

## “Book Reviews” of books read by Keith Oliver on Dementia

### First person accounts about living with dementia – autobiography/essays

**Dancing with Dementia – Christine Bryden (2005)** Sub-title “My story of Living Positively with Dementia” says it all. A superb book for anyone with an interest in YOD. If only one book of personal writings on the subject then buy/read this one. CB has lived with dementia since the age of 46 (in 1995) and has used her skills, talents and energy to advance the cause of raising public awareness and challenging public mis-conceptions around dementia. CB had a high powered job as a senior civil servant which she lost due to the illness but nowhere is there a sense of negativity. She writes extremely well about what it is like to live with dementia and the reader related to her human story which is grounded in good science as well. I read it a second time a year later –hopefully more details will stick the second time!

**Who Will I Be When I die? – Christine Bryden (1998, re-published 2012)** – Originally published 3 years after diagnosis. The book is part auto-biography and part information about dementia (Alzheimer’s in particular). There are sections written in 2011 which brings one up to date which I found a positive feature of the book. A very good read which is similar in style to Dancing with Dementia and could be read as a prequel. It’s a pity I feel that the title is rather off-putting because there is lots to draw from this book.

**Losing Clive to Younger onset dementia – Helen Beaumont (2009)** Sub title “One Family’s story” this again sums up the book. Helen was Clive’s wife and clearly she describes how YOD turned their life upside down. Clive was 46 when diagnosed and they had 2 young children. HB describes the way the disease changes Clive both personally and health wise to the point where he dies aged 51. Whilst it is a sad read, there is no self-pity, and HB used the experience to devote her life to raising money and awareness through the Clive Project in Oxon.

**My Bonnie – John Suchet (2010)** Read it Sept 2010 whilst I was undergoing diagnosis. Sub-title “How dementia stole the love of my life”. Again the sub-title is very illuminating as to how the book should be taken. It is a good love story, much of the book deals with life before the disease reared its head and then goes on to show the way Bonnie changes and gets worse. This is described by JS one senses with tears always in his eyes –the reader may well feel this as well. JS uses it to raise awareness of YOD and to raise the profile of the charity dementiaUK and their Admiral Nurses, which he does passionately.

**\*Iris – book/dvd – John Bayley (circa 2002)** – Again a love story but whilst very different from My Bonnie it not surprisingly paints a picture of great personal loss due to the illness. It is the story of their relationship rather than a story of the illness. The film was better than the book I thought – partly because of the acting of Jim Broadbent and Judi Dench, and the flash back technique showed that Iris was a brilliant, vivacious young woman whose mind was ravaged by Alzheimer’s. A pity it didn’t show her still managing to write (ala Terry Pratchett) whilst dealing with the illness. One felt as sorry for JB as one did for Iris and showed the frustrations and loss felt by a carer.

**Alzheimer’s – From the Inside Out – Richard Taylor (2007)** – up there with Bryden’s books, although a very different kind of book. Rather than a biography/coping strategy book, this is a series of essays in which Taylor opens his heart to the reader to explain the impact which Alzheimer’s has had on him and his family/caregivers. He pulls no punches and leaves the reader in no doubt of the way his life has changed since developing the illness. It is at times both upbeat and also downbeat.

**\*Amazing Grace : Enjoying Alzheimer’s – Ray Smith ((2004)** An excellent, positive biography of a carer whose wife Grace was diagnosed with YOD aged 56 in 1990 and although by 1992 it was clear she couldn’t be left alone at home Ray and Grace went on to spend a further 13 years of trying to fill their days with fun, travel and stimulating activities. They travel widely from their home in Scotland including trips around Europe and beyond to South America and India. Ray’s caring for his wife is complicated by the fact that one of their 3 sons has severe schizophrenia. The blurb on the back includes the following:- “For the 15 years after diagnosis we lived a full and active life together, refusing to let her illness get the better of us. We developed a special diet, and researched what supplements she should take to slow the progress of the illness... I can honestly say, with my hand on my heart, that despite finally succumbing to Alzheimer’s Grace truly enjoyed the twilight of her life”

**I’m still Alive : My Battle with Alzheimer’s rages on – Norman (“Norms”) McNamara (2011)** A brave attempt by “Norms” to combine his poetry and prose writing skills to raise awareness of YOD – he was diagnosed at 53 with Dementia. He retains on the whole a combative stance to tackling the disease and often stresses his desire for a cure.

