

Book reviews

I have a rare and precious gift, a wonderful relationship with my mother-in-law. A few years ago, she was diagnosed with Parkinson's disease. A year ago, she came to live with us. Living on her own was not possible any longer. Having a professional knowledge of Parkinson's disease (PD) is one thing, having a person with the disease move into your home, a very different thing. We started a journey of preparing the family to live with PD. Two books crossed our lives that deserve to be reviewed in an Occupational Therapy Journal.

Hester van Biljon

Title: Making the Connection between Brain and Behavior, Coping with Parkinson's Disease

Author:

Joseph H Friedman, MD

Dr Joseph H. Friedman, MD, is the director of the Parkinson's Disease and Movement Disorder Center of Neuro Health; Clinical Professor of Clinical Neurosciences at the Warren Alpert School of Medicine of Brown University; and Adjunct Professor in the School of Pharmacy of the University of Rhode Island.

Book Information:

Publisher: Demos Medical Publishing, New York
Date of publication: 2008
ISBN number: ISBN-10: 1-932603-42-5
Paperback.
Number of pages: 166
Price: \$19.95

The book has a foreword, a preface, an introduction, a prologue, 16 chapters, two appendixes, a glossary and an index. The convoluted content indicates that the book is not an organised, 'well planned' topic specific publication. In the prologue, there is an almost parental warning to caregivers "not to nag": "Nagging is demoralising for the nagger and naggee." "- let it go! There are better ways you can spend your energy." (Page xix)

Dr. Friedman states the aim of the book in the Introduction: "This book represent a distillation of more than two decades of experience with PD (Parkinson's) patients and their families. I wrote this out of a sense of obligation, partly from my love and respect for my patients and their supporters, partly because I love my work and partly because I think that my own personal intellectual journey depicts a tale that is educational for patient as well as for doctors." (Page xiv) The book is written for lay people with little or no medical terminology and short definitions and explanations of terms such as dementia and delirium. There is also a glossary at the back, with words such as apnea and apraxia and an index. The author's dedication to people with PD sets, in my opinion, the ambiance of the book and makes the reading of rather disturbing behavioral tendencies in PD palatable.

The book focuses predominantly on behavior, mood and cognitive tendencies in PD. Issues that affect treatment, rehabilitation, 'family life' and 'care giving' of people with Parkinson's. The first

few chapters are about personality, fatigue, apathy, depression, anxiety, dementia, hallucinations, delusions, confusion and delirium and compulsive behavior. The author shares his experience, opinions and an extensive knowledge of papers written -, research done - and case studies to illustrate these topics and their link with Parkinson's disease. He has an 'easy to read' style of writing but his approach to 'behavior' is very much the 'medical model method'. Discussion of medicating 'symptoms' such as anxiety and apathy are comprehensive with virtually no reference to therapies and support group benefits.

The last five chapters are less about behavior and more Dr. Friedman's opinion on sleep, surgery for Parkinson, driving, caregivers and family and a very interesting chapter on 'Why you should not go to the Emergency department and why you should' – if you have PD.

Dr Friedman indicates "this book is intended to be a source of practical information." (Preface) There is practical advice throughout the book, but in my opinion the author still falls short of his intent. He makes no mention of occupational therapy and the 'practical' value the profession offers in the management of behavioral problems. He only once mentions physiotherapy calling it 'Physical therapy' (Page 165) recommending "a respiratory therapy consultation for chest PT". No mention is made of Speech Therapy even though he touches on the frustration that the inability of not being able to communicate effectively causes. In a book on behavioral problems, he mentions psychotherapy three times! Calling it 'talk therapy' and recommending "talk therapy for caregivers and patients that suffer from depression" (Pages 47, 56 and 157).

Despite these shortcomings I can still recommend the book as it is a welcome change to the many books available on PD that focuses primarily on movement and physical problems associated with Parkinson's. Occupational Therapists will find many insights into the prevalence and cause of behavioral problems that would affect the treatment and rehabilitation of their PD clients.

Reviewed by:

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Title: There is Life After Being Diagnosed with Parkinson's Disease. (3rd Edition)

Author:

John Pepper

Mr. John Pepper is an entrepreneur, a very successful entrepreneur. He started a small printing company in Kimberly, South Africa, in the early sixties. In 1987 his company was listed on the Johannesburg Stock Exchange. In 1992 he was diagnosed with Parkinson's disease. He is currently retired, a respected representative and advocate for People with Parkinson's and the South African Parkinson's Association.

Book Information:

Publisher: Self Published by John Pepper & Associates cc.
Date of publication: 2008
ISBN number: ISBN No. 0-620-28370-X

Paperback.

Number of pages: 192

Price: It can be bought for R110.00 from the author himself; johnpeper@telkomsa.net or ordered via post; Private Bag x5, Brynston, 2021, South Africa.

