

# Stroke Survivors

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# Stroke Survivors

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# Preface

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The percentage of stroke survivors has increased dramatically since 1950, making strokes a major cause of long-term physical disability in the United States. Extensive research has been done on the physiological and physical adjustment to strokes. This research has been effectively conveyed to stroke survivors through many excellent publications distributed by the American Heart Association or made available through other sources. But until recently, we knew little about psychological issues confronting stroke survivors.

We do know that depression, anxiety, and disruption of sexual function frequently go along with recovery from strokes. While a few studies provide us with a first glimpse into the processes of adaptation to a stroke, they do not adequately address the complex processes associated with the psychological adaptation to strokes. We do not have a comprehensive portrait of the recovery process or recommendations for stroke survivors, personal (family, relatives, friends) caregivers, or professional caregivers regarding this recovery process.

In this book, we report on a study we conducted and reflect on our own experiences as men and women who have had strokes or have provided psychological services to the survivors of strokes. We offer stroke survivors and their caregivers an opportunity to listen to the stories told by other survivors and caregivers about poststroke feelings and processes. These stories are filled with the depression and anxiety that have been identified in many previous studies. However, they also reveal

optimism and even a sense of excitement about the new challenges and self-insights that emerged from the stroke experience.

## What Is a Stroke?

Many people think of strokes as somehow related to heart attacks, but they are more accurately thought of as *brain attacks* (a term being used more and more frequently by professionals in the field). A stroke is the disruption in the blood supply to the brain, either from outside or from within the brain. When the blood supply is cut off to one part of the brain, it does not receive the oxygen it needs and the result is damage to the brain cells. The medical term for stroke is *cerebrovascular accident* (CVA).

Many medical workers are skilled in educating patients about the trauma and aftermath of strokes. We urge you to consult with these professionals. Our study in no way replaces the need for expert medical diagnosis or treatment. What we want to share with you are some of the experiences of having, coping with, and recovering (partially or totally) from a stroke. The people we interviewed tended first to define a stroke as an event that is big, scary, and confusing. It doesn't seem to have any clear source and often brings about major changes in physical and mental functioning as well as transformations in physical appearance.

A stroke influences not only one's body and mind, but also one's relationships with others and—even more important—one's sense of self. Recovery truly requires a "recreation" of one's self-image and feeling of self-worth. This is at least as difficult as regaining one's bodily and cognitive functions, such as walking, eating, or talking; it is made more difficult because of the need to "rewire" one's brain and body. Hopefully, this book provides assistance to stroke survivors and caregivers in this challenging recreative process.

## The Research Project

Our study was conducted with seventy stroke survivors from northern and central California, specifically from the San Francisco Bay Area

and the Sacramento area. A broadly representative sample was selected, with more than one-fourth of the people being interviewed coming from so-called minority populations. Our central California stroke survivors are similar in attitude and life-styles to survivors living in many Mid-western and Southern communities in the United States, while those from the San Francisco area are representative of men and women from urban centers as well as from affluent and middle-class commuter communities in the United States. One half of these interviews were conducted between 1990 and 1992 by doctoral students at the Professional School of Psychology and by two of the authors, William Bergquist and Rod McLean. A further set of thirty-five interviews were conducted with stroke survivors and caregivers during the fall of 1992 by students in a master's-level program at the same school.

The interview schedule used in this study was developed by the authors and the graduate students in San Francisco and Sacramento who were conducting the interviews. While the interview schedule was much too long for anyone conducting a one-hour interview with stroke survivors and caregivers, it served as a solid guideline for the interviewers when they were working with the open-ended interviewing processes of this project.

## Organization of the Book

*Stroke Survivors* is divided into four parts, each consisting of three or four chapters. Many of the chapters are written by Rod McLean, who is a stroke survivor. He offers a detailed personal account of having and recovering from a stroke. We supplement his chapters with others that contain the stories and insights from the seventy stroke survivors we spoke with.

Part One focuses on the stroke experience itself, as well as describing precursors to the stroke and the survivors' early poststroke experiences (usually in the hospital). In Chapter One, Rod offers his personal experiences and insights regarding the stroke. Chapter Two follows up by providing a synthesis of the experiences that many other stroke survivors shared with us. It also touches on factors that may have precipitated their strokes. In Chapter Three, we pick up the thread of Rod's

narrative, focusing on his early hospital experiences. Chapter Four concludes this first section of the book with a synthesis of our interviews regarding the survivors' initial confrontation with the reality of their strokes.

Part Two deals with the immediate aftermath of the stroke. The stories in this section primarily concern the early rehabilitation process, usually in a rehabilitation center. In Chapter Five, Rod picks up where he left off in Chapter Three, offering unique insight into the rehabilitation process. Chapter Six provides a complementary survey of the rehabilitation experiences of the other stroke survivors we interviewed. It also discusses perhaps the most important phenomenon associated with the rehabilitation process: the experience of being a "new person" following the stroke. The next two chapters shift our attention from internal matters to external relationships. In Chapter Seven, Rod describes changes in his relationships with other people following his stroke. Chapter Eight contains a more general analysis—based primarily on the interviews we conducted with stroke survivors—of the impact of strokes on personal relationships.