**Before I Forget : A daughter’s Story – Fiona Phillips (2011).** I was surprised how positively I felt towards this book. FP writes with the same passion with which she speaks about her family, and the way dementia has impacted upon her parents and herself. I guess the Canterbury element (she was born and partly raised in Canterbury) added to my connection to the book

**\*The Little Girl in the Radiator (Mum, Alzheimer’s and Me) - Martin Slevin (2012) –** The author manages to tell the powerful tale of his mother’s decline through dementia without falling into the usual painful traps. One gets a real sense of the person who was his mum and the use of humour mingled with sadness is a powerful combination. The title? Well you’ll have to read the book to find out more.

## Second person writing about dementia – guide books, essays, analysis

**\*Coping with Early Onset Dementia – Jill Eckersley (2011)** Excellent, readable, inexpensive, up to date little guide to YOD. It is comprehensive and gives lots of practical, relevant support. Is written in a matter of fact style and whilst realistic, it is as positive as the illness allows. Useful for anyone involved with YOD – sufferer, carer, clinician, student or lay person. Part of the “Coping with...” series. Really essential for anyone with a diagnosis of YOD.

**Understanding Alzheimer’s Disease & Other dementias – Dr Nori Graham & Dr James Warner (2009), part of the BMA Family Doctor book series** - At £4.95 a real bargain. I used this book a lot during the diagnosis period. It explained in clear terms what the illness is/entails and then how the tests/diagnosis will work. It is based upon access to nhs care so is very relevant and well illustrated. Great section on web-sites and signposted support.

**Services for Younger people with dementia and the role of Clinical Psychology – Reinhard Guss, Jayne Hawkins, Sinclair Lough, Jo Allen – BPS Briefing Paper 23 (2006)** – Found the outline of needs of YOD folk to be clear and how the medical/voluntary sector can support them to be very interesting. The case studies are helpful.

**Younger People with Dementia – (ed) Sylvia Cox & John Keady (1999)**- Interesting in parts. Need to have an academic understanding to get a lot from the book which is a series of essays some of which are better than others. Frustrating that some problems identified in the 1990s haven’t moved on a lot. Good on carers, including young carers and the section entitled “Opportunities and threats” was especially relevant. Quite expensive at £25.00 p/b

**I’m Still Here – John Zeisel (2010)** He talks about non drug treatments for Alzheimer’s and suggests that his creative therapies (art, music, poetry, drama, dance) will help create a better life for someone with Alzheimer’s. Certainly not YOD focused and more designed for a carer or a home to use with their loved one(s).

**When someone you love has Dementia – Susan Elliot-Wright (2010)** – read it with the BMA book during diagnosis. Not as helpful for someone with the illness as it is for their carer. Good in parts but very wordy with no illustrations.

**100 Simple Things you can do to prevent Alzheimer’s – Jean Carper (2010)** – One of the best self help Alzheimer’s books I’ve come across. It charts 100 suggestions to beat AD happening or slowing it down if you have it. All of the ideas are explained quite clearly in 3 – 4 page segments, and grounded in scientific research.

**And Still the Music Plays : (Stories of People with Dementia) – Graham Stokes (Second Edition 2010)** – Well written with a large degree of empathy for folk with dementia. The book is made up of 22 British case studies, each 8 -12 pages a good length to get a feel for the person who is the focus of the study. There are a very wide range of issues outlined in the book.

**\*Explaining Alzheimer’s and Dementia - More than memories – David Moore (2010)** Based on work conducted in West Sussex which places the service user and carer at the centre of the process, and in so doing has some interesting points to make. Could be said that it is a bit superficial. Has a useful section on speaking and listening to folk with Alzheimers.

**\*The Forgetting - David Shenk (2001)**- The book is divided into 3 stages – early, mid and late stages of the disease and uses case histories of some famous people alongside scientific research to describe the disease in a very readable, accessible manner. It challenges some widely held theories about the disease and the capabilities of those who have it, and retains a fairly positive approach whilst recognising the significant problems associated with having Alzheimers.

**\*Keeper – Living with Nancy, A journey into Alzheimer’s - Andrea Gillies (2010)** A stereotypical study of an older person with dementia which I struggled to relate to. What was more interesting were the descriptions of famous people who had dementia, a number of whom were YOD cases,

**\*Person Centred Counselling for People with Dementia – Danuta Lipinska (2010)** Whilst well written I didn’t get much from this book as I didn’t really engage with the subject matter. For people fulfilling this role I can see the book would be useful.

**\*Contented Dementia – Oliver James (2008)** – After the 3 main elements of the programme, which indeed are not really realistic, I found this book quite patronising and not really helpful/interesting Widely available.

