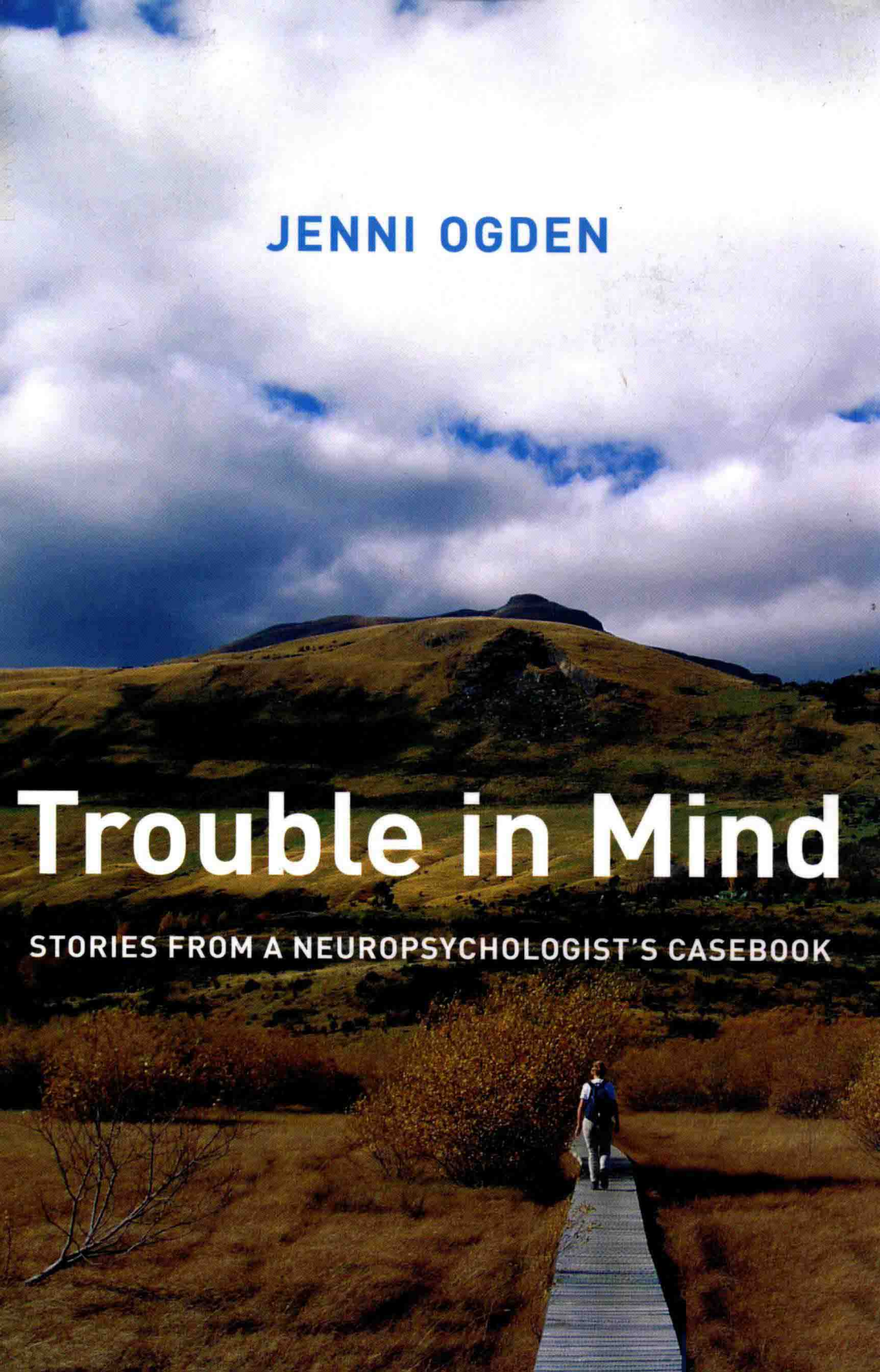
JENNI OGDEN
Trouble in Mind
STORIES FROM A NEUROPSYCHOLOGIST'S CASEBOOK

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Jenni Ogden

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In memory of the most studied single case in history,
HM (1926–2008), who taught us about memory by losing his.