Part Three examines stories concerned with returning to the "real world" and discovering or inventing a life-style built on the new realities and new sense of self emerging from the stroke recovery process. Our account of this phase in the recovery process begins in Chapter Nine with Rod's description of returning home. Chapter Ten focuses on the changing realities of the stroke survivors' lives and is based on the interviews conducted by our research team. In this chapter, survivors speak of what they have lost and gained from the stroke experience. Insights from survivors also provide the focus of Chapter Eleven. This chapter synthesizes the responses to the question we asked at the end of every interview: what would the survivor like to say to other survivors that might help them with their own recovery?

Part Four offers another perspective on stroke recovery. It looks at this process from the viewpoint of the caregivers—both personal (relatives and friends) and professional. All four chapters in this final section underscore the need to extend understanding and support to the caregivers, who play such a critical role in the recovery process. Chap-

ter Twelve focuses on how family caregivers assist survivors in this process. Chapter Thirteen looks at what the family caregivers consider to be the gains and losses and lessons learned from their experience. In Chapter Fourteen, Barbara Kobylinski describes her experiences in helping survivors and their families. In Chapter Fifteen, she offers her thoughts on the processes of healing and letting go as a professional caregiver. Readers who want to know more about a typical rehabilitation process may wish to read these last two chapters first.

An epilogue concludes the book, in which Rod shares with us the lessons he has learned from his own experience and the ways he has been able to put these lessons into practice. This book synthesizes the lessons learned from individuals who have had to cope with a stroke that either they or someone close to them has experienced. What do they have to say about the recovery process? What can be learned from the many stories we heard regarding the critical factors in promoting successful recovery from strokes? What are the implications of our findings for future stroke rehabilitation programs and policies? Given that we are at a crossroads with regard to health care in the United States and are engaged in a radical reconceptualization of disabilities and recovery processes, the insights reported here should be of considerable interest to those involved in new perspectives and new policies. The millions who confront the awesome challenge of stroke recovery and caregiving need, want, deserve, and demand our compassion—and even more important, our understanding and assistance.

## **Intended Audience**

Our primary audience is made up of stroke survivors and their caregivers. In reading this book, they can develop an increased awareness of the capacities still present in survivors as well as the limitations imposed by a stroke. The book is also meant to foster greater understanding and appreciation of the attitudes, skills, and knowledge needed to effectively cope with this major life intrusion. And the very act of sharing stories can speed the recovery process.

Health care providers and other concerned members of the health



care community are a second audience for the book. We offer a coherent developmental portrait of people who have successfully coped with strokes. Using this portrait as a model, these leaders and helpers can more effectively address the distinctive needs of survivors of strokes and their caregivers and can help empower them. Unfortunately, the stories that many stroke survivors and caregivers have offered us too often contain instances of insensitivity or even indifference on the part of professional caregivers. These frequently overworked professionals can be excused for their own distress and fatigue—which can lead to insensitivity and indifference—as they confront the complex changes now occurring in health care facilities throughout our society. There is no excuse, however, for the seeming failure of at least some professional caregivers to fully appreciate the distinctive needs and goals of stroke survivors. This book hopefully will help increase this understanding and appreciation among these professionals.

## Acknowledgments

We wish to express our deep appreciation to the people who agreed to be interviewed for this study. Such a project could not have been conducted without the generous cooperation of many stroke survivors and caregivers, who volunteered to share their insights into the complex and challenging processes involved in “the reconstruction of self.” While their names have been changed and their identities sufficiently protected to preserve their anonymity, we thank them for agreeing to expose their experiences, hopes, and fears to unknown interviewers.

While many of our informants indicated that the interview gave them a wonderful opportunity to talk with someone (often for the first time!) about their stroke experience, they were most interested in the value of their experience for others who are also recovering from strokes. Hopefully we have earned the trust of these thoughtful men and women and have produced a book that will be of use to stroke survivors and those who care for them.

We also wish to acknowledge the extraordinary talent and commitment of our student interviewers. We’ve recognized their contribu-

tions of time, effort, wisdom, and words to this study by listing them as case contributors at the end of the book. We thank all of them for their exceptional work. And on a more personal level, we would like to express our deep appreciation for the care and respect shown by our life partners, Kathleen O'Donnell, Joette Scoma, and Gerry Kobylinski. They have all provided guidance, encouragement, support, and some much-needed editing for this book. We are indebted as well to mentors in our past—whether they be a grandmother (Anna Briesch), parents (Herb and Carol McLean), or colleagues (Robert Shukraft and Carol Howard)—for their constant encouragement and inspiration. We also wish to note our gratitude to the many health care workers—physicians, rehabilitation specialists, nurses, counselors, and teachers (notably Elizabeth Piccard and Christy Baker of Florida State University)—who have cleared a path for us in acknowledging the role that psychological factors play in the processes of rehabilitation. Finally, we even want to thank those few men and women who have said no to us—who have attempted to place unnecessary limits on us in terms of our personal accomplishments and the scope of this research. They have inspired us to try harder to clarify our goals for this study and for our individual lives.