**\*The New Culture of dementia care – Kitwood & Benson (1995)** A series of 3 -5 page essays which are still in many cases very relevant. The aim was to raise the status of the service user by placing them more at the centre of their care. Looked at the role of GPs and a number of the essays looked at folk in care homes. Found it frustrating that some concerns expressed in 1995 are still concerns 16 years later.

**\*Learning to Speak Alzheimer's – Joanne Koenig Coste ((2003)** –First 40 pages holds nothing new. Then it moves into the realms of advice for carers and people without experience of Alzheimers. A few funny anecdotes lighten the mood in places.

**Musicophilia – Oliver Sacks (2011)** – This took me over 2 months to read. It focuses on the importance and impact of music in a wide range of mental conditions and had moments of interest. He did make reference to dementia as one of the aspects illustrated by his experience with patients he knew. At 390 pages it was 100 pages too long for me.

**\*Your Guide to Alzheimer's Disease - Prof. Alistair Burns (2005)** – A useful little guide with some clear, concise information covering all aspects of AD. Only negative I felt was the use of the label "sufferer" which goes against the grain. During the mild to moderate stage he talks about the "hidden phase" then followed by the "apparent phase"

**\*Living with Alzheimer's Disease – Dr Tom Smith (2004)- new edition** – A little guide book which covers all aspects of the disease as written by an aware, interested GP. Highlights were understanding some of the science and symptoms, the diagnosis process as it should be, managing the early/mid/late stages.

**\* Reducing your risk of Dementia – Dr Tom Smith (2011)** – Helpful book in the campaign to raise public awareness. A companion read to the above book which updates some of that content whilst educating the UK public about some of the risks, consequences of dementia and some coping strategies in order to live well –his choice of words. Smith widely refers to some sound British and world-wide scientific research.

**\*The Creative Arts in Dementia Care – Jill Hayes & Sarah Povey (2011)** – Some of the philosophy was a bit precious, but when it got into using drama, music and poetry with PWD then it was better. I liked the idea that people with dementia can be more capable than professionals sometimes think. Could be useful for therapists and staff working with those of us with dementia in homes or as carers (professional and/or family.)

**\*Person centred dementia care – making services better – Dawn Brooker (2007)** – An excellent, no nonsense approach to dementia care which updates and expands upon the work and thoughts of Tom Kitwood. DB also utilises Christine Bryden's Dancing with Dementia with a wide range of quotes.

**\*Connecting through music with people with dementia (a guide for caregivers) – Robin Rio (2009)** – Because this book focuses very much on the older group with dementia I found this of limited use, the only part I could engage with were around the emotional connection with music

**\*Dementia, mind, meaning and the person – (ed) Julian Hughes, Stephen Louw, Steven Sabat (2006)** – a series of essays by a range of US/UK authors many of which were very interesting and accessible, although the content of some was too complicated for me. A number built upon the work of Kitwood by using some case studies, and these were those which were of most interest

**\*Early Stage Dementia – Lorraine West (2003)** – a practical guide written by an Australian which outlines all aspects of the early stages of dementia irrespective of age. Useful, DESPITE the irritating use of the term "sufferer" which most authors manage to avoid

**\*Hearing the voice of People with Dementia – Opportunities and Obstacles – Martin Goldsmith (1996)** – One shouldn't be put off by the age of this book. As the title suggests this covers ground which is just as relevant today and many of the obstacles and opportunities remain just as relevant today. The author was based at Stirling, and follows on from Kitwood's work and the project was funded by the Joseph Rowntree Foundation. A MUST READ FOR ANYONE WISHING TO ENGAGE THOSE WITH DEMENTIA IN THEIR SERVICE.

**The Dementia Guide - Living Well After Diagnosis – Alzheimer's Society (2013)** – Although there are a number of similar books available none are as comprehensive or as sensitively written with the person affected by dementia in mind. The content is informative supported by the pictures, and the layout is user friendly. A must have (and free!!) Don't let the advertising posters put you off!!!

**The Dementia Care Workbook – Gary Morris & Jack Morris (2010)** – useful for those running courses on dementia care, but probably not so for the general reader. Well written with a mix of factual content, case studies and tasks to explore within a course situation.

**Tom Kitwood on Dementia : A reader and critical summary – (ed) Clive Baldwin & Andrea Capstick (2007)** – An excellent blend of the great man's original writing and a 21<sup>st</sup> century analysis of his work. Essential reading for students of dementia, although not an easy to access text for the general reader or someone with dementia. I made notes on a number of sections which after re-reading became clearer. Baldwin & Capstick's writing really enhanced my understanding of Kitwood – looking beyond the legend!