Trouble in mind, I'm blue,
But I won't be blue always,
'Cause the sun's gonna shine in my back door someday.
Richard M. Jones

Preface ■

Trouble in Mind is a book that will deepen your understanding of how and why brain disorders change lives. It is written for students studying psychology or medicine, patients who have suffered brain disorders and their families, the health professionals who work with those patients, and the general reader who is intrigued by the brain, mind, and behavior. It is not a neuroscience, neuroanatomy, or neuropathology book, or even a neuropsychology assessment or treatment book. It is perhaps more akin to a neuropsychologist's memoir: a collection of stories about real patients whom I worked with over the years whose behaviors, emotions, or thinking abilities had become disordered, disrupted, or unusual as a result of some type of brain disease or damage.

Patients don't exist in a bubble but are at the center of a complex, interrelated system of family members and health professionals. So although my primary focus is on the patient, every story is enriched by the people in that system as well, caught up in the fallout from what is often

a life-changing and sometimes life-threatening brain disorder. Insights into the human psyche come from many sources: the courage demonstrated by a patient who, because of a stroke, has lost the ability to walk and speak but can still comprehend; the denial, anger, grief, and acceptance family members experience as they help the patient struggle with rehabilitation; the empathy and helplessness felt by the neuropsychologist assessing the patient; the exciting discoveries made by the researcher about the workings of the mind because the patient altruistically agrees to participate in an experiment; and the satisfaction therapists gain from watching the patient get a little better and a little stronger every day, until their help is no longer needed.

Ten of the 15 patients who are the stars of this book also featured in the second edition of my textbook, *Fractured Minds: A Case-Study Approach to Clinical Neuropsychology*, published by Oxford University Press in 2005. But in *Trouble in Mind*, the emphasis is on the patients, whose cases—if first introduced in *Fractured Minds*—have been rewritten, with added richness about the interactions between the patients, their families, and the health professionals who dealt with them. I retained 10 of the original cases, either because their disorders were so rare that they were the only patients I ever met who had them or, in the case of patients with more common disorders, because their stories were especially revealing, moving, or uplifting. The five new patients who have made their way into this book allowed me to demonstrate, through their particular stories, a wide range of responses to some of the most common neurological disorders.

Details that could identify patients have been changed, including, in most cases, their given names. Rather ironically, the one exception to this is HM, the famous amnesic. In spite of the thousands of research

articles written about him, for 55 years only a small circle of researchers and caregivers knew his identity. On his death in December 2008, his name and image were finally released to the public. As one of the honored few to work with him, I knew his name—Henry Molaison—and face as long ago as 1985, but even today I still think of him as HM. A photo I took of him back then can now see the light of day and is reproduced, along with his real name, in Chapter 7.

To keep the book within reasonable limits, I have not covered the range of disorders included in *Fractured Minds*, but I hope that my selection will satisfy readers who are seeking more information and understanding of some of the very common disorders, such as head injury and Alzheimer's disease, as well as those readers who are simply fascinated by the strange and sometimes bizarre behaviors—such as failing to recognize familiar faces—caused by damage to that squishy gray organ inside our skulls.

In this "sequel" to *Fractured Minds*, only the first chapter discusses clinical neuropsychology and neuroanatomy in any depth. Some readers might want to skip much of that chapter and go straight to following chapters, each of which concentrates on the story of one, or occasionally two, patients with a particular disorder. I have kept detailed research findings and theoretical analyses to a minimum in these case-study chapters, and where especially interesting articles or books are mentioned, I do not cite them formally in the text, to avoid interrupting the story's flow. At the end of each chapter the reader who wants to learn more can find a short section of further reading, including articles, books, biographies of patients, and even novels where one of the fictional characters has the same disorder as the real patients in that chapter and often faces the same struggles and challenges—but in a more literary manner!

So walk alongside me as I enter the hospital wards and rehabilitation units to assess, counsel, and learn from the patients who arrive there daily, shocked and shaken and often changed forever, but harboring strengths they do not yet know they possess, but that will serve them well through the long and challenging months ahead.

