Cutting It CLOSE
Surviving a stroke in the Craters of the Moon

Sit Still, Do Nothing • Pulling a Rabbit Out of a Hat
Taking Time to Tell Your Story • A Toe-Curling Experience
FEATURE STORY

A Stroke in the Craters of the Moon
A conservationist battles stroke and the elements in the Craters of the Moon National Monument.

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In March 2000, I had what my doctor termed a “medium” stroke in the left part of my brain, causing damage to my right arm and leg. I did well with the usual stroke care and lots of therapy.

About three months later I completely lost my taste. Until today I can only taste canned corn with a vague sense of salt, sugar, vinegar and hot spices.

I call my mouth the “pit of hell.” It is raw, my teeth are decaying, and I strangle a lot. My lips are covered with small cracks and are dry. The taste is awful.

Neither my doctors nor dentists have explained or helped with this problem. Can you or your readers? I would so love to taste food again.

Edna P. Jackson, Stroke Survivor
Burlington, Washington

I just read your magazine for the first time. I really enjoyed reading about other people who have had strokes and survived them.

My husband had a massive stroke at age 66 in July 2000. He was paralyzed on his left side and suffered brain injury also. I was unable to care for him at home so I took him to Florida to be near our daughter. We placed him in a nursing home in Gulf Breeze, and we stayed there for 19 months. Although he had good therapy, he was never able to walk, but he was optimistic throughout this ordeal.

After a new nursing home was built in White Hall, Arkansas, we moved there and arrived at the facility on June 9, 2002. He was adjusting to the routine and new people and seemed to be doing well, but on June 14, he suffered a heart attack and passed away.

I knew nothing about stroke when this happened, so I read everything I could find on the subject. It does my heart good to see people surviving this terrible thing. The after-effects of a stroke sometimes linger for years. My husband was not one of the lucky ones, but his determination and attitude helped him a lot. He was always ready to get his therapy and always told me, “I’m going to beat this.” I believe his attitude helped him. I miss him very much and still find myself reading anything I find on stroke.

Shirley J. Worthen, Caregiver
Pine Bluff, Arkansas

I’ve just finished an article from your September/October 2000 issue. It was entitled “Where Compassion Comes From.” I think it’s the most wonderful article I’ve read since my stroke on April 6, 2002. It also made me a little ashamed of myself.

About a month ago, I wrote your magazine a letter that I didn’t really want to mail. It was so negative about everyone from my own family to the local social service agencies.

I had only recently been introduced to your magazine. But somehow that 2000 issue worked its way into my life. About halfway through that article I started thinking I had written it, because it described my feelings exactly.

Since my first letter, I’ve learned to talk with my family. I’ve found a social worker that cares. I’ve learned to cope with stress. I’m having a complete turnaround!

I would also like to thank you for another article simply titled, “What If,” in the September/October 2003 issue. Thanks, and keep up the good, positive work.

James Allen, Stroke Survivor
Raymore, Missouri

Letters may be edited for length and scientific integrity. The opinions presented are those of the individual and do not reflect those of the American Stroke Association.
Up to 40 percent of patients with “mini strokes” and ischemic strokes have silent heart disease, so doctors need to evaluate their heart risk even if stroke patients don’t have symptoms, according to an American Heart Association/American Stroke Association scientific statement published in *Circulation: Journal of the American Heart Association*.

Stroke survivors found to be at high risk may also need non-invasive testing, according to the statement’s lead author, Robert Adams, M.D., professor of neurology at the Medical College of Georgia in Augusta.

Coronary heart disease, transient ischemic stroke (TIA — known as “mini stroke”) and ischemic stroke all result from vascular disease, where blood flow is restricted to either the heart or brain. The panel of researchers found a link between silent heart disease and TIAs and with silent heart disease and ischemic strokes originating in large vessels to the brain.

“Compared to patients with strokes caused by blockage in small vessels in the brain, patients with TIAs or large-vessel strokes have a higher likelihood of also having coronary artery disease, whether or not they have a clear history of heart disease,” Adams said.

“There are data to indicate that some people already have significant heart disease by the time they have a stroke even though they don’t have any recognized symptoms of heart disease,” said Adams, past chairman of the American Heart Association’s Stroke Council Leadership Committee.

The authors reviewed literature on short- and long-term outcomes of stroke survivors. Overall, they discovered that the risk of heart attack or sudden cardiac death after stroke is much greater in the long term than in the short term. They concluded that up to two years after stroke, the risk of fatal heart attack compared to having another stroke is relatively modest.

In long-term population studies that followed patients for up to six years, there was more significant heart disease risk that equaled or surpassed the risk for recurrent stroke. Twenty-four percent to 45 percent of deaths were related to vascular disease other than stroke.

The authors don’t recommend routine testing for all stroke patients, and they say testing doesn’t need to occur while patients are hospitalized immediately after stroke. However, all people with stroke should undergo a comprehensive assessment and doctors should encourage them to reduce their risk factors for heart disease, via smoking cessation, diet, physical activity, etc.

“Stroke survivors should understand that they need to be concerned about preventing another stroke, but also preventing heart disease, even if they don’t have recognized heart disease symptoms,” Adams said.

‘GO RED FOR WOMEN’

The American Heart Association recently launched the Go Red For Heart campaign with the National Wear Red Day For Women. The ongoing program urges women to take charge of their cardiovascular health, make it a top priority and live a stronger, longer life.

In a survey of women’s health conducted by the American Heart Association, only 27 percent said their health was a top priority. This may help explain why heart disease and stroke claim more women’s lives each year than the next seven causes of death combined, and nearly twice as many as all forms of cancer.