**Dementia Positive – John Killick (2013)** – as the title suggests this little book provides a realistically positive approach to living with dementia based upon the author's professional experience and the stories of a number of people affected by dementia. I found the first half of the book particularly inspiring and as close as anything to my thinking.

**Excellence in Dementia Care (Research into Practice) – (ed) Murna Downs & Barbara Bowers (2008)** – A very comprehensive guide of essays from most of the well known authorities on dementia and written for under graduate students rather than the general reader. Having said that I read 90% of the essays, most of which were set in the UK. A new edition is likely for which I had been asked to write a foreword to a section which included involving service users.

**Living Your Best with early stage Alzheimer’s – Lisa Snyder (2010)** – Not to be confused with young onset this book is a helpful, positive guide for all ages who are diagnosed with Alzheimer’s. Although American the majority of the information is relevant for British readers. Written in a conversational, supportive style I found it helpful and would have appreciated reading it around the point of diagnosis.

**You’re worried you might have Alzheimer’s – Mike Bender (2013)** – A large manual designed for self help or as a resource for supporting a group. Many positives by way of layout, structure and content but also some negatives associated to the author’s approach. For more information read my longer review in the Journal of Dementia Care Jan/Feb 2014.

### Novels with dementia as a central theme in the book

**\*Still Alice – Lisa Genova (2009)** – A brilliant novel which I really related to. The main character is an American lecturer in her mid 50s who is diagnosed with Young Onset Dementia and the story tracks how the disease develops in her, and the impact it has not only on her but on her husband and her grown up children – e.g. do they want to have a genetic test to confirm whether they have the rogue gene or not. Although the character is female so much of her experience and feelings are common to me. A very sensitive portrayal which the author then does a similar job with **Left Neglected (2011)** which I also gained a lot from reading.

**\*Lost (a novel) - Alice Lichtenstein (2010)** – The main character is a wife and carer aged in her mid 50s whose architect husband is in the middle stages of young onset dementia. The husband wanders off during a snow fall and disappears prompting a search from the emergency services. The author then weaves together the lives of the main characters – the carer, the husband, the searcher and people who touch their lives. A very good read, though not as powerful as Still Alice – again an American author/story.

**The Wilderness – Samantha Harvey (2009)** – Despite clearly being a well thought of book in literary circles, hence the shortlist for the Orange Prize in 2009 I found this book hard going. The blurb looked promising, but I found the plot confusing and didn’t empathise or relate to the characters.

**Grace and Mary – Melvyn Bragg (2013)** – An intriguing read with lots of twists which a fiction reader could wish for. Switches in time did lose me at times, but that’s more due to me than the novel. Clearly MB has a solid grasp of how dementia impacts through his mother and this is applied well in the book.

**Turn of Mind – Alice La Plante (2011)** – A “who done it” which has as a main suspect the main character who has Alzheimer’s. As with all crime fiction there are twists and surprises and the author did keep me engaged throughout the plot. Occasional use of flash back is fine and a limit number of characters helps to follow the story. Also helped by a very spaced out print layout which some might find off-putting and wasteful but actually helped my reading of the text.

**Ashes – dvd (2011)** - It certainly doesn't do any favours for those with dementia and is not an easy view. The acting is very good from both Ray Winstone and the other lead actor, and the plot is really engaging and has some smart twists and turns which give it a feel of a thriller.

### Fiction intended for teenage readers

**\*The Memory Cage – Ruth Eastham (2011)** – I really got a lot out of this book. It gripped me from the start to the finish, partly because of the dementia element to the plot/characters, but more because of the twists and turns as the story unfolds. Thoroughly recommend it to adults as well as teenagers.

**\*Back to Black Brick – Sarah Moore Fitzgerald (2013)** – A good novel which will I’m sure engage its teenage readers whilst also appealing to adults. A good plot and interesting characters. Occasionally the twists in the plot lost me a little but I was able to regain the gist of the story and felt some empathy with the characters. Again like The Memory Cage it’s grandparent/child as the main characters.

**\*The Dementia Diaries – Matthew Snyman with some Kent teenagers (2012 in Kent)** – Although not fiction this book is presented in the style of the “Diary of a Wimpy Kid” books which will appeal to youngsters from the age of 9 – 16. This is in places a very good resource for schools and families in viewing dementia through the eyes of today’s teenagers. Five teenagers tell the story of their grand-parent accompanied by some appropriate artwork and a very useful factual section at the end of the book. Nice introduction by Angela Rippon.

*\* indicates this book is available to loan through Kent County Libraries*

**Keith Oliver, Canterbury, Kent – last updated November 2013**