

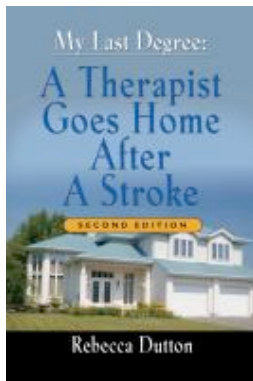
My Last Degree:

A Therapist
Goes Home
After
A Stroke

SECOND EDITION



Rebecca Dutton



What happens when an occupational therapist who specialized in stroke rehabilitation continued her education by going home after a stroke? She discovered problems that are overlooked by traditional therapy, from bed mobility to getting on an airplane.

My Last Degreee

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2nd Edition

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ISBN 978-1-60145-832-2

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Printed in the United States of America.

BookLocker.com, Inc.
2013

CHAPTER 1

INTRODUCTION

As an occupational therapist (OT) who specialized in stroke rehab I knew that $\frac{3}{4}$ of a million Americans have a stroke every year. This statistic didn't become personal until I had a stroke at age fifty-eight. How was I going to live in a house with one bathroom on the second floor when I couldn't walk up even one step? Maybe I could stay briefly at an assisted-living facility. Then I learned that middle-class families are going to suffer sticker shock when they see the cost of long-term care.

Here are a few facts about an assisted living facility near my home. In 2010 a one room studio apartment, three meals a day, and housekeeping costs just under \$49,000 per year. If they wash my personal laundry it costs an extra \$1000 a year. If I want a one bedroom apartment it costs over \$72,000 a year. Assistance costs extra. At this facility that means an additional \$7,000 to \$11,000 per year. If I want more than two baths a week I have to pay \$5 for each extra bath. This facility pads its activity schedule with Bingo six days a week and has a small interior courtyard with nothing growing in it so this is not a high-end facility. Five other assisted living facilities I visited charge similar fees. If I had moved into a studio apartment at this facility eight years ago after my stroke I would have spent \$400,000 by now.

After touring this facility I realized that assisted living fees don't cover medical costs like drug co-pays and premiums for health insurance, utilities like a telephone and TV, basic toiletries like toothpaste and toilet paper, and personal maintenance like clothes and haircuts. That means I have to hold money back for these out-of-pocket expenses when deciding what I can afford.

I've never been poor, but the money I set aside for retirement will last only a few years with this kind of financial drain. Since I had a stroke at fifty-eight my long-term financial plan was to return home and stay as long as possible. The cost of long-term care is a big incentive for working smarter instead of harder. I need to stay in my own home for as long as possible.

A Mysterious Cause of Strokes

Spring break was over and I was looking forward to teaching my favorite module on stroke rehabilitation. While getting ready for work, I couldn't stop falling backwards on the bed as I closed one eye to put on eye make-up. As a therapist, I knew this wasn't normal. I could still walk with both eyes open so I foolishly drove myself to the hospital. I walked into the emergency room and signed myself in. A few hours later, a neurologist came to see me and confirmed my worst fear. I was having a stroke. By dinnertime I was paralyzed.

Doctors initially told me "we don't know why you had a stroke." A year after my stroke a neurologist showed me my MRI. I saw dozens of tiny pinpoint lights in the sub-cortical part of my brain. These tiny lesions don't produce stroke symptoms at first, but they significantly increase the risk for a visible stroke. Unlike blood clots that suddenly interrupt blood flow in large arteries, small blood vessels are gradually clogged by cholesterol filled plaques.

Cholesterol creates plaque inside blood vessels. Plaque has a soft core of dead white blood cells and a hard surface that is calcified and stiff. When plaque narrows a small blood vessel so no blood can get through, a tiny bit of the brain dies. When enough tiny lesions get close to each other they join to form a bigger lesion. This causes a visible stroke that is called a **lacunar stroke** (lacuna = lake).

My lacunar stroke happened in my brainstem which is good news. A brainstem stroke doesn't produce the severe language and cognitive deficits associated with strokes that attack the brain. However, the brainstem contains the bridge to the cerebellum which controls balance. Here is an example of how badly this stroke affected my balance. On my first day home from the hospital I fell down a full flight of stairs. I landed on my back and tumbled head-over-heels to the bottom. As I fell I could see the wall passing by but had no sensation of falling. This lacunar stroke also paralyzed my right arm and leg so I call my right side my **hemiplegic side**.

