

# Appendix 3

## HELPFUL BOOKS

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Here are some of the books that I found most helpful at our most challenging time and since then. Below I have listed them, with brief comments, in the order that (looking back) I would have found most helpful. It's not a judgement on their value or importance, just the order in which they could have been most helpful to me. Of course, that is my personal perspective.

Robin Thomson.

### **Seven simple introductions**

**John Zeisel, I'm Still Here, London: Piatkus, 2011**

The person with Alzheimer's is still the same person with whom we can relate, but it is a different relationship. That is the main point of this warm and beautifully written book. It also gives a basic understanding of Alzheimer's and its main symptoms and their effects, together with detailed practical guidelines for communicating and building the new relationship.

This was the first book I read, at a time when I was struggling to understand what was happening. It was a revelation, giving a clear and sympathetic understanding of the person living with Alzheimer's.

**John Dunlop, Finding Grace in the Face of Dementia, Wheaton, IL: Crossway, 2017**

I read this book later than Zeisel but I would put it equal at the head of the list. It gives a clear and warm introduction to the medical facts, along with practical advice on how to relate and care. Dunlop's position as a geriatric physician gives authority to the medical part, while his experience caring for his own parents makes his practical advice compassionate and authentic.

**William Cutting, Dementia: A Positive Response, Exeter: Onwards and Upwards, 2018**

Good medical material with a lot of practical advice. It covers similar ground to the other introductions. Dr Cutting especially advocates a very positive and active response to the early stages, with the conviction that this will help people to lead a full and even comfortable life.

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**Simon Atkins, First Steps to Living with Dementia, Oxford: Lion Hudson, 2013**

Written by a GP, another clear and sympathetic overview, from medical facts to practical responses. Quite brief, so easy to assimilate!

**Tina English: A Great Place to Grow Old, London, Darton, Longman & Todd, 2021**

A simple and accessible introduction to working with older people in general. The chapter on Dementia gives a clear and comprehensive overview in just 20 pages, while the next chapter on Carers is helpful in examining the challenges that carers face and some resources for supporting them.

**Lee-Fay Low, Live and Laugh with Dementia, Chatswood, NSW: Exisle Publishing, 2014**

This has a simple focus: how to maintain active relationships with the person living with dementia. It is extremely practical and full of optimism, with fascinating case studies of people at different stages of dementia, enabling you to assess what stage your situation has reached. I wish I had read this sooner.

**Stephen Miller, Communicating Across Dementia, London: Robinson, 2015**

Clear guidance on how to talk, listen, provide stimulation and give comfort to people living with dementia. The author covers almost all the relevant areas in a sensitive way, turning key principles that other recent books advocate into simple and practical guidelines, with many examples.

### **Personal stories**

Any of the books above gives a good starting point for understanding. Along with them it will be good to read these personal accounts.

**Sally Magnusson, Where Memories Go, London: Two Roads, 2014**

The story of her mother, Mamie, her gradual descent into Alzheimer's and the struggles of her children as they cared for her. The detailed accounts of their actual situation and the gaps in the system rang true to our experience. I kept nodding 'Yes, just like us' and was eager to learn what happened next.

**Oliver James, Contented Dementia, London: Vermilion, 2009**

This is based on the story of Penny Garton caring for her mother, but that is the .

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starting point for a much wider exploration and definite guidelines for supporting people with dementia. It is a very particular approach. I found some of it less applicable, but the main thesis was really helpful: the person with dementia needs to be respected within their present world and frame of reference. So don't keep asking questions; learn from them; enter into their world. And always agree

**Robertson McQuilkin, A Promise Kept, Carol Stream, IL: Tyndale House Publishers, 1999**

A remarkable story – quite short – of faithfulness and love, caring for his wife for twenty-five years. Very inspiring.

**Jennifer Bute with Louise Morse, Dementia From the Inside: A Doctor's Personal Journey of Hope, London: SPCK, 2018**

Jennifer Bute's experience of early onset dementia enables her to speak 'from the inside'; to show the many positive aspects, in contrast to common fears and stereotypes. As with Wendy Mitchell's book, her insights are valuable for caregivers and family too.

**Robin Thomson, Living with Alzheimer's – a love story, London: Instant Apostle, 2020**

When Robin's wife, Shoko, was diagnosed with Alzheimer's disease, they had no idea what lay ahead. They learned the hard way, going through relentless pressure as Shoko's personality gradually changed and she lost her capacity in many areas – but not her constant affection and love. They also experienced love and practical help from family and friends, backed up by health and social care professionals.

