

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 Degree: A Therapist Goes Home After a Stroke

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# **MY LAST DEGREE:**

**A Therapist Goes Home After a Stroke**

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## TABLE OF CONTENTS

<b>CHAPTER 1: INTRODUCTION.....</b>	<b>1</b>
My Two Strokes.....	1
How Hard is It? .....	4
Keeping Hope Alive.....	6
Saving My Sanity on the Weekends .....	7
Dealing with the Hospital System.....	8
Setting the Stage for Success .....	9
The Bottom Line .....	10
<b>CHAPTER 2: REGAINING MOBILITY .....</b>	<b>13</b>
Bed Mobility is a Burden .....	13
Standing Up and Going Floppo .....	15
Wheelchairs Can Wreck a Home .....	17
Squats are Your Friend .....	18
Balance Skills You Need at Home.....	21
Canes, Walkers, Braces, and Shoes .....	23
Multitasking Means Having a Life .....	25
The Most Dangerous Room is the Kitchen.....	27
Inexpensive Home Modifications Prevent Falls .....	28
Low Endurance is a Deal Breaker.....	30
The Bottom Line .....	32
<b>CHAPTER 3: RECOVERY OF AN ARM AND A HAND.....</b>	<b>34</b>
The Functional Value of the Hemiplegic Arm.....	34
Why Recovery is Harder for the Hand.....	38
Good News from Constraint-Induced Therapy.....	39
Electrical Stimulation for the Hemiplegic Hand.....	40
Evaluation of the Hemiplegic Hand is Outdated.....	42
Making the Hemiplegic Hand Functional .....	44
Finding the Ceiling.....	52
The Bottom Line .....	54
<b>CHAPTER 4: BASIC SELF-CARE .....</b>	<b>58</b>
Gadgets versus What You Carry with You.....	58
Getting Clean Sitting on a Shower Chair.....	60

*MY LAST DEGREE*

You Can Floss One-Handed .....	64
Does Leaning Over Help You Don a Shirt? .....	65
Donning a Short-Leg Brace the Easy Way .....	66
Having the Energy to Worry about Your Hair.....	68
Elastic Shoelaces Come in What Colors?.....	69
Don't Forget Outerwear .....	75
Houdini Puts on a Bra One-Handed.....	78
The Bottom Line .....	80
<b>CHAPTER 5: ADVANCED ADLs IN THE HOME .....</b>	<b>81</b>
A Small Army Got Me into My New Home.....	82
Baby Steps Come First.....	83
Mom, Answer the Phone.....	84
Taking Meds Wrong Can Kill You.....	85
Transporting Objects without Taking All Day .....	87
Bill Collectors Don't Care If You Have a Stroke.....	88
A Computer isn't a Luxury .....	90
I'm Not Washing My Clothes at a Laundromat.....	92
A Microwave Oven Saves the Day.....	94
Food Prep with Low and High Tech Solutions.....	95
Cleaning Varies from Easy to Difficult .....	99
Small Tasks that Fall through the Cracks .....	103
The Bottom Line .....	104
<b>CHAPTER 6: ADVANCED ADLs IN THE COMMUNITY .....</b>	<b>106</b>
Keys, Money, and Purses Come First.....	106
Eating Out Takes Practice.....	107
Paratransit Really Works .....	109
Shopping with Paratransit.....	112
Shopping for Clothes is Like Going to War .....	115
Good Timing is Free .....	116
Maneuvering in Crowds that Sit Down .....	117
Americans Love to Drive.....	119
Showering While I'm On the Road Again.....	126
A Plane Sounds Better than an MRI.....	127
Returning to Work .....	130
The Bottom Line .....	132

*A THERAPIST GOES HOME AFTER A STROKE*

<b>CHAPTER 7: PAIN CAN RUIN EVERYTHING.....</b>	<b>134</b>
A Subluxed Shoulder Really Hurts.....	134
Vigilance Fixes a Swollen Hand.....	135
A Cold Foot Can Ruin Your Sleep.....	136
Do Shoulder Range of Motion Lying Down.....	136
How Do You Relax Tight, Painful Muscles?.....	137
The Bottom Line.....	141
<b>CHAPTER 8: RECOVERY OF A PERSON.....</b>	<b>142</b>
Choosing to Live.....	142
Regaining a Social Life.....	143
My Perfectionism Comes Back to Bite Me.....	146
Stress Management Gets Out of the Back Seat.....	148
Being Depressed for Hours Instead of Months.....	149
Love and Lust.....	151
A Stroke Teaches You Want versus Need.....	154
The Big Question I Asked Myself.....	155
<b>Appendix A: Assisted Living.....</b>	<b>159</b>
<b>Appendix B: Concierge Service Anyone?.....</b>	<b>169</b>
<b>Appendix C: Council on Independent Living.....</b>	<b>171</b>
<b>Index.....</b>	<b>173</b>
<b>About the Author.....</b>	<b>175</b>