With nothing to do but lie in bed in the Intensive Care Unit I tried to touch my left index finger to my nose but kept missing. When I told the neurologist about this he ordered another MRI. The MRI showed narrowing of the right basilar artery that supplies blood to the

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cerebellum. In addition to controlling balance, the cerebellum also controls coordination. I had strength in what people called my “sound arm,” but lost fine-motor control of this arm. I had to wear a bib for weeks because I couldn’t get a utensil to my mouth without spilling food on my shirt. When I pulled my shoe off, it went flying across the room. When I reached for a glass, I knocked it over because I couldn’t stop my arm when it got close to the glass. These uncontrolled movements were infuriating because I couldn’t stop them even though I knew they were going to happen. They were like the super-fast movement that pulls your hand away from a hot stove before you have time to form a conscious thought to move. People who saw me walk with a cane in my left hand didn’t know I had trouble controlling a spoon with this hand. This loss of coordination made me hysterical. How could I go home with poor coordination in one hand and paralysis in the other?

Theories of motor control don’t have many suggestions for treating incoordination so I learned what worked by trial and error. When I reached for an object I had better control if I moved slowly. It helped to imagine I was reaching for an object embedded in Jell-O. This left-sided incoordination gradually went away so I call my left side my **sound side**.

Incoordination also affected my oral muscles so my speech was slurred (dysarthria) and difficult to understand at first. Incoordination of my diaphragm was an even bigger problem. At first, I exhaled explosively with one big gasp. I had to take an extra breath to finish even one sentence. Now I can say more before running out of breath. I speak clearly enough for people to understand me on the telephone, but I slur my words when I get tired at night. It’s still tiring to project my voice for extended periods of time in a group because I have to take so many deep breaths to make my voice heard.

Time Lost Is Brain Lost

The American and National Stroke Associations try to get people to the emergency room quickly with their FAST campaign. FAST stands for face, arm, speech, and time is brain. However, these are warning signs for strokes that attack the front of the brain. The

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American Stroke Association estimates that twenty-five percent of strokes cut off the blood supply to the back of the brain where balance, coordination, and vision are controlled.¹ The scary thing about poor balance and incoordination is that emergency room personnel ignore them as warning signs of stroke. People who had a stroke in the back of the brain had a significantly longer time ($P < 0.01$) from admission to when a clot busting drug was given.² Door-to-needle time was longer because they had nausea, vomiting, and dizziness instead of the FAST symptoms. When I had a second stroke a neurologist said my sudden return of impaired balance was probably caused by an ear infection. It wasn't until I told him I had acquired double vision and lost the ability to distinguish between hot and cold in my hemiplegic leg that he agreed I had another stroke. Both stroke associations need to promote the list of Five Sudden, Severe Symptoms outlined by Dr. Lynden, the director of the stroke program at Cedars-Sinai Medical Center. Symptoms should not be dismissed if they are sudden or severe or both.

- Sudden trouble seeing on one side
- Sudden severe dizziness, loss of balance, difficulty walking, or incoordination
- Sudden severe headache with no known cause
- Sudden numbness or weakness of the face, arm, or leg on one side of the body
- Sudden confusion, trouble speaking, or understanding

Small blood vessel disease is frustrating because surgeons can't get into them to save us. Surgery, like inserting a stent in an artery after removing the blockage or repairing malformations, works only for *large* blood vessels. Unfortunately, preventing strokes caused by clogged small blood vessels is as boring as watching paint dry. For now controlling blood pressure and taking cholesterol lowering drugs (statins) are the only ways to prevent strokes in small blood vessels. If I had been able to tolerate statins I wouldn't have wasted six years trying different drugs to lower my cholesterol. I kept going off statins because they gave me severe constipation. It wasn't until I had my first colonoscopy that a gastroenterologist told me about Miralax powder.

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Unlike laxatives that gradually lose their ability to stimulate the gut, Miralax powder pulls water into the intestines. Miralax is so effective that I take it in teaspoonfuls instead of the capfuls recommended by the manufacturer. Tell the people you love not to ignore high cholesterol or high blood pressure because they don't feel sick.