The goal of Go Red For Women is to raise women’s awareness of this problem. “Our focus is to empower women to reduce their risk of heart disease,” said Nieca Goldberg, M.D., assistant professor of medicine at New York University. “The Go Red For Women campaign outlines a plan to help women take action against cardiovascular disease and make heart disease prevention part of their life, because your heart is your life.”

By calling 1-888-MY-HEART (694-3278), women will receive:

- A comprehensive brochure with information on heart disease and stroke
- A wallet card with questions to ask a doctor and a chart to track blood pressure, cholesterol and weight
- An American Heart Association red dress pin to wear to show support for the cause

By registering at americanheart.org/women, women will receive electronic newsletters with information on heart disease and stroke plus updates on AHA programs and products.

You can also support heart disease and stroke research and education by purchasing designated products and gift items from companies such as Walgreens, Ross Dress for Less, Pantene and Swarovski Crystal. Part of the revenue will be donated to the American Heart Association.

Diabetes and Silent Strokes

A recent issue of Stroke: Journal of the American Heart Association reports more consequences of the diabetes epidemic: Having diabetes along with high blood pressure (hypertension) dramatically raises the risk of “silent strokes.”

Silent strokes occur when smaller blood vessels in the brain become blocked. Although they don’t cause classic stroke symptoms — sudden headache, dizziness or loss of motor skills — multiple silent strokes increase the risk of stroke in the future. Silent strokes are markers of hypertension-related brain damage and are closely associated with cognitive problems, vascular dementia and are partly associated with Alzheimer's disease.

The study involved 360 Japanese patients with hypertension but without cardiovascular disease. Of these 159 also had diabetes. Studying brain MRIs, the researchers found silent strokes in 82 percent of patients with diabetes and hypertension and in 58 percent of those with hypertension alone. Three or more silent strokes were found in 62 percent of those with both diseases and in 35 percent of those with hypertension alone.

Hypertension-related organ damage was more advanced in diabetes patients, indicating that blood pressure control is very important for people with diabetes. According to the American Heart Association, 40 to 60 percent of people with diabetes have high blood pressure.

People with hypertension who don’t have diabetes should be vigilant in taking steps to avoid it, such as controlling weight, eating a healthy diet and exercising regularly. In addition, they would be well advised to take an oral glucose tolerance test at least once a year to check for impaired glucose tolerance and insulin resistance.

Like all retirees who have been accustomed to going to an office every workday morning, I started looking around for a place to go and a job to do after coming home from the hospital. My stroke had kept me in the hospital for six weeks, during which time I had lost much of the strength required for normal daily activities.

I became keenly aware that building my strength back should be at the top of my priority list. Since I could not return to my old job because of the physical and mental stroke deficits, my new job was obviously to RECOVERY.

I felt I owed it to myself and my family to make every effort to be successful in my new position. Eighteen months of outpatient therapy gave me a good idea of the exercises needed to rebuild my strength, so after my insurance benefits expired and continued therapy was no longer affordable, joining a health club seemed to be the next logical move. I was fortunate to find a club where the staff and members have been extremely encouraging and supportive.

I quickly learned that you don’t endear yourself with the other members by taking in doughnuts like at my other job. Doughnuts worked well on a cold winter morning in Building Inspections but were looked down on at the wellness center. Fresh apples, in season, were very popular. The social activity at my new “office” has certainly been an important reason for my continued attendance.

Most of the articles about good health that I have read emphasize the importance of exercising to prevent heart disease and stroke. Since 42 percent of male stroke survivors have a second stroke within 5 years of the first, I want to do everything possible to be in the 58 percent who do not have another one.

Although I realize there are no guarantees that my exercising will prevent another stroke, physical INACTIVITY is one of the major risk factors for heart disease and stroke. It seems logical that ACTIVITY can help in prevention. Check with your doctor before you start a strenuous exercise program. Your doctor knows your health status and may have specific recommendations. A good fitness center should have qualified trainers who can help you find the correct exercises for accomplishing your specific goals.

Thanks to the strength and endurance gained from my exercising, I can still enjoy my favorite outside activity, sailing. Granted, it now requires more effort than before, but so does everything else. Thanks to the daily activities at my new office, I have the strength to make that extra effort.

David P. Layton, Stroke Survivor
Greensboro, North Carolina
RISKING SUCCESS

In 1990 I had a stroke during an elective procedure to correct an AVM. It resulted in right side paralysis. I was 30 years old. I had played the guitar since I was a kid, but after my stroke, I didn’t touch one for six years. I now play a special kind of guitar called an electric baby sitar. Although it normally requires two hands, I play it one handed. I modified it with a piece of cardboard separating my weak hand from the strings. I use my left hand to “massage” the strings on the neck. My thrill is to flip my hand over the top of the fretboard and apply a percussive technique. I’ve never seen anyone play the guitar in this way. It sounds positively magical.

Currently I accompany fellow musicians at open-mic nights at some clubs in the Greenwich Village area. People seem very receptive to the quality and originality of the sounds I create. Playing guitar has reaffirmed that it is joyful beyond belief to get back to extracurricular activities.

I recently started a new career as a real estate agent with Prudential Douglas Elliman in New York. What a great organization for taking the risk that I might succeed after spending many years convalescing. They identified great potential (and rightly so!) despite the adversity that has challenged me.

I look forward to your magazine for information and inspiration. I like to see others in similar situations experiencing the joy of attempting anything meaningful to them. The attempt alone is worth it. Success is the icing on the cake, but cake without icing is delicious, too!

Robert Gellman, Stroke Survivor  
New York, New York
In August 1995, 20 years after my 22-year-old life was turned upside down by my mother’s stroke, it happened again when Rex, my husband of just one year, had a stroke sitting across from me in our office at home. He bent down to pick up something and said, “Honey, something’s very wrong.”

