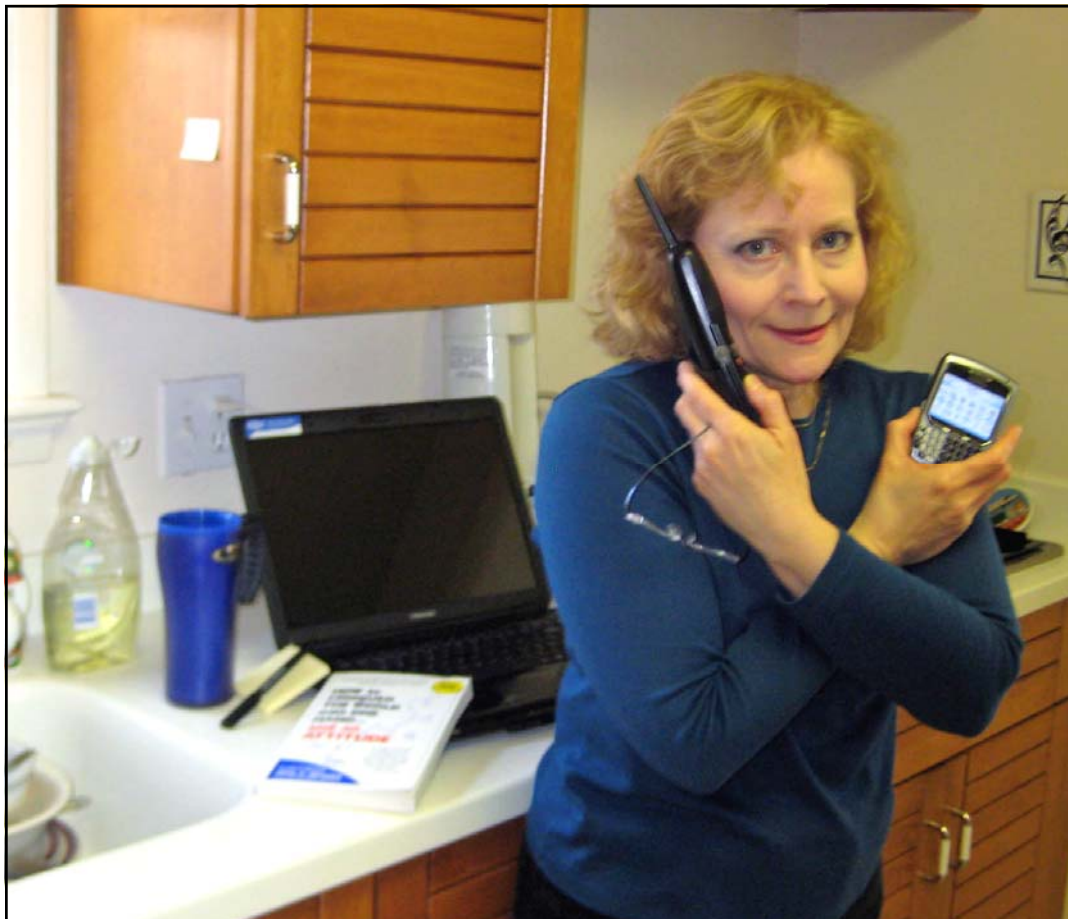


Stroke Survivor
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Paul E. Berger & Stephanie Mensh

*Co-Author of the Internationally-Acclaimed
"How to Conquer the World With One Hand...And an Attitude"*

Stephanie Mensh's
Conquering
Aphasia & Stroke
for Caregivers





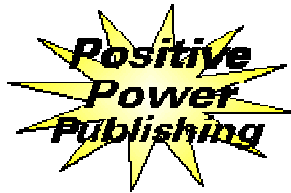
Stephanie Mensh's Conquering Aphasia & Stroke for Caregivers

*From the co-author of the internationally-acclaimed
"How to Conquer the World With One Hand...
And an Attitude"*

By Stephanie Mensh
and Paul E. Berger

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This book represents one person's experiences and
is not intended to be medical advice.

Cover photo by Paul E. Berger



Introduction

My name is Stephanie Mensh. My husband, Paul Berger, had a stroke from a ruptured brain aneurysm over 20 years ago. Paul was 36, and I was 31. One day, we were an average young two-career couple; the next day we both became different people. My personality doesn't really fit the "caregiver" temperament. I never wanted to be a nurse or social worker or teacher—I certainly admire the people who can do these jobs well. And I am sure that Paul never wanted to lose his speech and the use of his right arm and leg!

We are both stubborn, determined, goal-oriented people, who didn't want to watch life go by without jumping in and enjoying ourselves. We were always looking for books and guidance on overcoming stroke, but didn't find much that addressed our real life, down-to-earth, everyday experience and budget. So, we collaborated on a series of articles. Then we wrote Paul's story, chronicling over 10 years of his challenges, successes and failures, "How to Conquer the World With One Hand...And an Attitude." Of course, Paul's story includes me, but it focuses on our adventures from his perspective.

We continue to write and make presentations on successful stroke recovery from both the survivor's and the caregiver's perspective. We have a monthly e-newsletter where I write a column for caregivers. I also wrote a series of articles for caregivers published by "StrokeSmart," the magazine of the National Stroke Association.

This E-book is a compilation of key **caregivers'** issues and solutions, tested in my own relationship and among those caregivers I have had the honor of observing. It is divided into the following chapters, each with related resources:

- Coping with Change
- How to Be Supportive While Building Independence
- Building the Caregiver Team
- Time Management Tricks
- Money Issues & Caregiver's Employment
- Living with Stress...Stress...STRESS !
- Care for the Caregiver
- How the Survivor Can Help the Caregiver

I invite you to visit our StrokeSurvivor.com website for other information, and to collect all our books and products. Details appear at the end of this E-book.

