taken since my wife started to show signs that she was no longer coping mentally. We have no children and no other relatives live nearby. I felt on my own, and my GP, though sympathetic, was unable to offer any support at that stage.

Over the following months, I watched the symptoms get worse, but still there was little help. When tested she showed only marginal signs of dementia. She is an intelligent woman, capable of covering up her weaknesses. What I needed to know, apart from confirming my fears, was how her condition was going to impact on me and on the Christian ministry in which I am engaged. My wife is, of course, my first concern, but there are many others that depend upon me. But there were no signposts that I could find, and I felt isolated.

Dementia often affects moods and sometimes the ability to comprehend relationships. This is not the same as not recognising someone you should know (often a sad consequence of advanced dementia); it is about understanding why they are in your life. I could no longer take for granted that this was my wife with whom I shared a life of love. In many ways, my wife had disappeared, and I have had to learn how to develop and sustain a loving relationship with this changed and changing woman.

More than a year after the first signs she was referred to a memory clinic and given a brain scan. She has now been diagnosed with Alzheimer's Disease. For over 40 years I have had the blessing of a wife who was truly the perfect help to me and to my ministry. Now that help has gone. Sometimes even the simplest of administrative tasks, such as putting items into envelopes is too confusing. The person who has been such a wonderful help now needs help, but does not always realise it.

I am slowly discovering the various resources that are available to carers, but all these have to be sought. It would be wonderful if GPs had packs they could hand out with all the information, or some other single source of information was available. Through the Alzheimer's Society I have discovered a monthly support group. I could have wept through the first meeting as the sense of isolation was lifted. I found myself surrounded by fifteen other men and women who *genuinely* understood my isolation. Together we shared our experiences, with those further down the road offering encouragement to those of us just learning.

But although we are now finding some support, watching the woman I love slowly vanish out of my life is painful and makes me feel lonely. Some days we can laugh and enjoy things together, but other days are just a mess as the reality that is in her mind collides with the reality of what might be called normal life. When my wife's condition makes her feel that no one understands her – especially me, and I cannot get through – we are both left feeling isolated and lonely. I can speak kindly, and perhaps she will let me give her a hug or kiss. I hope somehow that will touch her soul. Then I retreat into writing my private blog, as it seems that this outlet and my time with God are the only places I feel free to share how I really feel.

Anonymous