

Author's Note

Why I Wrote This Book

This book is intended for those who have suffered from a brain injury and know it, for those who have suffered a brain injury and will not know it until they recognize aspects of their lives in these pages, for those who have family members or friends who have suffered a brain injury, and for those who are simply interested in the magnificent inner workings of the most powerful computing device on earth: the human brain.

Stories of my fellow concussion survivors have flooded the media in recent years: returning combat veterans who have suffered traumatic brain injury (TBI), professional athletes who are demanding accountability from sports leagues and helmet makers, and some of our country's youth who have suffered troubling sports concussions. Given the *millions* of TBIs that are even reported each year in the United States alone, this is, yes, a quiet plague of epidemic proportions. Yet our society is only grudgingly coming to recognize that concussions are serious and life-changing injuries that may have lingering, undiagnosed symptoms such as emotional difficulties, fatigue, learning problems, and social problems that can last a lifetime.

In my experience, the medical community's standard of care for certain classes of TBIs has not yet caught up with effective new treatments that are available. There are many excellent physicians who have been exposed to current research in "brain plasticity" (wherein parts of the brain can be trained to compensate for other, injured parts), especially younger physicians working with sports injuries and rehabilitation. However, it is unfortunately true that many M.D.s, including leading neurologists—as well as putative leading rehabilitation institutions—are as of the time of this writing unwittingly out of date when it comes to accurately diagnosing and treating concussion. This is unspeakably sad for those who are needlessly suffering and believe they have nowhere to turn.

The later chapters of this book that cover the science behind my recovery may also be highly revealing for those who suspect that they suffer from some form of attention difficulty, such as ADD, or suspect that a family member does. In the process of my recovery I realized that many of the features of such attention difficulties significantly overlap with those manifesting as concussion symptoms. From the many anecdotes I've heard from my university students, and others, I think we should be highly suspicious that some of these attention difficulties are rooted in prior, sometimes even mild, head injuries. How many times have I heard, "Oh, yes—now that you ask, I did start having this trouble last year after I had that [car accident/ skiing mishap/ skateboard fall/ soccer concussion].. . ."

The small changes that can occur in one's brain from even a quite forgettable bump on the head can masquerade in subtle ways such as personality oddities, trouble with multitasking, sleep disturbances, and even just growing old. Who would have thought to consider that slip on an icy doorstep five years ago as the culprit behind having a slight sense of being out of sync at unpredictable times, or having trouble managing appointments?

As a professor of artificial intelligence and cognitive science, I have shared some of the concepts covered in this book about how brains work with my classes, including the ideas behind several leading-edge cognitive restructuring, and neuro-optometric, treatments. It has been striking that I have never failed

to have, in each such course, at least two students talk to me after class about their extreme interest in the material because of their own information- processing difficulties. This suggests to me that the kinds of brain difficulties experienced by *concussives* (as in, those who have suffered concussions)—albeit in much milder forms than my own—are far more widespread than we might traditionally suspect, especially among high-functioning, intelligent people who are very good at masking such problems.

One of the things concussives share is the feeling of having become an alien being. We still walk and talk and act as though we are part of the human race, but it doesn't feel that way inside. Essential parts of our brains that convey what it means to be fully human have disappeared—vanished in that moment of impact when we tripped on the stairs, or crashed into an arena wall. Instead there is a strange feeling of nostalgia, a longing for who we used to be.

Normals— those who haven't suffered from concussions— will take for granted the countless small operations their brains perform as they think and gracefully move their bodies through the day. But a concussive loses the ability to manage the staggering complexity of the systems that implement these operations, and as a result loses not only basic cognitive and motor functions, but also a larger sense of self- identity, and identity in relation to the world. This makes us odd beasts—a cross between what amputees may experience with phantom limb syndrome, and what *hemispatial neglect* patients have when they suddenly lose half of their world: On the one hand, with a phantom limb, amputees are constantly reminded of what they used to be, of being whole. On the other hand, neglect patients are missing part of themselves and their world, and while they feel a sense of loss, they can no longer even imagine what it is they are missing. For a long time I lived in such a dual- natured limbo.

This book captures my harrowing yet ultimately fascinating odyssey as a concussive. For almost a decade, and even while struggling mightily—sometimes just to get through a doorway, or down a flight of stairs—I was constantly observing, analyzing, and recording the events unfolding in my life, and the ways in which my damaged brain was trying to make sense of them. I took twelve hundred pages of notes, and through them I became the subject of my own long-range experiment in cognition— exploring the relationship between mind and body, and the inner mind and outer world. Along the way I learned a great deal about how the *healthy* human brain works as well— leaving me in awe of this sublime and formidable computational device.

The book's title is a play on the phrase *the Ghost in the Machine*— and thus an indirect allusion to the seminal French philosopher René Descartes's idea of a mind- body dualism. Descartes believed these two agencies were separate— that the mind existed separate from the body. Oxford philosopher Gilbert Ryle disagreed, and in 1949 used the phrase to poke fun at Cartesian dualism. Although the jury is still out on this question, I know from personal experience— such as on a snowy night we'll soon see in downtown Chicago— that the mind and body are intricately intertwined. But the meaning of the title goes beyond this duality. Readers will come to understand that the ghost in my book is the sense of my true self—the “me” that was sent into exile in the moment of a car crash. Years later I underwent cognitive treatment based on the new principles of brain plasticity. Shortly thereafter, one evening outside my office at DePaul University, I felt the ghost return. My old self—the ghost of who I had been and who I so longed to be once more—had come back. I wept tears of joy that I was no longer sentenced to life as an alien living among real humans.

Above all, this is an illustrated tour through the odd, awe-inspiring, painful, scary, tragic, and fascinating world of brain injury, but one that in this case has the all-too-rare happy ending—an ending that is yet

also likely to be possible for many thousands of those still exclusively locked into more traditional treatments (or non-treatments, as the case may be) for concussion.

As recently as four years ago I was told by local experts in the Chicago medical community that the only course of action I could take to deal with my symptoms was to learn to live with them. This would have entailed giving up my tenured position as a university professor, retiring into poverty from all forms of work, giving up the custodianship of my children, and perhaps becoming a ward of the state.

And yet today, through the courageous work of two brilliant Chicago-area researcher-clinicians, each of whom works at the leading edge of brain science relative to certain kinds of traumatic brain injury, I am almost without symptoms. The efforts of Donalee Markus, Ph.D., who rebuilds brains by using puzzles, and of Deborah Zelinsky, O.D., who accesses the visual cortex and regrows brain pathways using prescription eyeglasses, gave me back my life.

This is my story.

From *The Ghost in My Brain: How a Concussion Stole My Life and How the New Science of Brain Plasticity Helped Me Get It Back*, on sale now. Reprinted by arrangement with Viking, an imprint of Penguin Publishing Group, a division of Penguin Random House LLC. Copyright © 2015 by Clark Elliott.