Best wishes,



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Coping with Change

A stroke changes the lives of the stroke survivor, the family, and everyone around them. This change is frightening. The more serious the stroke, the deeper the fear and the broader the change. Paul's stroke was caused by bleeding in the brain. He had brain surgery, followed by a series of related health problems, like aspirational pneumonia from impaired swallowing. My first reaction was shock and fear: fear for Paul's life, and fear of the unknown. Like most caregivers, I knew very little about stroke, and less about what the doctors were doing. It had not yet hit me how much our whole world was changing.

Changes After Stroke. Paul and I had been married for four years, and had settled into a comfortable routine, with fairly traditional roles. Since we both worked full time, we shared some chores, like making dinner and paying bills. When Paul first came home from the hospital, everything changed. He was unable to walk or talk. He could not do work, or do his chores, or even take care of his own needs. The professionals assume that the family—especially the wife—will naturally take over once the survivor is discharged. Becoming Paul's caregiver was difficult, a blow to my independence and self-confidence, as well as his. I was afraid that I could not take care of him. I was afraid that I would not like the new Paul, or the new me.

Fear of Change. Fear of change is one of the leading fears among people everywhere, in every walk of life. While I recognized that other families went through wrenching changes—job loss, deaths in the family, divorce—when the stroke happened to us, I felt like we were the first people to ever have this problem. In retrospect, I realized that I had learned lessons similar to ones described by Carly Fiorina, the first woman CEO of the computer company, Hewlett-Packard, who was fired from that position. At a meeting I attended, Ms. Fiorina quoted these points from her memoir, "Tough Choices," that hit home for me as a caregiver:

- Everyone is afraid of something. Courage is not the absence of fear. Courage is acting in spite of your fear. Facing change and doing something new makes you feel afraid. It's part of the human condition. Be an actor, not a victim.
- We can't choose our circumstances, but we can choose our response to these circumstances. It may not be easy, but there are constructive, positive ways to respond and move forward.
- Look for the "gift" in the bad things that happen. After the public humiliation in the media of her firing from HP, Ms. Fiorina said that she found a gift: "Now, I am not afraid of anything."

I also found inspiration in a little book that Paul used to help him cope with the changes in our lives, "Who Moved My Cheese," by Spencer Johnson, M.D. This is a caregiver-friendly book—it is short and easy to read in one sitting. These points were most helpful to me:



- “When you stop being afraid, you feel good!”
- “You can learn to deal with change...be more aware of the need to keep things simple, be flexible, and move quickly.”
- “It seemed his progress was two steps forward and one step backward. It was a challenge, but he had to admit that ...it wasn't nearly as bad as he feared it might be.”

Male v. Female Caregivers. Over the years, I have met a number of husbands who were caregivers, and believe that they generally approach the changes differently than female caregivers. Some researchers have published articles and textbooks on these differences. Bringing in help is one of the ways that husbands often manage the care when the wife is the stroke survivor, while wife caregivers seem to think that they need to do absolutely everything themselves.

I continued to work full time, not only for financial reasons, but to retain my own identity and feel the rewards from the job. So, I hired people to share in the household responsibilities and caregiving, including a daytime companion to take Paul to therapy sessions, drill homework exercises, and run errands for about 6 months. Fortunately, Paul's parents helped us with some of these expenses.

We Never Stop Changing. Although the stroke changed our relationship, I have worked very hard to focus on the parts of Paul that have *not* changed—his inner spirit, personality, and heart, and the experiences we share. I continue to remind myself that a person is more than the strength of his muscles or how well he speaks.

As I found ways to maintain our household, and rebuild Paul's self-esteem and independence, I found that more of my own self-confidence and independence returned. Every stroke is unique and how the survivors, caregivers and families cope is unique and constantly changing. Many stroke survivors, like Paul, can change in positive ways, continuing to make tremendous progress toward independence years after the stroke. And many caregivers, like me, can overcome fear, take control of some parts of their lives, and enjoy the feelings of accomplishment in meeting these changing demands.



Trust

You don't read much about the concept of trust after stroke. Trust is a powerful emotion that can significantly affect the survivor and caregiver. A stroke survivor loses trust in his physical abilities, in his health, and often in the doctors and professionals because they cannot "cure" the stroke.

Problems with trust spill over into the survivor's relationships with their spouse, family, and friends, making a difficult situation worse.

After Paul's stroke, his language problems were so severe that I couldn't trust his "yes" or "no" answers to simple or important questions, like, "Are you in pain?" Paul questioned everything, repeatedly. Sometimes I thought his questions showed that he didn't trust me. Most of the time, he was having trouble understanding the discussion because his aphasia confused the meaning of the words.

Most adults have experience in building, and sometimes in re-building trust with co-workers or customers or among friends. Here are some thoughts to begin to rebuild trust after stroke:

- Recognize the loss of trust, and how frightening, alone, and angry this can make both the survivor and the caregiver feel.
- Communicate about these feelings. Most discussions after a stroke focus on taking care of health concerns and physical needs. Take time to deal with adult emotions.
- Start small. Find something to share that has not been changed by the stroke.

Resources:

Ms. Fiorina describes her rise and fall and transformation in her memoir, "Tough Choices: A Memoir," by Carly Fiorina (2006).

"Who Moved My Cheese," by Spencer Johnson, M.D. (1998),
www.whomovedmycheese.com

"Men As Caregivers: Theory, Research, and Service Implications," Editors: Betty Kramer, PhD; Edward Thompson, Jr., PhD (2001)