His vision was full of color and he described my white shirt as “glowing.” I thought perhaps a migraine and helped him to the bedroom. Within five minutes, his left side had become weak and he couldn’t stand. Because of my mother, we both knew what was happening. Over the next 36 hours, the stroke took every bit of control of his left side, from his face to his toes. Rex was 39 years old.

They told me Rex had had a lacunar infarct. That sounded like a rocket crash landing on the moon! The doctor said it was a very small stroke in a very bad place. As best they could tell, Rex had small vessel disease, likely caused by a number of years of untreated hypertension (high blood pressure) and Type 2 diabetes. Sort of a double whammy when it comes to stroke risk, but no one had ever mentioned that, so Rex dallied on taking medication.

While Rex was still in the hospital learning to drink and eat without choking, his health insurance company decreed that hypertension and diabetes caused the stroke. As those were pre-existing conditions, they refused to pay a dime for his care.

I emptied several IRAs to come up with the cash to keep him in the hospital as long as possible. Finally, we simply could not afford for him to stay another day, and I brought him home. He could not walk at all. He was incontinent. He was deeply depressed and suffered from severe anxiety attacks.

Even though I was still trying to work and work at home, he needed care every minute. Since we had no money for help, that meant everything came from me.

Shortly after Rex’s stroke, we joined other survivors and caregivers in starting an Internet organization now known as SAFE — Stroke Awareness For Everyone. SAFE offers online support groups and stroke information, such as The Stroke Caregivers Handbook, by Joyce Dreslin, a 42-page book about the challenges facing caregivers of stroke survivors. To download a free copy, go to www.StrokeSAFE.org.

Eight years after the stroke, Rex is still in recovery. He uses his graphics training to produce “Brain Currents,” a newsletter for the American Stroke Association of Central Indiana. I am still involved with SAFE, managing Stroke Developments, an e-mail discussion of stroke news. Both Rex and I actively participate in SAFE’s online support groups for stroke caregivers and survivors all over the world.

A few months after Rex’s stroke, I ran into a business colleague. She put her hand on my arm and said cheerily, “Suzanne, surely Rex must be all better now, right?” That is what most people think happens when you have a stroke, especially when you’re young. Just get a little bed rest and you’ll be just fine.

It isn’t that way, of course. Once a stroke happens, you live with the consequences for the rest of your life.

Suzanne Rampton, Caregiver
Indianapolis, Indiana
THINGS I LOVE TO DO

Hi, my name is Andrew. I'm 8 years old. I will be in the third grade this year. I had a stroke when I was 3 1/2. I was in the hospital for over three months. I could not walk or talk or use my right arm.

I love to play baseball. I love to play golf. I love to play catch with my father. I love to go fishing with Nana and Grandpa and with my friend Steve.

I love to do exercises with my mom. I couldn't play video games, but I can now. I know how to type with one hand. I can swing the bat with two hands now. I can hold onto the fishing pole with my right hand. I can do mini-golf with my right hand. I catch the ball with my left hand, pop the ball up in the air, flip the glove off, catch the ball bare handed as it comes down and then throw it. I can do this really fast now.

Andrew Reinsvold, Stroke Survivor
Germantown, Wisconsin

— Susan Palakowski

MINUTES OF TERROR, MONTHS OF WORRY

On February 22, 2002, my oldest daughter Stephanie, age 8, woke up with a bad headache. We had just moved to Salina a few days before, and I thought that she just hadn’t been getting enough sleep, so I gave her some Tylenol and sent her back to bed. About 10 minutes later I heard her screaming that her head was really hurting.

I went into her room and told her to lay down on my bed. She got up and started to walk to my room but ran into the wall. Still not thinking much about it, I helped her into my bed. Not more than five minutes later she was screaming that she couldn’t see, that her head was really hurting, and she started to vomit.

I thank the Lord every day that we were only a few blocks from the hospital. My husband and I rushed her to the ER. She was still vomiting and screaming and saying that she didn’t want any needles. They quickly rushed us into the triage and then back into ER. The doctor came rushing in and ordered scans. He sent us to a private room and told us that he didn’t know what was going on but it wasn’t good.

After what seemed like an eternity, he came in and said she had a brain tumor that was bleeding out. They had called a life-flight helicopter and were going to transport her to a bigger hospital 75 miles away. He said she was in bad shape.

After they intubated her and put her on the helicopter, my mother drove us to Wichita, Kansas. There we were informed that Stephanie was in surgery and they didn’t know how long it would be. It felt like hours before the neurosurgeon came out and informed us that it was not a brain tumor but a hemorrhagic stroke. They had taken over a half-liter of blood from her brain. He said that another 20 minutes, and she wouldn’t have made it.

She was paralyzed on her left side. We were told she might never walk again, but I never gave up hope. I worked with her every day, moving her leg and arm muscles.

Stephanie is doing great. She still drags her left leg and carries her arm. Though she speaks normally, we still aren’t sure of the amount of brain damage. I thank God every day for giving us another chance to have our baby girl with us.

Angela Kay, Caregiver
Salina, Kansas

Andrew and the 18” bass he caught by himself this summer.
“My goal after the stroke was to walk without a cane,” says John Kawie. “I had been reading a book that described meditation. I thought it could help me walk because that was a balance issue, which to me was less a physical problem and more a mind-over-matter thing. I thought meditation would be perfect.

“Before going to rehab one day I meditated, and while meditating I visualized walking without a cane. Later, I was standing at the elevator, and I felt like I had forgotten something — it was my cane. My first instinct was to go back and get it, but then I said ‘what the hell’ and got on the elevator, walked to the subway and went to rehab. The first thing my PT said was ‘Where’s your cane?’ What a great feeling it was to say ‘back in my apartment.’ I am a big believer in meditation. I think it should be part of rehab.”

