

“Rabbit’s clever,” said Pooh thoughtfully.

“Yes,” said Piglet, “Rabbit’s clever.”

“And he has Brain.”

“Yes,” said Piglet, “Rabbit has Brain.”

There was a long silence.

“I suppose,” said Pooh, “that that’s why he never understands anything.”

— A.A. Milne, *Winnie-the-Pooh*

“I’m not lost for I know where I am. But however, where I am may be lost.”

— A.A. Milne, *Winnie-the-Pooh*

■ ■ ■ CONTENTS

*Preface / xiii*

- ONE     Haphazard: In Denial / 1
- TWO     The Room at the End of the Hall / 25
- THREE     A Bear of Very Little Brain / 39
- FOUR     My Travels Begin / 51
- FIVE     A Mind in Mutiny:  
           Holding on through Memory / 75
- SIX     The Swallow Lady / 93
- SEVEN     The Wheelchair and the Urinal / 139
- EIGHT     Jack the Bird Man / 165
- NINE     Home, Therapy and Forest Bathing / 217
- TEN     Fragments: Searching for Normality / 263
- ELEVEN     Recovery: Some Final Thoughts / 301

*Select Bibliography / 309*

*Acknowledgements / 311*

*About the Author / 315*

■ ■ ■ PREFACE

*Every forty seconds someone  
in North America suffers a stroke.*

*Every four minutes someone in  
North America dies from a stroke.*

*Stroke is the leading cause of disability  
in North America.*

*The Defiant Mind: Living Inside a Stroke* took me over a year and a half to write, pecking one letter at a time with the index finger on my left hand. Eventually I learned to use my thumb to hit the space bar. This process was by no means as slow as signalling each letter of each word by blinking one eye, as was Jean-Dominique Bauby's method of dictation when he composed his exquisite *The Diving-Bell and the Butterfly*. Yet, compared to my typing eighty words a minute prior to my stroke, I lumbered along writing this book, like the tortoise in Aesop's fable. I was determined to win the race, but my lone finger had difficulty keeping up with the pace of my thoughts. Those thoughts ran ahead like the hare, who stopped, every so often, to nap. Meanwhile, my finger poked and plodded along, and I finally crossed the finish line, my thoughts and finger arriving at pretty much the same time.

The book is completed, even though my right hand and arm, foot

and leg still suffer from the effects of spasticity. And even though, as far as I know, I've emerged a somewhat altered person. Later, much later in my recovery, an internist told me that the difference between a heart attack and a stroke is that after a heart attack you at least know who you are.

My story begins with the first hint that something unusual was happening to me, on a day that began like any other and ended with my body and brain suffering a frontal assault of such magnitude that I was left severely disabled. The actual attack lasted for several hours, perhaps days. No one knew for sure how long my brain was under siege or how many brain cells had been destroyed. The initial CT scan taken the evening I ended up in hospital showed nothing, but a few days later, after another image was taken, the damage was writ large for everyone to see. I now had the road map for the attack on my brain stem, but no one seemed able or willing to explain why it had happened.

As is the case with all strokes, mine was haphazard and unique.

Perhaps the most frightening thing for me was that I was rapidly losing contact with the world I knew. Suddenly nothing made sense anymore. On the one hand, I wondered why all the fuss; on the other, I knew I needed help.

But what would help?

And who?

To exercise my brain and in the hope of finding out what had happened to me, I spent a considerable part of the second half of my first year of rehab reading books about the brain and a few about brain attacks suffered by other stroke survivors, including books by Jill Bolte Taylor, Bonnie Sherr Kline, Robert McCrum, as well as Jean-Dominique Bauby. Each one gave a disturbing if not chilling account of their stroke. They talked about the loss of cognitive powers, about being "locked in" (like Stephen Hawking with his ALS),

about being handicapped, about the stress put on relationships, especially family and marriage. And about the triumph of love and the power of the “will to be” as keys to the effectiveness of the lengthy rehabilitation process.

Their stories helped to show me some ways to recovery, and yet something important seemed to be missing from their accounts. No one discussed the role of mind and memory in reasserting a sense of self. Despite the huge pummelling I had taken, I began to realize that my fragments of memory confirmed not only “who I was” but gave me the “will to be.”

Another thing, their strokes were hemorrhagic — a bleed in the brain — the rarest form of stroke, while mine was ischemic — a clot or blockage in the brain — which is the most common type of stroke, accounting for approximately 82 to 87 percent of strokes.

One key point to know when reading this account: In the early days after my stroke, I lost my ability to forget. All the protective defences I had learned since childhood were destroyed. I was bombarded by the pandemonium of sounds, images, memories and emotions that flood our brains at every moment of our daily lives. At first I didn’t know how to cope with this explosion of sensations and thoughts, but slowly I learned to live again through my memories. As I lay in my hospital bed, memory became my salvation.

