

Review

Lucy Whitman, *People with Dementia Speak Out*. London, Jessica Kingsley, 2016, 297 pp. (Pbk). ISBN: 978-1-84905-2-900. £14.99.

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It was refreshing to read a book which is written by someone who has been a carer but doesn't seem to have had professional experience of people with dementia. Whitman claims that she has concentrated on younger people with early onset dementia but whereas there are some very inspiring stories from younger people, there are a fair few older people's (over 65) stories. This book is indeed a collection of people's stories which Whitman hoped would be people's own accounts, some with help from family or friends. However, she points out that this proved impossible and that two-thirds were interviewed by herself and that very few were written by people with dementia independently.

Some aspects of the contributors were truly inspirational, particularly those who had been diagnosed with early onset dementia. Graham, diagnosed aged 49, developed a whole new *raison d'être* in public speaking for the Alzheimer's Society. Jennifer, a doctor before diagnosis at 59, feels that "my dementia is a gift and I'm going to use it to educate other doctors" (p.66). Ross, diagnosed at 51, was truly amazing. He was a roofer who developed epilepsy with vascular dementia, and for the first time in his life began to speak in public about his experiences, first in Scotland and England, then at Alzheimer's Disease International Conferences in Istanbul and Singapore.

Most contributors stressed the support of family and friends. Some are aware of the stress placed on immediate carers. Lazarus, with early onset dementia, feels that as a consequence of this he lost his job, income, and when his marriage broke up, his home. He became a full-time residential student at Ruskin College, Oxford. He describes himself as a "fully paid-up member of the dementia resistance movement" (p. 184). Edmund also lost his job and became divorced from his wife; he decided "you can't go back. The place isn't there for you anymore" (p. 207). He put his energies into the

Scottish Dementia Working Group and, as Chair, helped to put together the National Dementia Strategy for Scotland and the Charter of Rights for People with Dementia and their Carers. He was awarded an MBE in 2011 for “Services to people with dementia in Scotland”.

The book covers people across cultures (Italian, Cypriot, Jamaican, Austrian (who fled to England on the Kindertransport) to name a few, alongside British people. It covers all walks of life: people who worked with their hands, drivers, people who worked in the arts and theatre. There seems to be a preponderance from the health professions: two GPs, three nurses, a lecturer in nurse education, a psychiatrist and a psychologist. I wondered if people with medical knowledge were more likely to take part in this type of research. However, it certainly emphasizes that dementia is no respecter of persons!

As a former chaplain, one of my main goals was to improve spiritual care of people with dementia both as inpatients and in the community. I was aware that spirituality was hard-wired and stayed until very late in the illness. To this end I developed an awareness raising course for local churches. Despite this I was surprised how many contributors in this study mentioned spirituality and religion.

Clarice pointed out that “the church community is very important for some people” (p. 132). Abdul, who still attended the Mosque for Friday prayers, said “If you go one place once a week regularly, then you make friends already” (p. 144). Pearl mentions her faith as Jehovah’s Witness. Ann claims “my friends, my faith and doing my talks keep me going” (p. 168). She also says that “between now and death, I will live life to the full and I will do that to the best of my ability and to the glory of God” (p. 168). Sylvia attends church regularly. She believes that “My faith in God enables me to accept the challenge of dementia; and I am confident that God will not allow me to be challenged to a greater extent than my ability to cope” (p. 175). Alex, who had a religious background, reports that he had become very anti-religion since his wife’s death. Yet he still prays daily at his wife’s monument in the garden and says, “I still have my faith, though it is a bit dented at times by the abundance of errant clergy” (p. 203). Mary simply states, “I find that life is best lived simply by being human and relating to God” (p. 245).

I feel this book is a good resource to health care professionals in both mental health and acute hospitals in that it gives us a chance to see ourselves as others (people with dementia) see us. However, perhaps it is particularly relevant to chaplains to encourage them to continue to provide spiritual care “in the vale of forgetfulness”. I am minded too that chaplains in our acute hospitals tend to have more patients with dementia than in mental health.

I will finish with another quote from Mary. “Just as any other person who experiences life through the lens of dementia, I live largely in the present moment. Although my thoughts at times turn to the past, I am committed to the sacrament of the present moment – the awareness that God blesses us as we are, in the midst of our very personal fears and hopes” (p. 245).