Chapter 2
Steve’s Story:
Living with Mild Cognitive Impairment

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ABSTRACT

Through a collaborative process with his co-authors, Steve shares his story of how he, at age 60, experiences life with mild cognitive impairment (MCI). Both audiotaped self-narration and an interview were used to elicit Steve’s story, which was transcribed by his wife, Gincy. After an introduction presenting the authors’ approach to this chapter and Steve’s background, he shares his story in his own voice, as audiotaped. A subsequent interview elicited Steve’s feelings about sensitive topics such as depression and anger to explore the full range of his thoughts and feelings about his situation. In the discussion, the third author places Steve’s story into a contextual framework by addressing the unique aspects of diagnosis at a young age and comparing his experience to the larger literature on identity, coping, and awareness in MCI and early dementia.

INTRODUCTION

In planning the collection of articles that comprise this book, the editors felt that their commitment to exploring the subjective experiences of people with mild cognitive impairment (MCI), Alzheimer’s disease (AD) and other dementias – particularly in relationship to identity and awareness – demanded inclusion of a chapter authored by an affected individual. In this chapter, the authors take a narrative approach to understanding what it means to live with MCI. More specifically, this chapter, like many others in this volume, demonstrates that what it means to live with a chronic illness, such as MCI or AD, can be best understood by listening carefully to the stories that affected individuals share (Telford, Kralick, & Koch, DOI: 10.4018/978-1-4666-8478-2.ch002
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2006). Consequently, the first editor and third author of this chapter, Dr. Cordula Dick-Muehlke, referred to subsequently in as Dr. D-M, invited Steve Heins to author this chapter with the support of his wife, Gincy. Steve and Gincy, who had previously participated in two panel discussions about the experience of living with cognitive impairment led by Dr. D-M, graciously agreed.

Dr. D-M first met Steve, now 60, and Gincy in the summer of 2010. At the time, the diagnosis of mild cognitive impairment (MCI) was fresh, having been made first in December 2009 by a neurologist and then confirmed in March 2010 at the University of California, Irvine Institute for Memory Impairments and Neurological Disorders (UCI MIND). Subsequently, further evaluation and follow-up has led to the identification of dementia with Lewy bodies (DLB) as the possible underlying cause of Steve’s MCI.

Steve grew up in Arcadia, California. In 1977, he received his bachelor’s degree in business administration from Cal Poly Pomona. After six years of military service, he moved on to McDonnell Douglas, where he designed and built airplanes for 12 years. Amazingly, Steve put together 48 commercial airplane “kits” that were sent to China and then provided instructions for building the aircraft via phone. After a successful career in aerospace, Steve landed at Disney where, in his own words, he “created the magic and kept it going.” Along with the engineering team, Steve was responsible for maintaining the park, the safety of the rides, and “keeping the illusion going.” These days, as Steve explains, he is doing all he can to prevent his MCI from progressing – including taking classes, volunteering, and speaking out as an advocate.

Steve met Gincy, his wife of 25 years, on a blind date. Gincy has a master’s degree in business and spent many years working in a variety of high-level administrative positions for companies like Western Digital and Parker Hannifin. The couple has one son, Robert, who was 13 at the time of his father’s initial diagnosis in 2009. Today, Gincy focuses on supporting Steve in his efforts to live positively with MCI, and Robert, who, as of the publication of this chapter, has just completed his freshman year at Chapman University.

Writing Process

Dr. D-M and Gincy used two methods to assist Steve with writing this chapter. Our three-way writing process was one of “doing together” or “doing with” rather than “doing for,” a key practice in person-centered dementia care (Brooker, 2007). Steve initially spoke his story into a tape recorder, and Gincy later transcribed the audiotape. Gincy guided Steve by cueing him at the beginning of each of two recording sessions to speak about topics that the authors had agreed upon, including his background, receiving the diagnosis, changes in identity, his reliance on Gincy to maintain the perception that he is “normal,” the “down side” (e.g., depression, anger) of living with MCI, and daily coping strategies. After reviewing the transcript, Dr. D-M conducted a home visit during which she interviewed Steve about topics such as depression and anger which were more difficult for him to speak about spontaneously in the audio-recording.

Steve’s story, as audio-recorded and then transcribed with language usage unaltered apart from minimal minor edits, follows in the next section of this chapter. Additional information Steve shared during the home visit is reported thereafter. Steve’s story, as told via the audio-recordings and the interview, is reported without comment in order for the reader to experience it in an unbiased manner. Headings have been inserted to guide the reader. Once Dr. D-M had organized the material from the audiotapes and interview into this chapter and drafted both the introduction and this section on the writing process, Steve and Gincy reviewed the manuscript. Limited edits made by Steve and Gincy included correcting