Reviewed by Jake Tumber, PT

This book is a personal account of the author’s life, living with chronic neck pain and headaches following a near-fatal car accident in 1996. She offers us an insight into her experiences in the healthcare system and her struggles of daily life, as she endeavours to obtain a diagnosis and effective treatment for her pain.

Lous Heshusius has an extensive teaching background in both her native country, Holland, and North America. She has authored multiple publications on the subject of disability studies in education, and held visiting professorships in Canada, the US and New Zealand. Since her accident she was unable to work in the same capacity, but has authored both this book and a follow up book in 2017, “Experiencing Chronic Pain in Society.”

Throughout the book she describes multiple experiences with doctors, specialists, therapists and alternative medicine practitioners. After each visit and round of testing, she is given another diagnosis to add to an ever-expanding list, that frequently doesn’t serve to get her any closer to any kind of solution. Over the years she becomes blasé about each new doctor or practitioner she sees. She knows that the same questions will be asked and becomes exasperated at having to tell her story over and over again, describing the daily battle she faces just managing her pain. After each visit her commentary describes that particular doctor’s bedside manner or their use of throwaway comments such as “just learn to live with it”, or “it’s chronic pain, it will never go away.” She is appreciative of doctors and therapists who give her time and listen to her story, even if they don’t have any tangible treatment solutions for her. She recognizes fairly early on after her car accident that she had to become her own advocate, as she both navigated the healthcare system and attempted to get her symptoms under control.

This is honest and compelling storytelling, with no hint of self-pity, but told with a degree of biting criticism, at times, and outright frustration at others. This is a well-educated patient with a non-medical background, who rationally tries to make sense of her condition, but wrestles with an insurance system and healthcare service that struggle to provide care and support for patients with chronic pain.
One insight I found professionally interesting was her view of the limitations of pain assessments during a doctor visit. She felt that because her pain fluctuates so often throughout the day, and sometimes by large amounts from minute to minute, she cannot accurately give an answer to the 0-10 pain score question. She felt that both the Numeric Pain Rating Scale and the McGill Pain Questionnaire could not give an accurate representation of the multitudinous array of sensations that someone with chronic pain experiences. This resonated with me because I have experienced similar patient comments when asking them to complete pain questionnaires and outcome measures.

At stages through the book she makes reference to philosophy and literature to describe her pain experiences and frustrations with the medical profession. In particular how difficult she found it to express her pain sensations to doctors and her friends and family. She rightly states that her lack of open wounds or scars, and the fact that she looks “normal”, makes it hard for others to comprehend the nature and intensity of her pain. Thus, she often refers to chronic pain as “the invisible disease.”

A few of her doctors do provide her useful management strategies. She learned about mindfulness and writes about taking pleasure in music and nature, appreciating their calming effects as she deals with her unpredictable pain. However, she also describes social isolation and the gradual loss of friends that paints a picture of loneliness and the grief of a life lost to chronic pain.

I have read this book twice now, initially five years ago, and again this year. After reading about her daily struggles and interactions with various healthcare professionals I reflected on my own practice as a full-time clinician and the need to be sensitive to each patient’s life and background during assessments and treatments. This book would be appropriate for doctors and therapists to read, especially if they are involved in the treatment of chronic pain, but also to understand that every patient has thoughts, hopes and fears prior to a consultation.