Keeping Hope Alive

In the beginning, being a therapist was a hindrance. For the first month I scared myself half to death because my experience as an OT told me everything that could go wrong. Fear made me intermittently hysterical and disrupted my early treatment. I tried not to think about what life would be like with strokes on both sides, but sometimes the dam burst and I sobbed for several minutes.

I don't know how I would have coped with these **emotional meltdowns** without the compassion of therapists and friends. When I sobbed uncontrollably, my PT would roll my wheelchair to an empty corner of the gym, squat down to look me in the eye, and talk to me. It didn't matter what Michelle was saying. She distracted me and made me feel less alone. When I calmed down she had me go back to work which gave me something to think about besides my fear. A friend used another approach when she came to visit and found me crying in my room. Bobbie put her arm around me and just listened. I cried harder at first, but I felt less alone. Once I stopped crying, I was able to visit with my friend who stayed for a short while.

There were times when some staff were unsure about what to do when I broke down. After watching helplessly for a few seconds, one therapist ignored my sobbing and made me complete a task. This was an awful experience. When my distress was ignored, I felt even more embarrassed about breaking down in a room full of strangers. It's difficult to know how to comfort someone you don't know well, but Michelle and Bobbie used two different strategies that worked for me.

One approach I didn't find helpful was being repeatedly told "you are getting better." I heard this phrase so many times that I stopped paying attention to it. In the first two weeks my PT insisted that I was getting better, but I was depressed because nothing was getting easier. Being a therapist didn't help. I couldn't look down at my

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body to analyze what I was doing while I was doing it. It turns out that Michelle was helping me less and less so walking was getting harder because I was gradually doing more of the work. When I was a therapist I didn't explain I was doing this to my clients either.

Saving My Sanity on the Weekends

Five hours of therapy each day kept me busy during the week, but therapy stops on the weekends. Network TV on the weekends is really bad. You don't actually think hospitals have cable TV. My visitors didn't fill up the long hours of free time. As I stared at the ceiling for hours, time went by so slowly that each weekend was an agony to be endured. Recreational therapy saved my sanity.

When Kathy visited my room and said she could help me play solitaire, I jumped at the opportunity to work on my sitting **endurance** and the coordination in my left arm. I enjoyed playing solitaire as a child but hadn't played it for years. Kathy lent me a deck of cards and a deck shuffler so I could play one-handed. At first, I could play for only fifteen minutes because holding my head and trunk upright was so exhausting. My uncoordinated left hand knocked the rows crooked every time I reached for a card. Yet I kept playing because I got caught up in wanting to win, even if I had to cheat.

Kathy helped me do other meaningful activities I was interested in. While reading has been a life-long leisure activity, holding a book or magazine one-handed was tiring because my sound hand never got a break. Kathy lent me a book rest and I was eventually able to read for two hours at a time, which made the weekends fly by. When she discovered that I'd done crossword puzzles all my life, she xeroxed large crossword puzzles so I could practice printing with my non-dominant hand. Writing was important to me because I wanted to write my own checks and manage my own financial affairs again. Doing large crossword puzzles was a fun way to practice writing. It forced me to think and was more interesting than just copying letters. Recreational therapy is a powerful adjunct to the other therapies in a rehabilitation hospital, especially on the weekends.

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Dealing with the Hospital System

The way a hospital is run is annoying, but I had the advantage of knowing how the system works. Patients are not allowed to do even simple things like use the toilet without a doctor's written permission. There is no point in arguing with the nurses. They are just following the doctor's orders. When I wanted something, I asked my doctor to write orders that stated what I was allowed to do. My doctor was reluctant to grant my request to shower, so he had me evaluated by an OT. After observing me the OT talked my doctor into giving me showering privileges with supervision. My OT was an advocate in other ways, too. Leslie also sent an order to dietary to put a rocker knife on my tray with every meal. This adapted knife allowed me to cut my food one-handed instead of letting it get cold while I waited for someone to cut it up.