*June 1994*

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# **PART ONE**

## ***Having a Stroke***



## What's Happening to Me?

I'm Rod McLean. I'm a stroke survivor. As a matter of fact, a neurologist described my stroke as a "spontaneous hemorrhage from an angioma or arteriovenous malformation in the left parietal area." In other words, a blood vessel in the left side of my brain had a weak point and burst. And it hurt! I was told later that I was within seconds or minutes of dying. But I guess I was as lucky as I could be, for it just happened that one of the best neurosurgeons in the region was right there when I was carried into the emergency room. He jumped into action to open my cranium and halted the rupture within moments.

The big one! It sure was. I think it was a Wednesday, late afternoon. Patty—a friend of mine—and I decided to walk four or five blocks to the fast-food restaurant. About halfway back, something started happening. It was really strange! I was invaded by an instant and massive headache. Everything started to become different—I didn't know what it was. I looked at my feet, but they didn't seem as though they were mine. I had to concentrate to make sure they would do what they were supposed to, because I noticed that I was having a harder and harder time walking.

At the same time, Patty became aware that something was going on. When she asked me questions, I heard and understood everything, but then I couldn't understand that I was forgetting whatever it was she had said. Not only that, her voice sounded like an echo. I had no reference point and quickly became afraid; I was scared of the unknown.

I noticed the sun was too bright and that I was seeing things surrealistically. My walking became wobbly, but Patty helped me get home.

Gary and Rolf, close friends and roommates, were out in the front yard; they saw something was wrong. In a way, I guess I was relieved to see my friends because it gave me a sense of security. They could see that I was afraid and that I appeared disoriented. They asked what was wrong and, to no avail, tried to figure out something to relieve the situation. Meanwhile, I was staggering and falling around. I struggled to answer their questions and pleaded for help and solutions. Looking at Patty, I tried to reach into my right front pocket to get some money to give her so she could go get me some aspirin. But somehow I couldn't find the right words to convey my needs.

I was trying to do all these simple things at the same time, and nothing was working right! My friends didn't know what to do. They carried me upstairs and laid me down on my bed, saying that I would be all right. They left! I was in pain. Everything was so hot; my entire body was drenched with sweat. I tried to sit up to take my shirt off over my head. I had no balance; every time I fought to sit up, I kept falling back down. The last time I hadn't been able to sit up was when I was a baby! Inside I was screaming, but on the outside I had somehow forgotten how to do that. Next, I tried again and again to take my shoes and socks off—that was practically impossible, too. I'd reach for the laces, but my fingers would totally miss them and I'd fall over sideways. Eventually, my friends came back and saw that I was in worse shape than a few minutes ago. They both stared at me in the realization of my anguish, glanced at each other, and agreed that they should take me to the hospital right away.

Lying on my side, I was starting to completely lose it; I was not really in control of anything. About all I could do was force myself to remain conscious—not really alert, but only distortedly aware that something was happening. Gary and Rolf carried me, limp, to the car and poured me in. Gary raced to the emergency room as Rolf held on to me. My body was still sweating and I was so hot that I had to hang my head out the window. It was odd. All the sounds—my friends' voices echoing and the outside sounds, such as the rush of traffic, cars honk-



ing, the wind, and everything else—angered me to the point of extreme hatred. I felt like lashing out to destroy and eliminate the grating noises that became an overwhelming irritation. My brain was throbbing, exploding with pain. Everything around me was aggravating the problem. I wanted it all to stop!

When we got to the hospital, they carried me into the Emergency Room and put me on a gurney. I was in tremendous pain. I was lying on the bed—out of control. I wanted out! As I internally screamed to escape, my brain continued to grasp for explanations or solutions. At the same time, I had no control of my body; my limbs and torso were writhing back and forth. My instinctual body was trying to get away from this unbelievable pain, too. But since the brain didn't have control, the body was just fighting it all. A nurse came in and looked at me rolling around, obviously in outrageous pain. She held up two fingers and asked me how many I saw. Remember, I was still in a pure rage. When she made that request, my wrath exploded and destroyed my image of her.

I noticed my vision was warped and distorted, and the colors were skyrocketing and forming different patterns; it was like the grand finale of a fireworks extravaganza, and it was all happening in my mind. When I blinked my eyes again and again, I discovered that what I saw was the same whether my eyes were open or closed. Either way, I was *not* seeing things as they were in reality. "Oh my God, I'm blind!" I thought.

Then, for some reason the writhing and internal chaos seemed to cease. I didn't hurt, feel, or hear anything anymore, though I was still scared. I realized that up to that moment, I had been totally exuding anger and hatred. While I was consumed with this hatred, I felt that if I were physically able, I would have flailed about and crushed anything in front of me.

My thought process shut down. My mind's eye rapidly flashed before me scenes from my entire life—from birth to the present. I was floating away into another dimension as if I were watching myself; maybe my spirit was separating from my body. In retrospect, it all seems so strange. Earlier, my body and mind had been working on instinct as I writhed and contorted, attempting to get rid of the horrendous anguish