Certainly the price is right for cash-strapped stroke families: It doesn’t cost anything except maybe the price of a book or a class or a tape. And it’s simple. I have meditated for 15 years and taught classes for 10, and meditation is nothing more than sitting still doing nothing. Anybody can do it. And there’s scientific evidence that it has beneficial effects on all sorts of things of concern to stroke survivors.

For instance, every heart patient who goes to Columbia Presbyterian Medical Center in New York City is offered an optional program of massage, yoga and meditation. They have found that the patients who manage pain and reduce anxiety better are the ones who participate in that program. It has proven effective in combating high blood pressure and is often prescribed for patients with chronic pain.

Studies of the meditating brain using sophisticated imaging techniques have shown that the brain doesn’t shut off when it meditates. It blocks information coming into the parietal lobe. That part of the brain orients us in time and space, so shutting it down allows us to drop our sense of limits and feel more connected to a greater whole.

Other studies found that meditation increases theta waves, which are the patterns right before we go to sleep — except the meditating brain doesn’t slip into sleep. Alpha waves, which are those associated with conscious thought, also decrease during meditation. In other words, the mind stays awake but relaxed.

*Oming Pretzels*

Many people hold a stereotype of meditation I call “oming pretzels.” It’s the idea that real meditation
requires you to sit in a yoga posture called full lotus. Most people take one look at that and think, “I can’t do that, so I can’t meditate.”

Meditation is not about how you sit. I’ve meditated every day for 15 years and have never sat in full or even half lotus — nor could I meditate if I did because I’d be in too much pain. You can sit on a chair, the floor, the side of your bed, anywhere you can be comfortable. You can even lie down, though I don’t recommend it because most people are conditioned to go to sleep when they get relaxed lying down. The primary considerations are that you are comfortable and in a posture that allows you to breathe deeply.

**Monkey Mind**

Most people equate meditation with emptying the mind of thought. Unfortunately, what happens when we try to still our minds is we realize our minds are like monkeys frolicking at the zoo. We remember a tidbit from yesterday, think of an item on our to-do list, jump to some worry about the future, pull up a petty irritation or an ancient grudge. In other words, when we try to sit still and do nothing, we become aware that the stream of our consciousness is a raging torrent of thought and emotion. Because we aren’t successful in calming that flood right away, we figure we can’t meditate, so we give up trying.

The goal of emptying your mind sets you up for failure. You won’t likely ever empty your mind of thoughts. Your mind thinks. That’s what it does, you can’t shut it off. But lucky for us, we’re not our thoughts.

**Sitting on the Banks**

Imagine your mind is a river and your thoughts are like leaves on the surface. Put yourself on the banks of that river and watch the leaves go by, labeling each one: sad thought, happy thought, angry thought, depressed thought. Some of the thoughts will be charged with emotion and will pull you into the river. When that happens, your breathing will become shallow. If you notice your breathing has changed, simply take a deep breath and pull yourself back to the banks of your stream of consciousness and begin to label your thoughts again.

Don’t be discouraged if you spend more time in the river than on the banks of your mind. The ability to watch your mind with detachment takes time to master, but practicing it even ineffectively produces calm and concentration.

**A Practice, Not a Status**

Although any time spent in meditation is refreshing and positive, it’s really the daily practice of meditation that provides the positive benefits. It’s more effective if you do it every day even for a short time rather than for a long period inconsistently — 15 minutes, or even 5, will do.

The effects of any practice are cumulative, that is why practice makes perfect. Don’t expect huge changes at the beginning, although most people in my classes report more patience after just a week or two of daily practice.

The calm and concentration that meditation produces is not a status that you achieve and then never have to worry about again. To possess those qualities of mind and emotion you must visit them every day, just like with blood pressure medicine.

“Since my stroke, meditation has become a major part of my life,” says John Kawie. “A stroke may have damaged your brain, but it hasn’t damaged your mind. When you meditate, that’s the part you really use, your mind.”

**Types of Meditation**

- **Concentrative** uses techniques such as repeating a phrase or sound or breathing in a particular way in order to focus the mind: Transcendental Meditation is an example
- **Mindfulness** Buddhist tradition of peaceful acceptance of what is: sit still do nothing
- **Movement** focuses on heightened awareness of movement: Tai Chi is an example

**Books**

- *Wherever You Go There You Are* by Jon Kabat-Zinn
- *The Wooden Bowl* by Clark Strand
- *The Power of Now* by Eckhart Tolle

**Web Sites**

- tm.org
- soundstrue.com
- dhamma.org
- whatmustibethinking.com
Craters of the Moon National Monument is a forbidding landscape. Located in southwestern Idaho, the land is remote, waterless and, more often than not, baked by a relentless sun. The few who choose to walk there are wise to bring plenty of water and a second pair of boots. The sharp rocks and endless ridges of blistered lava can shred a thick rubber sole in an afternoon. It’s a hell of a place to be stranded and left to die.

When Robert Limbert — a flamboyant naturalist, explorer, outdoorsman and photographer, who was famous for his trick shooting — came to Craters of the Moon in 1920, he called it a place with “bubbles, rolls, folds, and twists, as if a giant’s frying pan of thick gravy furiously boiling had been frozen instantly.” Limbert embraced the bleak landscape of Craters of the Moon, helped give it a name — he thought the area looked like the lunar landscape — and protected it. In 1924, with H.T. Stearns of the U.S. Geological Service, he convinced President Calvin Coolidge to make a national monument of more than 50,000 acres.