Acknowledgments ■

Thank you to the many patients and their families—those featured in this book and all the others as well—who taught me much of what I know about the importance of having a healthy brain, a strong mind, and a giving spirit. Thank you also to my more formal teachers, mentors, and colleagues, especially Michael Corballis, Suzanne Corkin, the late Dorothy Gronwall, Edward Mee, and Lynette Tippett. Thank you to my many students whose enthusiasm for stories about real patients fed my passion, and to the many great neuroscientists and clinicians whose writings and wise counsel did likewise. I am especially grateful to Ken Heilman, Muriel Lezak, Kevin Walsh, and Barbara Wilson, each of whom has modeled for me what a "good doctor," in all of its meanings, is.

My agent, April Eberhardt, my Oxford University Press editor, Joan Bossert and the wonderful OUP team—especially Tracy O'Hara, Jenni Milton, Arun Prasath, and Jesse Hochstadt—have turned the manuscript into a book and

kept me "on task" with patience, good humor, and good judgment. Their faith in this book and their belief that I know something about its subject matter makes all the difference!

Thank you to Michael Leunig, the Australian poet, cartoonist, and cultural commentator, declared an Australian Living Treasure by the National Trust of Australia in 1999, for generously allowing me to reprint in Chapter 11 his heartwarming cartoon "How to Get There," from his book *A Bunch of Poesy* (Angus & Robertson, 1992).

Kind permission to use the title of the great blues song "Trouble in Mind" as the title of this book, and to reprint the first verse of the song's lyrics was granted by Hal Leonard Corporation (**Trouble in Mind**, Words and Music by Richard M. Jones, copyright © 1926, 1937 Universal Music Corp. Copyright Renewed, All Rights Reserved).

The lyrics of the first verse of "Goodnight Irene" are reprinted in Chapter 2. Huddie Ledbetter (1888–1949), better known as Lead Belly, was the first to record the song in 1934 while he was in the Louisiana State Penitentiary, but he had been performing the song since 1908. The lyrics of an earlier version were published in 1886 by Gussie Lord Davis; whether he adapted it from a song he heard or wrote it himself is lost in the mists of time.

Back in the present, various members of my family have contributed with good humor and the occasional insight to discussions on the troubled mind, and have cheerfully ignored my moans about sitting at the computer instead of lying in the sun with a good novel. So here's to all of them, with thanks: John, my husband, and our four children and their families—Caroline and Walter; Jonathan, Sharon, Sophie and Danielle; Josie, Stephen, Belize, Ted and Louie; and Joachim. Almost as many as patients in this book.

Contents ■

1 ■

Backstory: The Basics of Clinical Neuropsychology

Writers of fiction are warned to put backstory where it belongs, at the back! Backstory is the plethora of peripheral or "historic" background information a writer believes the reader needs to know to fully appreciate why the fictional characters in their novel feel and behave as they do. Fortunately *Trouble in Mind* is not fiction, so I have opted to put the backstory in the front. I believe that students and health professionals in particular will find this chapter a useful introduction to neuropsychology and basic neuroanatomy, and that it will aid their understanding of the theory behind the case studies that follow. I hope it is also of interest to many general readers, providing, up front, answers to some of the questions that are sure to occur to them as they read the case studies. Another advantage of putting the backstory at the front is that it is quickly out of the way, freeing readers to immerse

themselves in the world of each patient without being distracted by too much theory.[1]

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Brain disorders are among the most common disorders suffered by humans; by the time we are 30, most of us will know someone—a family member or close friend, or even perhaps ourselves—who has had to cope with brain damage of some sort. Perhaps your grandparent was diagnosed with Alzheimer's disease (AD), or your partner suffered a stroke, or you had a friend whose head was bashed in in a car accident and as a consequence struggled at school or work for months, unable to concentrate or function normally in a noisy environment. In my role as a clinical neuropsychologist, I have met many such people over the years, and in the chapters that follow I relate the stories of some of them: people whose lives have been turned upside down when that most mysterious of organs, the brain, is damaged or diseased.