**Wendy Mitchell, Somebody I Used to Know, London: Bloomsbury, 2019**

The writer was diagnosed in 2014 as having young onset Alzheimer's, at the age of 58. She writes and speaks all over the country about her condition, giving a remarkable picture from the inside. Although she and others like her are a minority, their insights are really valuable for families and caregivers.

**Wendy Mitchell, What I Wish People Knew About Dementia, From Someone Who Knows, London: Bloomsbury, 2022**

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Wendy Mitchell's recent book is described as a 'practical guide to living with dementia'. It took her 'many years to work out strategies that enabled her to "live well with dementia"... Her book is a compilation of these strategies: a kind of how-to manual for people with the condition and those who support them.' (Review by Nicci Gerrard in The Guardian, Tue 1 Feb 2022)

**Jude Wilton, Can I Tell You About Dementia? A Guide for Family, Friends and Carers, London: Jessica Kingsley Publishers, 2013**

This isn't really a story, but it comes through the words of 'Jack', a person living with dementia, describing his experience, which gives the basis for simple, practical and encouraging advice.

**Lucy Whitman (editor), Telling Tales About Dementia, London: Jessica Kingsley Publishers, 2010**

A collection of thirty stories by those caring for a parent, partner or friend with dementia. They reflect their experience of pain and loss, their struggles with finding support, and the hope and love that they also discovered. The whole book is moving and informative.

### **Some comprehensive perspectives**

You might choose to begin with these books instead of the simpler introductions above.

**Julian Hughes, Alzheimer's and Other Dementias (The Facts), Oxford: Oxford University Press, 2011**

Fairly short but remarkably detailed and authoritative, with good material on the personal and spiritual care of people with dementia.

The next two books go side by side:

**June Andrews, Dementia: The One-Stop Guide, London: Profile Books, 2015**

This is comprehensive, as its title suggests, covering the medical, social, practical, financial and legal aspects. That means that some parts are brief, but it's a reliable overall guide.

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**Simon Atkins, Dementia for Dummies, Chichester: John Wiley & Sons, 2015**

This covers the same ground as June Andrews, as part of the 'for Dummies' series. Although it is so comprehensive, I personally found Dr Simon Atkins' earlier and shorter introduction (First Steps to Living with Dementia, see above) simpler and clearer at several points.

There is a later edition of this book, published in the USA and somewhat modified for readers there. It is called Alzheimer's & Dementia for Dummies, Hoboken, NJ: John Wiley & Sons, 2016.

**Bernard Coope and Felicity Richards (editors), ABC of Dementia, Oxford: Wiley-Blackwell, 2007**

This is written for doctors and other medical personnel, so it is quite technical in parts. It covers all areas, with strong sections on person-centred care and the use and limitations of medication.

### **Reflections and further resources**

**John Killick, Dementia Positive, Edinburgh: Luath Press Limited, 2014**

The subtitle is 'A Handbook Based on Lived Experiences'. John Killick has worked with people with dementia and their carers for many years. He shares their experiences, often in their own words, to show creative ways in which we can understand and relate to people with dementia. It is accessible, practical and positive.

**John Swinton, Dementia: Living in the Memories of God, London: SCM Press, 2012, 2017**

A reflection on what it means to be a person in the context of a disease which takes away memory and threatens self-consciousness. Definitely not an introductory book but deep and ultimately very encouraging. It particularly brings out the importance of community and friendship to sustain relationships with those living with dementia.

**Joanna Collicutt, Thinking of You: A Resource for the Spiritual Care of People with Dementia, Abingdon: Bible Reading Fellowship, 2017**

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A comprehensive introduction: dementia itself and its medical and social effects; what happens to the person living with dementia, in relation to themselves, to others and to God; spiritual care – being present, making meaning and ‘re-membering’ the person. The final section has guidelines for dementia-friendly churches.

**Nicci Gerrard, What Dementia Teaches us about Love, London: Allen Lane, 2019**

The author reflects on her relationship with her father, who died from dementia. This led her to interview people of all backgrounds – living with dementia, caregivers, health and social care professionals, researchers – searching for answers to the deep questions and truths that dementia raises for us as individuals and as a society.

**Louise Morse, Worshipping with Dementia, Oxford: Monarch Books, 2010**

People living with dementia are still people, who can connect spiritually at deep levels. This is a collection of meditations, Bible passages, prayers and hymns for caregivers, people living with dementia, families, church groups and medical or social care professionals. Its simplicity is its great strength.