

Jennifer Bute recounts her experiences as a GP with early-onset Alzheimer's

DEMENTIA

A GLORIOUS OPPORTUNITY

key points

After a brief family history, the author describes how the first symptoms of early-onset Alzheimer's went undiagnosed and instead spurred her to find coping strategies for her developing cognitive problems.

After a number of decisive events the decision was taken to retire on safety grounds and plans to work overseas in retirement also had to be abandoned. But instead of prompting resentful antipathy towards God, the illness was accepted as a God-given opportunity.

Accepting dementia as God's gift led the author to help people understand what sufferers are going through. Resources have been developed to help GPs, church workers, family members and friends learn about the condition and treat sufferers with respect.

When I was asked to write about how my dementia affected my relationship with the Lord, my first reaction was to say it was the other way round!

I had a wonderful, godly father who brought me up to question everything and think outside the box. My mother died (from a coronary) when I was four and my father did a brilliant job bringing up four girls for the next ten years, until he married again. He taught me so much by the way he dealt with life's adverse events. Often I thought his suffering was allowed for our benefit so that we could learn, from him, how to handle such trials. I learnt from a child that I could live each day in God's strength and each choice to involve God made the next choice to turn to him, easier.

I qualified from Barts in 1968 having spent four months at Nqutu (Zululand) as a student, under the amazing Anthony Barker. After house jobs in medicine, geriatrics, surgery, paediatrics and obstetrics, and with lots of practical experience, I returned to Zululand where I worked at Mseleni Mission Hospital (with Africa Evangelical Fellowship). I had told God I was not prepared to be alone in charge of a mission hospital but it is always unwise to say that kind of thing as God has

a habit of making us face our 'refusals' to prove his great grace and power. I learnt so much there about the tremendous power of prayer. I came back and married Stanley whom I had met when he was head student at All Nations (my father was the Principal). We had three children and when they were all at school I entered General Practice where I worked for 25 years. My father had vascular dementia but he still knew who God was and could still pray fervently even when he no longer knew who I was.

Ways of coping

I had inherited familial hypercholesterolemia but had declined to take Simvastatin because of side effects, and I suspect the build up of cholesterol (13.6) was the cause of my transient ischaemic attack (TIA) in 2004. My GP sent me to the TIA clinic but I did not stop working (one didn't). However I noticed that I got seriously lost when visiting patients, so I bought a Satnav.

In January 2005 I had an odd experience whilst shopping suddenly being completely confused, unable to talk or pack the shopping into bags at the check-out. I was referred to a neurologist who told me, before I even sat down, that there was nothing the matter with me medically. I felt humiliated.

So I just determined to find better ways of coping. Stanley was good at practical solutions; I set up checks on my computer to ensure I was always safe and when greeted enthusiastically by people I thought I did not know, I just responded in kind.

I had a defining moment when chairing a mental health conference at work. I kept asking who everyone was, although they assured me they had known me for 20 years. I realised something really was the matter, and after collapsing on a long haul flight and needing to be met by a resuscitation team on touchdown, I reluctantly agreed to be referred to another neurologist and my cardiologist. Tests including a two-day session with the neuropsychologist who told me my intelligence enabled me to cover up and find unusual ways of solving problems. She could not say if I was, or would continue to be, safe working. I could not consider anything less than my previous high standards so I resigned, much to everyone's surprise as no one had any idea of the extent of my cover up. I was asked to continue doing appraisals although Stanley had to drive me as I could no longer find my way but could function perfectly well once there.

Definite diagnosis

It wasn't until May 2009 when the neuropsychology professor told me I needed to see Peter Garrard that I had a definite diagnosis of early-onset Alzheimer's. Stanley and I had thought of serving God together in Africa once I retired; he had been working with Tearfund's Disaster Relief Team around the world. In 2001 I returned to Mseleni after 30 years, for a sabbatical. I found it extremely difficult as I often felt out of my depth with the responsibilities and demands and had to live each day in his strength. I was the only doctor in outpatients/casualty seeing hundreds of patients every day. I was really surprised at the way God used the situation to honour him. When I received the diagnosis of Alzheimer's, we realised that neither of us could return to Africa, although I had realised for several years that I had some form of dementia. We both believed that it is not what we do for God but how we walk with him – our heart's attitude – that matters. So I said 'Well Lord here I am with Alzheimer's; I accept this unexpected gift from you. I'll see what you can do with it!'

I had learnt when Stanley was away for months at a time over the previous decade, that God's present for me was Stanley's absence (even if an unwanted present!) and from Paul's epistles that if we accepted God's gifts with both hands (ie enthusiastically) he could show his glory; he had certainly done that during those years. So it was not hard to respond positively to a more permanent 'present' of dementia. Nothing is wasted in God's economy.

Medication has made a tremendous difference to me. Most significantly it has abolished my awful olfactory hallucinations. It has enabled me to regain coherent speech, but reading is still hard. I used to speed-read and I find trying to read each word

separately, which means nothing without a context, too exhausting. Each new difficulty is a challenge as I seek new coping mechanisms I have also written several leaflets for family and friends. My first was adopted by the Wessex faculty RCGP for adaptation by any GP. There are so many things I know now that I wish I had known when a GP.

Church attitudes

I was amazed at my church's attitude to people with dementia, which indicated they did not understand many basic principles. I thought I could not bear to be treated like that when I became worse, so I persuaded my church to let me give a talk to the pastoral and staff team. This was so well received that I was asked to have it recorded and my son set up a website where folk could watch it and download my leaflets, which they could adapt for their own use.¹ I have been encouraged as several churches have adopted the visiting suggestions. I feel passionately that people with dementia should be as important to churches as anyone else; God sees us complete in Christ. We are all valuable members of his body. One Sunday a friend passed me a note in church (I had said to her I was unravelling and it was a challenge). She said her grandmother only unravelled things to make them more relevantly useful! This was a great encouragement to me!

We moved in April 2011 to Sandford Station, a place with on-site dementia care with brilliant staff and facilities. Stanley died quite unexpectedly four months after we arrived, just a week after my article was published in the BMJ.² He had always been my editor and supporter.

I have been so aware of God's hand of care and loving timing through this change. I am so glad that I live here as I am able to gain so much from talking with other people and their carers, listening to their stories, encouraging them and helping them understand some of their behaviours. I have had opportunities to do staff training locally also speaking to various groups of carers further afield at conferences on dementia. I am amazed how things have progressed as I also respond to questions and concerns through my website from folk around the world. I consider it a privilege. Each is an opportunity to share what I have learnt within the certainty of knowing God's love and acceptance as I am.

Jennifer Bute is a retired GP in Somerset



God has a habit of making us face our 'refusals' to prove his great grace and power

references

1. See www.gloriousopportunity.org
2. Bute J. A Patient's Journey: Dementia with cardiac problems. *BMJ* 2011;343:d4278 bit.ly/A44eID