Having worked as a nurse's aide before I went to college, I knew not to make a request at the end or beginning of a shift. Shifts usually change at 7:00 a.m., 3:00 p.m., and 11:00 p.m. New staff coming on duty aren't free to answer call buttons because they have to attend a meeting to learn how clients did on the last shift. Staff who are going off shift don't want to start a task they can't finish before it's time to go home. Here is an example of how I made the system work for me. I was most successful when I asked for a shower at 5:00 a.m. This gave the aide assigned to me time to rearrange her workload so she could go into the shower with me at 6:00 a.m. Then she could stay with me until I finished showering without having to stay past the end of her shift at 7:00 a.m.

Even though I had worked in a rehabilitation hospital, I didn't know nursing staff feel stressed out by their large caseloads. Some aides work double shifts to make ends meet. A simple way to get busy staff to help me was to call them by their names instead of "nurse." I didn't know the names of every nurse and aide, but I made the effort to learn the names of the nice ones. Instead of sending impersonal store-bought thank-you cards, I typed individual letters on the computer in recreational therapy. Each letter described specifically how specific nursing staff had helped me. I gave the letters to the nursing supervisor who showed the letters to the nurses and put them in their files. At the facility I was in, nursing staff who are singled out for providing good

care are given an award and a \$200 prize. I think personalized thank-you notes mean more than the flowers and boxes of candy that nurses often receive.

The Bottom Line

Writing about my stroke experience taught me the power of story telling. Readers need to know why they should care about what I do. So I don't start by describing how to put on a bra one-handed. First I write about clothes that don't fit when my breasts are closer to my waist than I ever thought possible. I write about how I'd feel about saying "I'd love to come to dinner if you hook my bra when I get there." Seeing how a problem can affect your life will help you understand why you would want to change lifelong habits and learn to do tasks a new way.

As you read, remember that people cannot be reprogrammed like robots. Keep in mind that how one person succeeds doesn't always work for another person. I am particularly concerned about safety issues for stroke survivors who have different deficits than I do because their stroke affected a different part of the brain. A few examples of deficits that can affect safety are the inability to follow directions, poor safety awareness, poor hot/cold discrimination, and unilateral neglect. Therefore, I have underlined safety issues in the chapters to come when stroke survivors and caretakers need to be extra vigilant.

Don't be surprised if a new procedure or piece of equipment triggers anger or grief instead of enthusiasm. It's not how difficult a new procedure is that determines if you will learn it; it's what the task means to you. The meaning of a task is personal. Don't assume you know what the other person wants. Independence is a social contract that has to be renegotiated after a loved one has a stroke. After you and your family have talked, locate topics you want to revisit by using the Table of Contents or the Index. When you see a word in the text that is **printed in bold**, it's a key word that is listed in the Index.

The procedures in this book are written in enough detail so people who don't know how to do them can visualize what I'm talking about. Have you ever read instructions for how to put something together only to find some steps were left out? Skipping steps is a

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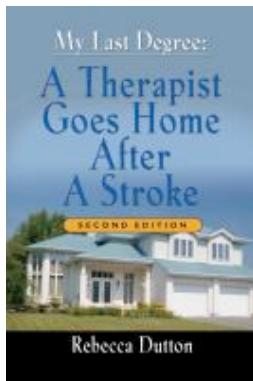
surefire way to confuse readers and make them think it's their fault. When I mention equipment I give you websites and store names. It is good to use non-medical sources. Anything sold in a medical catalogue is more expensive. Retail stores have discovered that senior citizens living on a fixed income want cheap adapted equipment.

Since I live alone many of the solutions in this book help me as a caregiver as well as a stroke survivor. Caregivers are fragile because they are pummeled by a triple whammy. They have to: (1) do the chores they've always done, (2) take on their partner's role, and (3) be an amateur therapist. For example, a wife may take out the garbage, take the car to have the oil changed, and change the batteries in the smoke alarms. A husband may cook and do laundry. Taking on three roles is physically and emotionally exhausting. Every solution that makes life easier for a caregiver also makes life easier for a stroke survivor too.

It is hard to think clearly during the first month after a stroke when everyone is experiencing shock and grief. It's hard to express your concerns to the health care team when you don't know what they are yet. Understanding how a stroke affects your ability to stay at home is a first step. I hope this book helps you think ahead and speak up. When baby boomers overwhelm the health care system, stroke survivors and families who are proactive will have more options.

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