



Reading about self-help books on dementia

Dementia is full of loss and loneliness. One progressively loses neuropsychological abilities; relationships change, some are lost; one feels in danger of losing one's self. Some behavioural change in dementia may be seen as filling up this developing emptiness. Family carers can become progressively isolated from social contacts and at the same time are losing their intimate confidant(e) who has previously been with them through difficulties in life. Healthy people, when alone, access memories and internal objects to accompany them. The person with dementia, although still having access to the affective aspects of objects, may need to carry photographs, diaries and notepads to structure the gaps in cognition; a self-help book may add to this collection.

No treatment is a cure. Most clinical management is aimed at psychoeducation, at ameliorating behavioural and personality changes and teaching coping skills. Bibliotherapy fits into this approach. There are many books on this topic and my choice has partially been constrained by time. To collect the books I used a library search and found others at conferences.

A self-help book needs to contain useful information and ideas for solving problems. It should also be written in a warm and sympathetic style. Individuals will differ in the books that appeal to them and inevitably most books are written for the carer. Some are written from personal experience of having dementia or caring, and others are by professionals or voluntary organisations.

Books by patients and carers

I found only a few books written by people with dementia or their carers. These lead the reader through the particular emotional journey that the patient or carer has taken.

Dancing with Dementia is written by Christine Bryden, the Australian author who was diagnosed with Alzheimer's disease at the age of 46, but whose diagnosis subsequently changed to frontotemporal dementia. Although she acknowledges the struggle she had assembling words, thoughts and notes the author reflects on living positively with dementia. She was supported by her family, her Christian faith and the Alzheimer's movement. She travelled the world in the cause of dementia and was elected to the board of Alzheimer's Disease International. It is a readable book

which describes her meeting with Nori Graham and includes an email from Steve Sabat. It is a particular story with more general points: advice not to move house; the pain of stigma; the value of routine, organisation and planning ahead; the isolation of patient and carer; affective memory outliving cognitive memory. The essence is that people with dementia can still live well and can still maintain old relationships and make new ones (including marrying after the diagnosis). The author casts aside the main fear that people have of the disease – 'loss of self' – instead relying on God and her new identity as a 'survivor'.

Lisa Snyder, a social worker, for many years supported patients with earlier presentation of Alzheimer's disease through education, counselling and guidance to families

In her book *Speaking Our Minds* she has transcribed interviews with seven individuals with dementia in which they express their thoughts and feelings about what it is like to have the disease and the impact on their lives. The people interviewed are of different age, ethnicity, religious background and coping style. They speak of things that give their lives personal meaning and the author adds some explanatory and empathetic comments. The book is not a practical guide but individual readers will find resonance with at least some of the stories. Each person is an individual and are as different as individuals. As Betty, an interviewee, said 'a person with Alzheimer's disease is many more things than just their diagnosis. Each person is a whole human being'.

Books by carers seem to have been written by those with considerable religious faith. This may be because their faith instils hope and the belief in a better life to come, and the wish to share their spiritual experience. However, all professionals know many carers who are sustained by their past relationship with the patient rather than by religious belief.

In *Living Daily with Dementia* Shirley Ashman tells of her father an ex-miner with pneumoconiosis who developed vascular dementia. As a Baptist the author describes not only the practical help available but also spiritual aid. The book is written as a diary with day-to-day recollections and entries. It has a pedestrian feel and I would have sympathy with those who found it unreadable – 'not a lot to report today'. The book ends rather abruptly on the day that father is admitted to residential care and gives the erroneous impression that that is the end. On the positive side it does introduce the idea that uncharacteristic behaviour may be a result of the illness and should not be

taken personally or the patient blamed. Some useful contacts in Wales are listed.

Alone with Dementia by Margaret Jeremiah, a Quaker, is a bleak account of uncharacteristic anger and aggression associated with vascular dementia and the move of her husband from a small village in Norfolk to a residential care home. The style of writing is rather cold and sparse, and will not appeal to everyone, but may reflect a way of coping.

A Guide to the Spiritual Dimension of Care for People with Alzheimer's Disease and Related Dementia by Eileen Shamy crosses the divide between books written by professionals and those written from personal experience. Drawing on her work as a clergywoman with older people in care and caring for her own mother with Alzheimer's disease, it was originally published in New Zealand where the work was undertaken. The foreword by Bob Baldwin mentions the unwitting sidelining of older people with confusion by the Church. There are many references to *The Bible* and discussion of discrimination and negative attitudes among people who are usually caring. There is a brief description of Alzheimer's disease for a non-clinical audience and suggestions about how to communicate most effectively with people with dementia. The book discusses worship needs at different stages of the disease and urges clergy and congregations to be aware of Alzheimer's disease and not to allow people to drop through the cracks of the pastoral care network. There is mention of the importance of rituals, familiar music and the recognition of clergy clothes and symbols.

Publications by charitable bodies

Publications from charitable/voluntary bodies are on the whole excellent. However, *Understanding Dementia* (published by Mind and available from their online shop) contains rather unhelpful criticism of general practitioners which sets professionals and carers into adversarial camps.