I visited Craters of the Moon — not for the first time — in April of 2000, just as President Bill Clinton was deciding whether to expand the monument’s size thirteenfold. I was a conservationist with 15 years of fieldwork in Idaho, and I supported the expansion. A few months earlier, I had met with Interior Secretary Bruce Babbitt’s key staff and made the case that Craters was a good place for President Clinton to exercise his executive power to protect public lands. Political opposition would be small, and the landscape was grand, at about 692,000 acres, and of particular interest to Babbitt, a geologist by trade.

I headed out in mid-morning with three friends, Miguel, Katie and Doug, for a day of exploring. Laidlaw Park is a kipuka at the edge of the preserve — an island of grass surrounded by miles and miles of lava flows. It was everything I remembered, and better. Cinder cones rise from the flat terrain to afford long views of the lava and land beyond. These mountains of cinders are the only elevation in an otherwise flat terrain; they seemed to encourage me to rise out of the black landscape and take to the sky. When we crossed out of the kipuka and into the lava proper, we saw spindle bombs — the volcanic bubbles made of rock that flew miles from the eruption of shield volcanoes — and the Blue Dragon flow, a frozen river of shiny bluish lava.

It was a fabulous, topsy-turvy landscape. When I dared look up from my feet, I was engulfed in an immense expanse of pure, black rubble, a wild rock ocean that threatened to rise and swallow us. Along the edges of the lava, and in hidden pockets, life endured. In kipukas we discovered dainty, fragrant wildflowers: wire lettuce and scorpionweed, wild...
"I took an inventory. My right eye didn’t work. My face was caked with something, either dirt or blood, probably both. My right leg wouldn’t move, and my right arm wouldn’t do what I wanted it to."
onion and scabland penstemon, dwarf monkeyflower and Indian paintbrush, syringa and cinquefoil, bitterroot and blazing star. And signs of animals: kit fox, sage grouse, badger and mule deer. In the concrete of lava rose solitary limber pines.

We stopped and looked at Big Southern Butte, which loomed over the lava field more than 30 miles away. I had a bad headache and asked Katie for an aspirin. No, make it two. We turned around and walked to the south, first together, then apart, in a soothing, enveloping mist of light wind, fog and rain. I thought about getting to my car and relaxing. I thought about a beer, a Moosehead, and chips with hot salsa. I kept walking, hopping from one rock to another, lagging behind the others.

Suddenly, I felt as though I were floating above the surface of the earth. For just a moment, my feet lifted off the ground. Then a sharp pain — I stumbled. My head hit the lava hard. I tried to get up, but my legs wouldn’t hold me. The pain was not from the outside, exactly. No, not at all. I tried to get up again, but it was as if giant cobwebs held me down. What has happened, I wondered. A gunshot? But I had heard nothing, and there was no one around to shoot a gun. I was sure it couldn’t be any sort of health affliction. I was 44 years old and in great shape. Just the day before, I had run a half-marathon, for God’s sake, and finished 88th out of 2,200 people.

The first sharp pain fell away, but the next thing I knew, I was writhing with the pain in my head, or in my lungs, I couldn’t tell. I was caught within myself, speechless, flattened. I lay semi-conscious in that black ocean of lava, drifting on my back. At first, I felt certain that I would soon be up and on with my walk. It was just a little quirk, surely. But I was slipping and help was somewhere back of beyond.

My friends and I had agreed to meet at the car if we didn’t see each other for awhile. They would wait for me for an hour, then two, then three. They would think that I had gotten lost and be annoyed; my predicament was just too unlikely to be a realistic possibility. Perhaps they would worry and look for me, but I was down in rocks, partially hidden from view. Already it was late afternoon, and the sun was getting low and the weather cool as the clouds raced by. I tried to call out, but what should have been hoots and hollers came out as grunts and mumbles. I was a gurgling baby and in trouble beyond what I could fathom.

I took an inventory. My right eye didn’t work. My face was caked with something, either dirt or blood, probably both. My right leg wouldn’t move, and my right arm wouldn’t do what I wanted it to. When I tried to move again, I found out there was less I could do. I wanted to move in a sensible direction — straight — but couldn’t do it. I scraped my head across the rough lava. It seemed that after hours I had to concede that I couldn’t fight this. I was living inside of death. This black lava would be my grave.

Now something was going bad with my mind. Was it my concentration or consciousness that was slipping away? Or was it my life leaking out on the lava? Time wheeled. Was it hours ago that I quit trying to do anything, or just a few moments ago? Time was in freefall and I was lost in it. Utterly frustrated and utterly desperate, I cried hard for the first time in more than 20 years.

I remembered when my father had a stroke. I was 12 and he was 54, an eloquent lawyer rendered speechless. He wore a white turban and a pirate’s eyepatch and pointed out the window of Tripler Hospital, a military hospital in Hawaii. It was baffling, my feeling of helplessness and his lack of understanding. But I understood this: He wanted the hell out of the hospital. In six months he was dead. So now I knew a piece of his death, and his torture.

The slanted piece of lava I was lying on slowly released me, and I started to slide toward a brush-filled gully below. I caught a branch with my good hand and that I had gotten lost and be annoyed; my predicament was just too unlikely to be a realistic possibility. Perhaps they would worry and look for me, but I was down in rocks, partially hidden from view. Already it was late afternoon, and the sun was getting low and the weather cool as the clouds raced by. I tried to call out, but what should have been hoots and hollers came out as grunts and mumbles. I was a gurgling baby and in trouble beyond what I could fathom.
held on with all of my strength. If I let go, I would be totally lost from sight. That branch was life and I clung to it.

I called out to the earth. No answer. What good is the silent earth, the earth that I worked to protect? I was rooted here among the rocks and bushes, a captive of the elements, like Gulliver tied by a thousand Lilliputians. A rainsquall hit for a minute and chilled me. Then the sun came out and cooked me. A spider walked by my one good eye, and I tried to move so it would go away, but it kept on coming, until I screamed inarticulately at it and blew it away. What could I do if I could barely divert the path of a spider? I could wait — wait for the sun to set, wait to die in that mild April night.