## CHAPTER 1

### INTRODUCTION

As a baby boomer, I used to feel a vague sense of anxiety about the aging of America. Adults age sixty-five and older are going to make up twenty percent of the U.S. population by 2030 – but that feels so far away. Besides, as an occupational therapist (OT), I was going to help baby boomers “age in place,” which means staying in your own home as you get older. This feel-good philosophy 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 even walk up one step? Still, I had an option my grandparents didn’t have. I could go to an assisted-living facility.

Middle-class families are going to suffer sticker shock when they look into assisted living. Here is an example of what one assisted-living facility costs. A *studio* apartment, three meals a day, and amenities like daily activities, cost \$3,000 a month or \$36,000 a year in 2004. In 2008 it cost \$3,500 a month or \$42,000 a year. If you actually need assistance in an assisted-living facility, that costs extra. These facility-based expenses don’t cover health insurance, medicine, the clothes on your back, or toilet paper. 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 only long-term financial option was to return home and stay as long as possible. It took a miracle and a small army to help me get there.

#### *My Two 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.

*MY LAST DEGREE*

My stroke was caused by cholesterol building up inside the small blood vessels of my brain. This is called chronic small blood vessel disease. Cholesterol build-up narrows the blood vessels and increases blood pressure, just as you increase water pressure by partially covering the end of a garden hose with your thumb. Increased blood pressure can make tiny blood vessels burst and disrupt blood flow to the brain. The episodes of sudden dizziness I experienced over the years made sense when I saw my MRI with numerous pinpoint areas of light shining through the sub-cortical areas of my brain. These tiny areas of brain damage don't have a permanent effect at first, but when enough pinholes get close to each other they collapse into a lake and produce a lacunar stroke (lacunar means lake). My "lake" formed in a structure called the pons, which is the bridge to the cerebellum. This was good news because a stroke that cuts off the blood supply to the cerebellum doesn't produce the severe cognitive and language deficits associated with other types of stroke. The bad news is that this stroke made my right arm and leg flaccid and severely impaired my balance. My right side is still partially paralyzed so I refer to it as my hemiplegic side.

Small blood vessel disease is frustrating because surgery can't save you. Surgery works only for *large* blood vessel disease, like inserting a stent in an artery after a balloon flattens the cholesterol build-up. I tried for years to get my high cholesterol down because heart disease runs in my family. Statin drugs made my triglycerides go sky high. Triglycerides are another group of fatty acids in the blood that are associated with heart disease. Statin drugs also gave me severe constipation that was relieved only by taking an increasing number of laxative pills. I tried six statin drugs before I found one I could tolerate with the help of Miralax powder, which pulls water into the gut. I don't know how long my blood pressure was intermittently high. It would be high one day and normal when I went back the next day, so my internist didn't prescribe blood pressure medicine. After six years, I decided to see a cardiologist. She started me on blood pressure medicine and prescription-strength fish oil to lower my triglycerides, but it was too late. The damage was already done. Tell the people you

*A THERAPIST GOES HOME AFTER A STROKE*

love not to ignore high cholesterol or high blood pressure because they don't feel sick.

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. In addition to paralysis on my right side, my left side was also affected. When I told the neurologist about this, he ordered another MRI. The MRI showed narrowing of the basilar artery that supplies blood to the cerebellum.

The cerebellum controls coordination as well as balance. 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 as it got close to the glass. I lost track of how many times I spilled while trying to pour myself a glass of water. The glass always overflowed because my hand couldn't pull the pitcher back in time. When I tried to click on a computer icon, my hand pushed the mouse well past the mark.

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 movements that pull your hand away from a hot stove before you have time to form a conscious thought to move. Incoordination can be a confusing deficit. 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 deficit 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 that I was reaching for an object embedded in Jell-O. When my left hand fumbled with an object, it helped to stop and rest for a few seconds. When I got back to the task I was struggling with, I was always more coordinated. This left-sided incoordination gradually went away, so I refer to my left side as my sound side.

Incoordination affected the oral muscles so my speech was slurred and difficult to understand at first. Incoordination of my

## *MY LAST DEGREE*

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 sustain a longer exhalation, which means I can say more before running out of breath. This gives me the option of choosing natural places in a sentence to take an extra breath to make my meaning more apparent. 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 deep breaths to make my voice heard.