The *Patient-Carer Pack* from the Alzheimer's Society includes space for personal information and contact numbers, as well as tips from other people with dementia about coping psychologically and practically with everyday problems. The information for patients is direct and factual with topics including advance directives, managing money and depression. The Society also produces many brief, readable publications, an excellent series of fact sheets for people with dementia, information sheets



about a diverse range of topics and diagnoses, and advice sheets addressing difficulties which may be associated with the illness (http://www.alzheimers.org.uk/Facts_about_dementia/factsheets.htm).

The Mental Health Foundation has produced *Still Going Strong*, a booklet about living with dementia, and a similar booklet for carers (*Becoming a Carer*; <http://www.mentalhealth.org.uk/publications>). The positive foreword is written by someone with dementia. The publication discusses practical planning for the future and gives tips on how to cope despite the disease. Within the same series is a booklet for children and young people *The Milk's in the Oven*, which is clearly written and would also be suitable for adults having difficulty understanding the disease in a friend or family member.

Age Concern has produced fact sheets to help older people understand care systems (http://www.ageconcern.org.uk/AgeConcern/care_information.asp).

Paying for care is a complicated topic. The pamphlets could have been written in simpler language – the patient needing care is unlikely to understand the content and families may also have problems unless given guidance. Age Concern in association with the Alzheimer's Society have published *Caring for Someone with Dementia* by Jane Brotchie, which is a clearly and concisely written publication for carers who are either currently in a crisis and needing information and reassurance or wanting to plan ahead. It is accessible, sympathetic and practical and describes what to expect from the time of diagnosis through the progression of the illness. It candidly covers possible and therefore permissible reactions to caring, with the advice that one is not being disloyal if one tells the doctor about problems at home. Relatives describe how they have regretted becoming carers. The book includes the role of different health professionals, what to tell children, how to manage incontinence and aggression, finding a suitable home, making legal and financial decisions (also covering Scotland) and the benefits for which the patient and/or carer may be eligible. It is particularly helpful in discussing how caring may affect the relationship between patient and carer, covering most negative possibilities as well as love and compassion.

The *Down's Syndrome and Dementia Resource Pack* by Karen Todd, Vicky Turk and Michelle Christmas is for family, care staff and other professionals. The emphasis is on the individual, including the pros and cons of discussing the diagnosis with the patient. There is recognition that the family carer of someone with Down's syndrome and dementia may be elderly and in need of care themselves. The resource is well laid out and easy to use for reference. There is an excellent account of behavioural and communication changes,

some of which is also valuable for people with dementia but without Down's syndrome.

Books by professionals

Understanding Forgetfulness and Dementia by Martyn, Gale and Smith is for patients, carers, relatives and friends, although really less for patients than for others. The book has a useful guide on using the internet as a source of further information.

A Problem Solving Approach to Difficult Behaviours in Dementia (Kelcey) is a brief booklet written by a psychologist for family and carers in the National Health Service and social services. It recognises that not every symptom or problem behaviour in someone with dementia arises as a direct consequence of the illness. It explores circumstances, interactions and consequences as well as thoughts about for whom the behaviour is a problem to enable the development of a strategy to deal with the situation; it urges taking the time to think about the behaviour rather than forcing the patient to change.

Alzheimer's Disease and Memory Loss Explained by Burns, Page and Winter is primarily for patients and family carers. It is a readable book and is particularly good at describing carers' possible reactions to the severity of the patient's signs and symptoms.

The Simplicity of Dementia is by Huub Buijssen a Dutch psychogerontologist (clinical psychologist) whose father developed dementia. The book provides some understanding for family members of what may be seen as a non-comprehensible 'mad' condition. Perhaps the disease is not quite as simple as the title suggests, but the book is written and laid out in a clear style, with discussion and quotations from carers, patients and other authors followed by a summary at the end of each section. A useful message is that in a battle between patient and carer there are only two losers.

Dementia. Your Questions Answered by Brown (a neurologist) and Hillam (an old age psychiatrist) is written for general practitioners, nurses and other health professionals, but will also be useful for some informal carers who are interested in learning more. The book is well thought out and clearly addresses commonly asked patient and carer questions, in addition to giving more detailed answers for staff.

Dementia, Alzheimer's and Other Dementias by Cayton, Graham and Warner answers frequent/likely questions from carers, family and friends, divided according to subject area, and has delightful cartoons at the beginning of each chapter. The book covers all aspects of dementia and has a crisp matter-of-fact

style. People are likely to use the book as a reference or read it chapter by chapter. It is an excellent practical book for family carers.

Summary

'You are not alone with a good book' is particularly true for patients with dementia and their families. Feeling that the author has recognised you decreases that hollow sense of isolation and loneliness. It is important that there is a range of styles to suit different individuals. Too positive a manner may emphasise the reader's relative failure. All publications have a list of contact addresses at the end. There are fewer publications available for patients themselves, although the Alzheimer's Society has an excellent series of information sheets. Professionals and voluntary bodies are able to distance themselves emotionally and say things that close carers might be unable to do. Even so, styles differ and one needs to feel touched by a book to feel that someone understands your predicament and hence to decrease the sense of loneliness.

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BROTCHIE, J. (2003) *Caring for Someone with Dementia*. Age Concern Books.

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