For once in my life, I became pure observer, watching the land with my one good eye. This was my world: the slab of angled rock, a bush, a few small flowers, a spider crawling by. I had chosen this beauty, or, perhaps, it had chosen me. I was part of this burned-out landscape.

I saw the sun in bright psychedelic, exaggerated colors of orange, red and clear yellow. I felt as well as smelled the fragrance of the desert. They were extraordinary to behold, and I felt no more than lava, no less. I gave myself to it, to its warmth, to its shining brightness, to its burning rays, to its cold stillness, to another day in the Craters. For a moment it was a comfortable place and every bit of beauty I ever knew. I felt meditative in the blinking sunlight. I relaxed: it would be okay to die right here.

Then a miraculous thing happened, my friend Doug appeared out of the mist. I had to get his attention. I tried to call his name and it came out garbled: “Kah-to, Ree-ta.” Doug swerved. “Kf-tah.” He’d heard me. He turned in my direction. “Fu-fat.” Doug came to me and just stared.

“Mike, are you okay?” I couldn’t answer him. “What happened?” I just looked at him blankly. He called for Katie and Miguel, and together they carried me to a flat spot. I had been there four hours.

All at once, everything changed: I was going to live. But there would be no more peace for me. Instead, what lay ahead was struggle — a fight to regain my mind and body. Wellness would be counted in geologic time.

Doug and Miguel stayed with me while Katie went for help: she took two hours travelling through the kipuka, made a phone call, and then came back with rescuers. In two or three more hours, a helicopter came and flew me to a hospital in Pocatello. Two weeks later, it was obvious that I was going to walk again, but I still couldn’t talk — or think worth a damn.

My left middle cerebral artery, the one in the body called “the artery of cerebral hemorrhage,” had been clogged with a blood clot, and that had killed a piece of my brain. The doctors gave me 325-milligram doses of aspirin, told me to take one per day, and sent me out into the world to regain my bearings. I took a year of therapy. I learned to talk again, relearned to write — and to live with the rough edge of existence.
During this time, Interior Secretary Babbitt moved ahead with plans to protect the Craters. Finally, on Nov. 9, 2000, President Clinton signed the proclamation putting 692,000 acres into the Craters of the Moon National Monument — nearly 13 times the 54,400-acre monument that had been designated by President Coolidge in 1924.

I had some blood in that designation, but I am no longer the same person who advocated it so diligently. Now the part of me that wanted to change the way the world works in 15 minutes — the part that insisted upon naming defeat and success — is gone. I see that everything is incremental — whether in health or politics. Incremental change is often all that we can do.

For my part, I have become mostly well. I can speak and think, even hike and run again. I have come to live with the fact that my stroke was the result of not drinking enough water when I ran so that a clot formed in one of my arteries. And I took no aspirin.

Six months ago, I walked alone in the original Craters of the Moon National Monument to see what I could and remember what it cost me. There, I rediscovered magical geological structures that Robert Limbert had named in 1924: the Amphitheater and Moss Caves, the Blue Dragon Flow and the Bridge of Tears Arch.

A stroke killed Limbert when he was 48 years old. Would it also kill me, somewhere out here, amid tall sagebrush and grasses on some fine day? On the top of the Watchman, a high cinder cone that I climbed for a view, I watched an amazing desert kingdom made of rock and wonder. I walked alone in the Craters, and, my God, it was good to be alive in such a burnt and rugged landscape.
When the time comes for one of you to carry on.

Every thoughtful husband and wife knows the time eventually will come when one of them will have to carry on alone, and perhaps spend many years as a widow or widower. The American Heart Association has prepared a practical, supportive brochure to help spouses prepare for life without their marriage partner. It will help you be ready “when the time comes” not only to handle the details and decisions that follow a spouse’s death, but also to deal with financial and practical matters – in short, to resume the business of life as effectively as possible.

Send now for our free booklet, When the Time Comes.

We encourage you to keep this helpful booklet with all your important papers. It covers crucial topics such as:

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- Preparing a personal affairs record
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- Post-death checklist: steps to take

For more information, please visit us at americanheart.org/plannedgiving or e-mail us at plannedgiving@heart.org.

Please send to: American Stroke Association
Planned Giving Department
7272 Greenville Avenue
Dallas, TX 75231-4596

☐ Please send me the free booklet When the Time Comes. (CCA)
☐ Please have a representative contact me to discuss how charitable estate planning can benefit me. (CCD)
☐ I am considering a gift to the American Stroke Association through my estate plan. (CCC)
☐ I have already included the American Stroke Association in my will/estate plan. (CCB)

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City _________________________ State ______ ZIP ________
Phone ____________________________
Birthdate __________ E-mail ____________________________
When Tim Podell was 12 years old, he wanted to be a professional magician. He was fascinated with magic tricks and he loved entertaining people. He graduated from college with a psychology degree, but stayed faithful to his dream.

He became a “50-miler.”

“That means I was able to make a good living as a magician without ever leaving a radius of 50 miles from home.”

Tim also wanted to become a television producer in his hometown of Ossining, New York. He had volunteered to assist in public access television during college — doing everything from shooting and editing film to hosting programs.

He had an idea of producing documentaries and commercials, so he bought a lot of television equipment. The day after the equipment arrived, he had an ischemic stroke. He was 24.

The stroke paralyzed his right side. He spent seven months in the hospital in recovery. After two years of rehab, he recovered many of his abilities. He walks now, with a slight limp and has residual paralysis in his right arm and hand. The stroke left him with no clue about what he would do with the rest of his life. He spent two more years getting back on his feet mentally and emotionally.

