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Book Review

Christine Bryden

Dancing with Dementia

My Story of Living Positively with Dementia

Jessica Kingsley Publishers, London 2005

200 pp.; GBP 12.95/USD 19.95

ISBN 1-84310-322-X

Christine Bryden was a senior executive in the Australian Prime Minister's Department when her life took a new turn, following a medical examination for extreme exhaustion and stress in her daily work. She offers a journey through the trauma of the announcement of the diagnosis of Alzheimer's disease (AD) towards hope and the development of projects.

While writing her book, Christine Bryden still presented an early stage of dementia. Despite her handicap in daily life activities, provoked by memory problems and some difficulties of comprehension, she led an active life, partly by dint of the support of her husband. She managed to become a real advocate for people with dementia: she set up local support groups for people with dementia, she addressed international conferences and was the first person with AD elected to the committee of Alzheimer's Disease International.

In this book, Christine Bryden shares her experience as a patient suffering from AD. She explains the way she lives with the illness, how she felt when her physician had given her the diagnosis and the way she feels when she is confronted with her difficulties during the various appointments with specialists. She also adds that the lack of hope associated with this neurodegenerative illness is so important that she would have preferred to have cancer: 'At least then usually there is talk of treatment, of chemotherapy, of possible remissions. There is none of that with a diagnosis of dementia' (p. 95).

In her description of the illness, she also specifies that having AD is more than suffering from memory loss. She often feels confused, as she expresses in the following sentences: 'Most of the time I live in the space I can see and the time called "now"... It is almost a "virtual world" ... I move ... and a new space opens to view ... like a new room in a computer game ...' (p. 99). 'We have no sense of time passing, so we live in the present reality, with no past and no future ... Sometimes this causes a lot of anxiety because we worry about the past or the future because we cannot feel that it exists' (p. 99).

The readers will be sensitized to the fact that dementia shows several varieties of symptoms. In opposition to the old concept of dementia that was seen as a unitary global deterioration of the brain, we definitely know today that the clinical presentation is heterogeneous. First of all, there are lots of different kinds of dementia and, inside the AD type, there are several variants. The

onset can be early or late, just as the evolution might be slow or fast. Most of the cases are sporadic but there are also hereditary forms. The majority of the AD patients shows neuropsychiatric disorders (60–88%), and most of them suffer from apathy and depression.

Finally, *Dancing with Dementia* might interest individuals affected by dementia as well as caregivers or even anyone who is confronted with demented patients. Indeed, besides explaining the illness and the way the author feels about it, several pieces of advice for a better communication with AD patients are presented. The book even finishes with different appendices, 2 of which are particularly interesting: one answers several frequent questions about dementia, and the other gives some addresses for further information.

Andrea Brioschi , Lausanne

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Dancing with Dementia: My Story of Living Positively with Dementia

By Christine Bryden. London: Jessica Kingsley Publishers, 2005 (200 pages).

This book is about a person getting and living with a diagnosis of dementia. It tells how the stigma and shame of having a diagnosis of dementia can be surmounted and how a person can live positively being diagnosed with dementia.

Christine Bryden was a top civil servant and single mother of three children when she was diagnosed with dementia at the age of 46. Since then she has gone on to challenge almost every stereotype of people with dementia by campaigning for self-advocacy, writing articles and speaking at national conferences.

This book is a vivid account of the author's experiences living with dementia, exploring the effects of memory problems, loss of independence, difficulties in communication and the exhaustion of coping with simple tasks. She describes how, with the support of her husband, Paul, she continues to lead an active life nevertheless, and explains how professionals and caregivers can help.

Christine makes an outspoken attempt to change prevailing attitudes and misconceptions about the disease. Arguing for greater empowerment and respect for people with dementia as individuals, she also reflects on the importance of spirituality in her life and how it has helped her better understand who she is and who she is becoming.

This book is very well done and is even better than her first book, titled "Who will I Be When I Die". The audience is people diagnosed with Alzheimer's disease and other dementias, and their caregivers. They will benefit by reading Christine's experience. People with dementia will feel that they are not alone with their problems and caregivers will be able to see how a person with dementia feels.

Review provided by: Lynn Jackson. Lynn is in the early stages of frontotemporal dementia. She is a founding member and current President of DASN International.

<http://www.alzheimerbc.org/We-Can-Help/Resources-and-Information/Library-Services/Dancing-with-Dementia.aspx>

Reading about self-help books on dementia

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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’.

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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.

<http://pb.rcpsych.org/cgi/content/full/31/3/118>