

Review

Kate Swaffer, *What the hell happened to my brain? Living Beyond Dementia*. London, Jessica Kingsley, 2016, 192 pp. (Pbk). ISBN 978-1-84905-6-083. £13.99.

Reviewed by: Revd Graham Peacock, Chaplain, Tees, Esk and Wear Valleys NHS Foundation Trust.

Email: grahampeacock@nhs.org

Kate Swaffer is an Australian who has early onset dementia. Prior to her diagnosis she held a variety of jobs and studied to degree level. Since her diagnosis in 2008–2009 she has continued to study and has also become a dementia activist and writer. This book offers 38 short chapters based on her lived experience but also her observation and experience of dementia services. Although Australian in focus, it offers insights and awareness from different countries and cultures.

The author notes that:

It is not an academic book, nor specifically focused towards the health care sector; it is not a book only for people with dementia or their families or care partners.

Yet, although wide ranging, it contains much that will inspire thought and reflection.

The book begins with a description of the author's life before dementia, where she had a highly demanding professional career as well as being the mother of two young children. It moves on to her first awareness of changes in her cognitive abilities, through to diagnosis. This part is comparatively short, but it serves to anchor the rest of the book.

The book then moves on and devotes much more space to the emotional impact of the diagnosis on both the person and their family and friends: it will confirm what many experienced chaplains are already aware of but will also take them deeper into the heart of what living with dementia feels like. This part of the book repays repeated reading as the insights are so acute; sometimes healthcare workers struggle to see the world through the eyes of those they work with. Interestingly, the author alludes to the fact that the diagnosis and journey has made her much more spiritually aware; she refers to her own response to this in creative writing, poetry (of which there

are many examples) and blogging. Since reading this book, I have also been keeping up to date with her blog (<https://kateswaffer.com/>).

Each chapter could be read independently from the rest of the book, for Swaffer's concerns and insights are wide ranging. Those who have worked with people with younger onset dementia will recognize the difficulties that services have in providing for their needs and it is a concern that the author frequently raises. She frequently refers to 'Prescribed Disengagement' and her feeling that services encourage the approach of withdrawing from normal life and getting used to care, rather than reengaging with life. However, it is a book whose insights can be applied to dementia care generally. Some may find her view on pharmacological interventions to be controversial (she feels that the resort to medication is often in lieu of psychological approaches); however, there are insights that all could profit from here on a greater use of grief counselling after the dementia diagnosis and the necessity of wider social support:

The other very hurtful part of living with dementia is that many of our friends simply do not want to engage in our journey, and if we aren't able to fit into their world any more, we are simply left out.

Yes, there is repetition (which the author admits) and the book can perhaps be over polemical at times; in chapter 26, she is extremely sceptical about the practice of defining and managing "challenging behaviours" and in chapter 35 she says:

It seems to me that many in the aged care and dementia sector are not really about person-centred care, but more about *purse-centred care*, and some of the people working at the top are not really that well-informed about dementia at all (*italics are the author's own*).

This is not a criticism; the author herself notes, "It is written from the perspective of my truth, and my own reality". Other books I have read with this ethos can sometimes come across as almost triumphalist: viz: "I have achieved/overcome", however Swaffer manages that rare mix of lament, vulnerability, positivity and hope.

I feel that this book would be an invaluable asset to any health care chaplain working with those who have dementia. The book moved me and caused me to question my own practice.

I would also unhesitatingly recommend it to those with an initial diagnosis of dementia, their families and friends and anyone working in the field of dementia. It will be a book I will keep, underline and constantly refer back to.