“Finally I decided I was ready to get out there and do something,” Tim says.

In 1991, he called Jean Craighead George, a children’s book author whom he had interviewed while working in public access television during college. He asked to interview her for a video, and she agreed.

Tim hired a film crew and visited Jean at her home in Chappaqua, New York. “When we got there, we worked out the details on how to shoot the video. I interviewed Jean about how she became interested in writing, the techniques she uses and how she develops characters and plot in her stories. We also took footage of her and her dog interacting.”

“Finally I decided I was ready to get out there and do something,” Tim says.

Tim took the video to all the publishing houses in New York, thinking they might be interested in his interviewing other authors. His idea was totally rejected. Disappointed but not discouraged, he sent his video to the School Library Journal, which reviewed it positively. The review said his video was a useful tool for encouraging students to read and write.

Soon Tim got calls from schools across the country wanting to order copies. With the help of some neighborhood high school students, Tim filled orders in the basement of his parents’ home. “We took 4 x 6 photos of the author and used rubber cement to attach them to the tape covers.”
From this small beginning in his parent’s basement, Tim started expanding his business. His father loaned him $6,000. Tim began contacting other children’s book authors for interviews. He began visiting librarian conventions and schools to market his work.

He also rented warehouse space where he could fill orders. Then he contracted with a nearby fulfillment company to mail the videos. He opened his own office in Ossining and hired a secretary to e-mail orders to the fulfillment company.

“Interviewing children’s book authors was really a fluke,” Tim says. “It was not necessarily a particular interest of mine at the beginning, but it has since developed as an interest for me.”

In his “Good Conversations” video series, Tim asks authors to explain their writing techniques, how they develop their characters and plot, what inspires them. Authors talk about what time of day they like to write, where they work and how many pages a day they produce. “In the interviews, I am not the center of attention. The whole point is for the author to be the center of attention.”

His videos reveal what daily life is like for the author. “Kids enjoy getting to know the author. The authors are no longer these mysterious people, but people like their mom or dad.”

He has interviewed more than 40 children’s book authors, including many Newberry Award winners, the Oscar equivalent for children’s literature. He has traveled across the country and even to Scotland to conduct interviews.

He loves the thrill of meeting writers. “I hope that enthusiasm comes across in my videos.”

His interviewing style is casual. He usually wears jeans and visits authors at their homes, because he wants them to feel at ease. “Plus I can’t tie a tie, so I usually don’t wear one,” Tim says. Although he sometimes has difficulty finding words since the stroke, this isn’t a problem in his interviews. He is proud that most people can’t tell he had a stroke.

Jerry White, director of the Entrepreneurship Program at the Cox School of Business at Southern Methodist University in Dallas, Texas, shares his insights on what it takes to be an entrepreneur. From his research, he identifies several characteristics of entrepreneurs:

- A can-do attitude
- Creativity
- Realistic thinking as well as optimism
- An ability to devise new and different ways of doing things
- Not being intimidated by people who say, “You can’t do that.”
- Possessing a sense of urgency about their ideas
- Having physical stamina
- Taking moderate, calculated risks, but not gambling
- Believing that their capabilities will surpass their risks
- Being excited by challenge
- Determination
- Commitment

He has also produced “All About the Book!” videos for elementary and junior high school students. In these videos, he talks to a panel of students about their reactions to a certain book. He explores the theme of the book and how that theme applies to their lives. Teachers say that these videos spark classroom discussion about social issues. Tim makes presentations to classes using the “All About the Book!” videos. When he makes his presentations, he

Financial Realities of Starting Your Own Business

- You must have or find the resources to support yourself.
- Very few businesses make a profit in the beginning.
- It usually takes three to six months to turn a profit.
- You must know the difference between profit and cash flow. Profits = revenue minus expenses. Cash flow = the checks that come in minus the checks you write out. Profits do not keep your business alive; cash flow does.
- You will need to do your own marketing at the beginning so most entrepreneurs need to be “people” persons.
- You need to have a realistic self-concept and choose a business that plays to your strengths. If you don’t like math, don’t start an accounting business.
- Grow slow and steady, not fast.
- Know your business before you start it. It usually takes three to five years to learn a business.
The F.T.M. Arm Training Program offers many stroke survivors a chance for continued progress. Our clinical trials have shown an increase in strength, range of motion, motor control, overall arm function, decreased tone in the hand and decreased compensatory movement patterns.

If you answered yes to the above questions, then the F.T.M. may be right for you.

Do you have some shoulder and elbow movement in your involved arm, but are unable to open your fingers?

Do you not qualify for constraint induced movement therapy because you lack the required wrist and finger extension?

The patent pending F.T.M. is a revolutionary new dynamic orthosis that allows stroke survivors to use their involved arm and hand for grasp and release activities during therapy that would otherwise be impossible. Our one-week and two-week arm training programs incorporate the latest stroke research findings.

Tim on the set of one of his videos

always includes some magic tricks to entertain the kids.

His next goal is to bring children’s literature to the big screen. He has already purchased the rights to the book Goody Hall from Natalie Babbitt, an award-winning children’s author and writer of the modern classic Tuck Everlasting. He plans to turn her book into a feature-length film, and has already talked to several production companies about the project. He has contacted other authors about turning their books into films as well. “Because I have developed a relationship with these authors, they know that I have their interests at heart.”

Tim attributes his success as an entrepreneur at least partly to his ability to stay positive. “I never take negative thinking to heart,” he says. “Some of my friends thought I was crazy to start a business after my stroke. I didn’t worry about that, I just moved forward. You need a strong belief in yourself to succeed. Listen to everyone’s advice, but weed out the negative things and focus on the positive.”