A scary fact about incoordination and poor balance is that people ignore them as warning signs of stroke because they are rarely mentioned in public service announcements. I had another small stroke two years later and had to go back to rehab to learn how to walk again. Yet even a neurologist suggested that 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. The American Stroke Association (2007) 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. A sudden onset of impaired balance, coordination, or vision should be taken as seriously as impaired speech or paralysis of a limb.

### *How Hard is It?*

Movie and TV scripts create unrealistic fantasies about how people recover from a physical disability. Stroke survivors need a story of recovery that is both hopeful and realistic. Regaining control of my body was harder than I ever imagined. In the beginning, when a therapist asked me to lift my hemiplegic leg, it was like asking me to lift a car. Well, maybe not a car, but my hemiplegic leg felt as though it weighed a hundred pounds. Moving my hemiplegic arm and leg took more concentration than learning how to drive a stick-shift car. Rehabilitation is mentally as well as physically exhausting.

One way to describe how difficult it is to move a paralyzed limb is to tell you what an experienced skier told me when he explained how to turn while skiing downhill. To turn, you shift seventy-five percent of

*A THERAPIST GOES HOME AFTER A STROKE*

your weight onto the inside edge of the downhill ski. These directions don't mean much to a non-skier. I felt the same way when my therapists asked me to make a fist or take a step. I didn't have a clue about how to follow my therapists' commands. In the first month after my stroke, I performed simple movements only by concentrating as hard as I have ever concentrated in my entire life and repeating every motion dozens of times.

As you do a movement over and over again, the brain grows new branches around the damaged area. These new branches are called collateral sprouting. Collateral sprouting is tricky because being able to grow new connections doesn't mean you can find them. I had a wonderful physical therapist (PT) who waited four to five seconds after she gave me a command so I had time to figure out how to do what she wanted. I never lost the ability to feel where my limbs were in space when someone else moved them, but I had a terrible time figuring out how to control the muscles I wanted to use. Those extra seconds Michelle gave me allowed me to search for the new connections my brain had created so I could do the movements she had asked for.

I never appreciated how difficult breathing can be for someone with a stroke. As a therapist, I had told my clients to stop holding their breath because it increases blood pressure. To my horror, I repeatedly held my breath when I was straining. Awareness and good intentions were not enough. I didn't learn how to breathe properly until six months after my stroke when a PT in outpatient rehab had me lean against a closed door and breathe in when I slid down and breathe out when I slid up. Now I know that if a movement makes me strain, I have to stop and plan when to breathe *before* I start to move again. This gives me one more thing I have to control in addition to my hemiplegic limbs. However, keeping my blood pressure down is important, so I try to breathe properly when I'm straining.

Finally, stroke rehabilitation is hard because it never completely ends. After being treated by three inpatient therapists, two home health therapists, and two outpatient therapists, I had been assigned dozens and dozens of home exercises. There was no way I was going to do all those exercises. Therapists call this "non-compliance" because each therapist sees only what he or she thinks the client should do. Xerox

## MY LAST DEGREE

machines make it easy for therapists to overwhelm clients with home programs.

When I went through the therapy process again after a second stroke, I asked my therapists to help me prioritize. I made a list of exercises I had been given by previous therapists that I was still doing. I showed the list to my new set of therapists and asked them which ones they thought were important to keep doing. When my new therapists wanted to add their own exercises, I made them aware of my current total. When the total got too high, I asked each therapist which two or three of their exercises they felt most strongly about. I can't maintain my commitment to a home program when it cuts into my time for socializing and having fun.

### *Keeping Hope Alive*

In the beginning, being a therapist was a hindrance. For the first month, I scared myself half to death by picturing everything that could go wrong. My 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. She had me go back to work when I calmed down, 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

*A THERAPIST GOES HOME AFTER A STROKE*

difficult to know how to comfort someone you don't know well, but Michelle and Bobbie used two different strategies that worked for me.

I was surprised by how many times a day everyone stopped paying attention to this repetitively used phrase. In the first two weeks my PT insisted that I was getting better, but I was depressed because nothing got easier. Being a therapist myself didn't help. I couldn't look down at my 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. I had done the same thing when I was a therapist and didn't explain what I was doing 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 LAST DEGREE*

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.

### *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 aren't 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. She talked my doctor into giving me showering privileges with supervision. My OT was an advocate in other ways, too. Leslie 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 for me.