As the world about me became more turbulent, I drew more heavily on my past. My hunger pains in the hospital triggered memories of nearly starving in my youth and caused me to relive a trip I took to Spain in the winter of 1964/1965. By recalling how I dealt with events that had dislocated me then — allowing me to survive — I found a way of relocating myself in the “now” and reclaiming who I was.

My stroke account moves in and out of past and present — between a past in which I lived amongst people inhabiting far-away lands

who spoke in foreign tongues, and a present in which I lived amongst people who occupied a world where I now felt like a foreigner and with whom I struggled to communicate with my new thick and unresponsive tongue. The travel memories in my book, which serve as a metaphor for the recovery of my self, recount the ways I found of saying, “I am alive and I am still thinking.”

When I was able to stay awake, my brain was hyperactive, flooded with ideas and impressions, to the point where I began to feel overwhelmed. When I was on the edge of sleep and feeling under siege, I asked myself:

How am I to avoid being overwhelmed?

How might I find my way back?

How might I rediscover my old self?

From my perspective, I ended up living inside the stroke. I was no longer in the everyday walkabout world as a functioning member of society. In the following pages I have attempted to provide a day-by-day account of what was happening to me, and what I learned that might help in future therapeutic practice. I describe the process by which my memories helped me to reassert who I was and gave me the will to continue. At times the endeavour was comical, at times fiercely depersonalizing.

I soon understood that I could either give in to the despair that haunts many stroke patients or figure out a way to rebuild all those bridges in the brain that define who I am. I knew I had to escape from the bottle of voices and ideas that threatened to overwhelm me. I needed to rediscover the regulator or “governor” that keeps the traffic in the brain organized and at speed. Otherwise chaos would set in.

Since my stroke, as part of my self-directed therapy, I have read widely about brain research. The ability of the brain to recreate or modify its structure is the foundation of the important and exciting work now being done on what is referred to as brain plasticity.

Therein, I believe, lies the promise of reconnecting and reformatting — in essence, healing — the traumatized brain.

Months into recovery when I was doing research on strokes and was particularly interested in researching the brain, I dipped into A.A. Milne's *The World of Pooh*, which seemed to sum up perfectly what a stroke entailed for the survivor and what it meant to many of the people a stroke survivor was likely to meet. A common response to someone who has suffered a stroke is that they no longer have a functioning brain and, if they do, it's lost and they're elsewhere. I suddenly found myself being treated like a curiosity at best, as an "untouchable" at worst. I felt I needed to keep saying, "I'm not a stranger, and I'm not a cabbage, I have eyes and, like Rabbit, I have brain."

My recovery continues, and I'm optimistic that one day I will regain at least 80 percent of my previous mobility. A whole community of people has contributed to my recovery: friends, neighbours, family, nurses, doctors, therapists.

Over the course of two years I learned that many health professionals make a puzzling and disturbing separation between the body and the brain. While therapists and doctors helped with my physical recovery, I learned that the restoration of my cognitive "being" was up to me. No one seemed interested in what was happening inside my brain. No one seemed interested in my "subjective" thoughts — experiences which J. Allan Hobson (who himself suffered a stroke fourteen years ago and is professor emeritus of the Harvard Medical School) argues should be central to stroke research and understanding.

Each stroke event is unique because each brain is unique. This is the mantra which is continually repeated by health professionals, but is too often ignored in treatment. My book advocates for a greater focus on the brain in stroke assessment and recovery, and for placing

a much greater importance on the subjective, anecdotal accounts of stroke survivors.

“Listen,” each stroke survivor should demand, “I need to be heard.”

At its heart, *The Defiant Mind: Living Inside a Stroke* is a book about the wonder that is the human brain, both before it has been damaged and after, when it’s struggling to pick up the pieces and make some sense of the muddle it has become — the jigsaw puzzle of scattered recollections, unidentifiable objects, inexplicable emotions, impenetrable ideas. Unfortunately, as our population ages, more and more people are going to experience strokes, although it is important to note that strokes hit at any age, from infants to teenagers to young and middle-aged adults. Disturbingly, the Heart and Stroke Foundation tells us, “. . . there has been an increase in strokes among people under sixty-five and an increase in all stroke risk factors for younger adults.”

At a time when the medical profession is bracing itself for an assault on the health system, health care professionals are actively looking for ways to make their interventions more patient focused. For this reason, months after I suffered my stroke, I decided I would write the story of my brain attack, giving an inside-out view of stroke and, more importantly, showing everyone that *recovery is possible*. Since many stroke victims cannot speak for themselves, my goal has been to write a book that provides a voice for victims, and gives insight and encouragement to families, friends, caregivers, medical professionals and the general reader by demonstrating that *rabbit* (that would be me and my fellow stroke survivors) truly *has brain*.