Some patients are able to accept a diagnosis of a terminal brain tumor with apparent calmness, but more often the early reaction is a multilayered one of disbelief, denial, anger, and grief.[2] Families likewise find themselves

[1] Throughout the book I use the medical term "patient" rather than "client," as all of the cases I discuss have medical rather than psychological conditions, and usually my first contact with them was when they were medical patients in a hospital. However, "client" is a more appropriate and empowering term for people seen in a psychology clinic, whatever the cause of their problems. I sometimes use the word "participant" when referring to a person (or "subject") who takes part in a research study, even if that person also has a medical disorder.

[2] The suggestions for further reading at the end of this chapter include *A Journey Round My Skull* by Hungarian author Frigyes Karinthy, a fascinating and insightful first-person account of what it is like to have a brain tumor and brain surgery. Other readable biographies and personal accounts of the experience of brain injury and disease include the books by the great Russian neuropsychologist Alexandr Luria and the volume edited by Narinder Kapur.

tipped into an unknown realm—a nightmare that they thought happened to other people and not to them. The doctors, nurses, psychologists, and all the other health professionals who assess, diagnose, treat, and care for these patients have chosen this as their career, and thus do not have these situations thrust upon them. They come to each new patient with experience, knowledge, and professionalism, to do a job to the best of their ability. At the end of the day they can go outside into the sunshine and take up their own lives, thoughts of their patients receding as they engage with their own loved ones. Yet at some point, usually at an early stage of their career, most of the professionals who work with these patients will have a hard time controlling their emotions, and may even have occasions when they have to make a sudden exit from the patient's bedside. It is often a particular patient who sneaks into their hearts—perhaps a small, sad child the same age as their own cheeky daughter, or an old man with the wise eyes of their grandfather who died just last year.

Medical practitioners and psychologists are trained to use science rather than intuition and emotional reactions to diagnose and treat illness, and while an objective and scientific approach is essential, clinicians must also be good communicators and listeners, skills that require more than an ability to express oneself clearly. Many professions that deal with human tragedy have few, if any, training hours devoted to teaching practitioners how to understand and cope with their own emotions, in part because emotions are the most elusive of things to deal with in an academic setting. Psychologists and psychiatrists may be an exception; because an important aspect of their job is to help people express and understand their feelings, learning to understand their own should be considered a prerequisite.

It is a fine balance, caring for people in a professional way without losing empathy. Learning to live with and deal appropriately with their feelings is part of the job of

all health professionals (and policemen and firemen and people who work with victims of natural and man-made disasters or who pick up the pieces after a terrorist attack). For health professionals or health care providers, caring is almost as important as knowledge and skills. Of course, if you or someone you loved was faced with having to undergo a delicate neurosurgical operation, and your choice was between an experienced neurosurgeon with an abrupt approach and a novice neurosurgeon with a wonderful bedside manner, I suspect you would choose the experienced surgeon. Let us hope that you would not have to make such a choice. Observe those doctors who are skilled communicators: when they are giving bad or difficult news to a patient they come across as calm, confident and knowledgeable, yet somehow they are gentle and empathetic at the same time. But it takes experience and practice—and humility—to achieve this.[3]

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As a discipline, clinical neuropsychology lies midway between *psychology*—the study of human behavior and the nonmedical assessment and treatment of psychological disorders—and *neurology*—the medical discipline concerned with brain and spinal cord diseases and treatments. Thus a clinical neuropsychologist is a psychologist who specializes in the psychological assessment, diagnosis, rehabilitation, and therapy of people with brain disorders. Some neurologists—medically qualified doctors—specialize in clinical neuropsychology; they are often known as *behavioral neurologists*. Clinical neuropsychologists who are

[3]In the suggestions for further reading at the end of this chapter I have included references for a number of books—accessible to the general reader—by medical practitioners Pauline Chen, Atul Gawande, Jerome Groopman, Kenneth Heilman, and Danielle Ofri. The practice and writings of these clinicians embody all the characteristics of a "good" doctor.