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 that nursing staff feel stressed out by their large caseloads and 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

### *A THERAPIST GOES HOME AFTER A STROKE*

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 that described specifically how four 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.

#### *Setting the Stage for Success*

My recovery was influenced by two powerful beliefs. I already knew about the power of persistence. It had been a thrill to see what some of the clients I had treated achieved, yet I was stunned by the obstacles that persistence helped me overcome. By persistence I don't mean determination, which is an intention, but a willingness to repeat one's actions. When I try something new, I frequently fail on the first attempt. Sometimes postponing my second attempt is helpful. I don't remember what mistakes I made yesterday, so I discover solutions by doing the task differently the next day. Happy accidents are as much a part of my recovery as my advanced training in stroke rehabilitation. My frustration is less intense the next day, which allows me to see that I get stronger, faster, and more coordinated when I repeat a movement. I eventually learned not to judge how successful I would be from my first attempt. My belief in the power of persistence is based on observable success.

The second factor that profoundly influenced my recovery was a change in my belief about the loving kindness of people. I had thought that the generosity I'd seen portrayed in movies was idealistic. I received help from fourteen people. Where would I be now if my friends and family hadn't come to my rescue? Their help propelled me towards independence so I could go home again. Yet it was hard for me to accept all of this kindness. I still saw myself as a therapist who helped others and a divorcee who had learned how to take care of herself. When an independent person suddenly feels helpless, it is easy to fall into a pattern of complaining or criticizing. I knew my reaction

## MY LAST DEGREE

to feeling helpless would create an emotional climate that influenced how people treated me. Knowing that I was doing everything I could do made it easier for me to be gracious about accepting help with things I couldn't do. Being as grateful as you can at the moment is both selfish and kind.

I paid attention to what people **volunteered** for. They offered to help with tasks they enjoy or could do with the least inconvenience. Listening to what they were willing to do worked out better than trying to guess whom I should ask to help with a specific task. Having small groups of people get together to decide how to help me was more successful than shanghaiing one poor soul who would quickly be overwhelmed. Loving kindness is powerful, but asking one person to care for a stroke survivor is setting up that person for failure.

### *The Bottom Line*

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 on how to put something together only to find that some steps were left out? Skipping steps is a surefire way to confuse readers and make them think it's their fault.

When I mention equipment, I give you websites and store names. You may not have the exact store I mention near you, but it is good to use non-medical sources for ADL equipment. Anything sold in a medical catalogue is usually more expensive. Retail stores have discovered that senior citizens want adapted equipment.

However, procedures and equipment don't take into account that a stroke happens to a person. A new procedure or piece of equipment can trigger anger or grief instead of enthusiasm. Because I learned so long ago what each ADL task requires, I am often startled and upset when I learn that my stroke disrupts yet another ADL. So before describing a solution, I talk about the impact the problem had on my life. Seeing how a problem can affect your life may help you understand why you might want to change lifelong habits and learn how to do tasks a new way.

When people disagree about what ADL tasks a stroke survivor *should* do, remember the meaning of a task is personal. It's not how

*A THERAPIST GOES HOME AFTER A STROKE*

difficult a new procedure is that determines if you will learn it; it's what the task means to you. If a stroke survivor resents having his or her mail opened, a caregiver may have to learn to watch a loved one struggle without interfering. Stroke survivors may gain independence in a task because it frees the people they love to do activities without being constantly interrupted. Independence is a social contract that has to be renegotiated after you have a stroke. Don't assume you know what the other person wants.

Before you get engrossed in reading about procedures and equipment, remember that people cannot be reprogrammed like robots. After you and your family have talked, locate the topics you want to revisit by using the Table of Contents or the Index. The Index contains key words that are spread out over more than one chapter. Key words are **printed in bold** in the text.

As you read, 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 understand multi-step directions, poor safety awareness, poor hot/cold discrimination, and unilateral neglect. Unilateral neglect is a lack of awareness of the hemiplegic side or even all objects on one side of the body. Therefore, I have underlined a few safety issues in the chapters to come when stroke survivors and their caretakers need to be extra vigilant.

It's hard to think clearly during the first month after a stroke when everyone is experiencing shock and grief. It's also hard to express your concerns to the health care team when you don't know what they are yet. It's easier to identify concerns if you have a better understanding of how a stroke affects your ability to stay in your home. I hope this book helps you think ahead and speak up. While therapists have the formal training and experience with other stroke survivors that you lack, you know more about your situation than they do. When baby boomers overwhelm the health care system, stroke survivors and their families who are proactive will have more options.

*MY LAST DEGREE*

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