Mr. Pepper approaches his PD with the same entrepreneurial spirit that he did his business. After hearing of his PD diagnosis in 1992: "I immediately set about changing my lifestyle, by doing everything I could to stave off the inevitable progression of the disease ... (and in 2001 he writes) ... my condition has improved to the point where I can almost forget that I ever had this dreaded affliction". (Page xiii) The aim of the book is to share what he calls his "good fortune" with

other people who have been diagnosed with Parkinson's. It also has value for all whose lives are touched by PD. Throughout the book he mentions neurologists, general practitioners, physiotherapists, occupational therapist and speech therapists.

The Content of the book is: A Preface by Dr. Colin Kahanovitz, Acknowledgements, and Introduction by John Pepper. Then follows six 'Parts' with their own chapters:

- Part 1: The reality of Parkinson's, Chapter 1 - First the Good News, Chapter 2 - Symptoms and List of Symptoms.
- Part 2: The process of rehabilitation, Foreword, Chapter 1 - Bodily Fitness, Chapter 2 - Diet, Chapter 3 - Stress Management, Chapter 4 - Medication, Chapter 5 - Attitude Adjustment, Chapter 6 - Mental Stimulation, Chapter 7 - The Final Piece of the Puzzle.
- Part 3: Thoughts and Actions, Chapter 1 - Side Effects of Medication, Chapter 2 - Possible Causes of PD, Chapter 3 - General Comments.
- Part 4: Aftermath
- Part 5: Warning
- Part 6: Conclusion, Recommendation, How to Set About Improving Your Condition, Pacing Yourself

The Appendix had seven sections: Putting your Mind to Improving your Health by Shirley Soll, A Journey of Self Discovery and Conquest by Estelle McIlrath, Thoughts of a Fellow Traveler by Carole Charlewood, Letter from Jules Klette, Letter from Wilna Jeffery, Detail of Symptoms and Exercises.

As in the previously reviewed book, this book lacks the 'finishing' of a professional publisher. A well-planned, organised layout of the content is missing and there is often duplication of subject matter e.g. 'symptoms' that are discussed on three separate occasions (pages 18, 92 and 147). The book also does not have an index, which will make it hard to use for academic and research purposes, but then that was never the aim of the book. The book is written in the first person and helps the reader to identify with the author, a champion of positive action in the face of a devastating diagnosis. This is in my opinion the primary appeal of the book, Mr. Pepper's enthusiasm and the passionate, energetic way in which he deals with his PD.

The first 'part' of the book looks at reasons why Mr. Pepper felt he got the disease. There follows an out of place chapter on symptoms. His opinion on why he got so much better, that he was taken off all medication in March 2002, eleven years after he was diagnosed with PD. His 'secret' for this improvement is simple and costs nothing: He advocates a positive lifestyle and a positive mindset in addition to the medical management of PD. "Only YOU can help to improve your own quality of life. Medication can help to facilitate your movements and bodily functions, but YOU have to do the exercise, in order to help your body to function properly, and YOU have to become positive about yourself" (Page 17).

Part two is 'how to' make the changes in lifestyle and mindset. He systematically explains his personal journey. Discussing exercise, diet, stress management, medication, attitude adjustment, mental stimulation and the last (for him most important) part is what Mr. Pepper calls the 'final piece of the puzzle'. He tells of how he discovered that he had to 'bypass the subconscious brain' when doing a movement such as walking or bringing a glass of water to his mouth. He noticed that if he thought about how to do a task the execution of the task improved. "Since I started to use my conscious brain to control most of my body movements, my overall condition has improved to the point, where I would count myself as more or less free of most of my PD symptoms". Page 80. What Mr. Pepper describes here, and that he had had to discover for himself (as none of the physiotherapist or occupational therapist he had seen had taught him this!) was to bypass the basal ganglia function (that regulates voluntary movements at a subconscious level and is affected in a pathology such as Parkinson's) and started use conscious motor planning or cognitive cueing to perform tasks.

In part three the side effects of medication is indicated and a more general discussion of possible causes of PD. Indicating his

personal experience with medical personnel, Mr. Pepper makes a very valid comment, that we all should take heed of: "Instead of filling patients with visions of doom and gloom, the medical profession could try to help newly diagnosed people with Parkinson's to take responsibility for their own physical and psychological well being, which, together with the correct medication, will go a long way towards staving off the ravages of this disease" (Page 91).

Part four starts with a very sobering account of how Mr. Pepper struggled to get his writings endorsed by medical personnel. How he was accused of 'raising false hope' and the general rude behavior he encountered when asking doctors and physiotherapists to read his book and comment on it. (Thankfully he does not mention occupational therapists in this section.) It ends with the value of support groups and some excerpt from his diary.

Part five has a more cautionary tone than the previous parts, probably included after his experiences with medical personnel. He states on page 121, "I am in no position to claim that; because I have been able to overcome many of the symptoms of PD, while still retaining others, about which I can do nothing; any other person with Parkinson disease, or Parkinson's symptoms, will be able to do the same."

Part six is a conclusion and recommendation with a step-by-step program of how to practically go about taking charge of and managing PD if you have been diagnosed with it. It is simple and easy to use program with a lot of motivation and guidance built into each step. E.g. "Don't try and cram too much into any one day, because that is how we create stress for ourselves" (Page 135).

The appendixes are: A few letters of affirmation and recommendation of Mr. Pepper's character and progress. A discussion of his PD symptoms, with some funny antidotes and practical advice on how he manages them. An exercise guide with photo's of the exercises he finds works for him, concludes the book.

This book has a South African flavour and is the personal account of Mr. Pepper's journey with Parkinson's. It is exudes energy, hope and motivation leaving the reader feeling empowered and strong. Nobody can read the book and stay untouched by the author's courage and spirit to face and make the best of a truly terrible affliction. As Occupational Therapists we rarely find clients with Mr. Pepper's volitional and verbal ability. Reading this book will give insight into what our clients PD experience. It will help us to inspire and empower, not only clients who have been diagnosed with PD, but all patients who have a chronic degenerative disease. Mr. Pepper's philosophy of 'taking charge of and managing' his health and his contagious enthusiasm has a lot to offer our patients with HIV/AIDS.

Reviewer:

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My mother-in-law had also read both books. I asked her which of the two books she thought was the best: "Mr. Pepper's book! He knows what he's talking about because he has the disease himself. You can leave his book on my table. I'm going to read it again."

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Title: Still Alice. What if you were to lose every memory you ever had ...

Author:
Lisa Genova

Book Information:

Publisher: Simon & Schuster UK Ltd.
www.simonsays.co.uk
Date of publication: 2009
ISBN number: ISBN-10: 1-932603-42-5
Paperback.
Number of pages: 293 Pages,
Price: \$12.99.

This is fiction, the story of a successful and acclaimed 50-year-old Harvard professor, Dr. Alice Howland. Alice is a psychologist who specialises in cognitive psychology and linguistics. She has a comfortable marriage, three independent, successful children and a busy productive life. Until she is diagnosed with Alzheimer's disease. This book tells the story of two years in Alice's life, from when she starts suspecting 'something is wrong' to the point where she becomes functionally (physically and mentally) dependant on others. The book is well written and NOT one of those soppy, 'ag shame', tear jerker that are so often written about people with incurable disabling diseases.

The author, Lisa Genova, holds a Ph.D in neuroscience from Harvard University. Her professional knowledge of Alzheimer's and cognitive and emotive function is obvious but she does not fall into the trap of profession specific language or ideology and the story is easily accessible for laymen. The book is also not 'a case study', it is layered and textured with descriptions of Harvard campus, the social lifestyle of students and academic personnel and family intrigues and interaction. Genova has the ability to write in such a way that you can access the actual experience of someone with Alzheimer's. The reader is 'shown' not 'told' what happens with

short-term memory loss. As Alice loses her memory and the structure of her thought processes, the author, on several occasions, lets the reader feel 'lost and disorientated' about a seemingly unconnected incident, which then later falls into place. Genova also touches on contentious issues such as suicide and euthanasia, but in such a subtle and impartial manner that you can miss it completely.

The treatment and management of Alzheimer's is accurately documented in the story, as is resulting vocational -, social - and interpersonal complications. The benefits Alice gets from a support group will warm the heart of any Occupational Therapist reading the book. The roles of various medical professionals also come into the story, but conspicuous in their absence are occupational therapists. For me, this was a frustrating aspect of the story, especially when Alice (in my opinion) starts requiring work accommodation, and would have benefited from assistive devices and adaptations to maintain personal care independence, 'just that little bit longer'.

This easy to read book is highly recommended to all who work with, know or live with persons with Alzheimer's. It offers an accurate and touching insight into the experience of having and/or living with such a disease. It also leaves you with thought provoking questions that keep rotating in your head and will make for interesting discussions in the rehabilitation tearoom. On page 252 Alice addressed a group of professionals:

"I often fear tomorrow. What if I wake up and don't know who my husband is? What if I don't know where I am or recognise myself in the mirror? When will I no longer be me? Is the part of my brain that's responsible for my unique 'me-ness' vulnerable to this disease? Or is my identity something that transcends neurons, proteins and defective molecules of DNA? Is my soul and my spirit immune to the ravages of Alzheimer's? I believe it is."

Enjoy the read!
Hester van Biljon