Tim took what was available to him — his background in public access television, a contact he had made in college and a loan from his parents — and created a successful career that enriches children’s lives.

Christopher Reeve inspires him, he says, as do the stroke survivors profiled in Stroke Connection Magazine. “They are all making a difference in the world despite their disability.

“I hope my story will inspire other survivors to pursue their dreams. There are so many people sitting on great ideas and not pursuing them. Just do it!”

F.T.M. Arm Training Program

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Without the F.T.M. With the F.T.M.

• Do you have some shoulder and elbow movement in your involved arm, but are unable to open your fingers?
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Completing a marathon is a life-changing event. So is a stroke.

Train To End Stroke is a marathon-training event that raises money to fund lifesaving stroke research and education. We’ll help train participants in 36 cities to finish a marathon or half marathon. Participants who complete this training and reach the fundraising minimum will be invited to travel with us to one of many exciting destinations.

Call (888) 4-STROKE to find out if this program is offered in your area. To help our efforts, encourage family and friends to participate in this event in your honor. Learn more about Train To End Stroke at StrokeAssociation.org.

I suffered a massive hemorrhagic stroke in September 2000 when an arteriovenous malformation (AVM) ruptured. I was age 33. My primary deficit was left-side hemiparesis, which I liken to physical schizophrenia. Given that my dominant right side is still functional, my partially paralyzed left serves as a constant source of frustration and a reminder of the ineffectiveness of my body.

At every stage of recovery, I’ve found that the medical establishment advocates a simple credo, “Don’t let your stroke define who you are.” Built on a foundation of the best intentions, it is meant to promote the quick achievement of strength and happiness.

I have found that trying to subscribe to this school of thought is ultimately counter-productive in the recovery process. In fact, I champion the exact opposite philosophy. As a stroke survivor, I would counsel others to allow the stroke to define who you are. I would even go so far as to suggest you lower some of your expectations. On the surface these may seem like defeatist attitudes, but they worked just the opposite in me.

Not letting the stroke be a part of you is another way of saying, “Get over it.” I know the doctors and my family and friends were only trying to help me recover more quickly. But following that advice promoted a hasty effort to put the event behind me instead of fully experiencing the tribulations inherent with traumatic brain injury.

Trying to skip the unpleasant part only revealed the need to fully experience all the adversity and negativity of this event before healing could begin. I found the return to a state of mind and body anywhere close to “normal” is a painstakingly gradual and potentially lifelong process. Not to mention frustrating. I always tried to project a strong outward image to the world, not letting on just how much my stroke had affected me both mentally and physically.
When I did that, people tended to respond more positively. They worried less about my well-being, thinking I had things under control. Everyone loves a hero, those people who don’t quit and beat the odds despite a stacked deck. I desperately wanted to be that person, but it was a facade.

Trying to live under the guise of strength was a dangerous exercise in denial. I was literally crumbling inside, reeling from the aftermath of an event that totally consumed my life. It is still incomprehensible more than three years later.

I had heard “use it or lose it” from therapists so often that I was sick with guilt every minute that I was not exercising or engaging in some motor function rehabilitation activity. The reality was that I possessed neither the energy nor capabilities to work that hard. Nonetheless, it prompted a feeling that I lacked the resolve to get well.

I felt I projected the impression that I was incredibly unmotivated. I even felt guilty for sleeping. If I really wanted my body back, why wouldn’t I be working at it 24/7?

Although I knew that depression and lack of motivation were normal feelings after stroke, it took me a long time and much professional guidance to accept them. More important was to understand that beating myself up was both psychologically damaging and a hindrance to my physical rehab.

I was unable to truly motivate myself in recovery until I allowed myself to be defined by this event. I had to embrace it, albeit begrudgingly, so that I could understand the new limitations that had been forced upon me. Like it or not, I was a new person and not an improved one, at least physically.

The full function of my dominant side was a blessing and a curse. I had been athletic, so I longed for the complex motor skills and coordination that sports demand. As I inevitably realized the extent of the physical damage, I allowed myself to understand that I was indeed disabled.

I have been slowly resetting my goals, realizing just how long the recovery journey can be and what I can realistically expect from myself. We all naturally compare ourselves to when we were healthy, but that’s not realistic when the body doesn’t work like it used to.

This shift has enabled me to approach rehabilitation with less frustration. Now I acknowledge anything my left side can do, no matter how insignificant, without comparing it to my unaffected dominant side. Although it is still my ultimate goal to achieve the same functional level as my unaffected side, I have “lowered the bar” in the interim.

Instead of trying to achieve unrealistic goals, like the quick return of function equivalent to my dominant side, I try to exploit my strengths. I retained decent gross motor function, so I beg my PTs and OTs to concentrate on what I can do with that instead of having me use a piece of silverware, which requires skills that seem light years away.

Despite therapists’ best intentions, there are simply certain tasks that cannot be performed, not for lack of desire or effort, but rather by the physical or cognitive limitations that dead brain tissue leaves behind.

I have tried to embrace what happened to me. That is not to say I have given up. Far from it. I just joined a gym and hired a personal trainer to work within the limitations that I still have. I never thought I would be in a gym after all the time I had spent in cold, stark hospitals and rehab facilities.

I recently saw a crudely posted sign that spelled in old, warped, plastic letters a message more relevant to the healing process than the medical profession’s credo. It said, “Give up all hope for a better past.”

I am what I am. That healthy, athletic 33-year-old with the undamaged brain has been altered, but I’m still here. And the future seems brighter than ever since I embraced what happened to me instead of hastily trying to get over it. Oh, did I mention that I’m taking my driver’s test next week? 

“I would counsel others to ALLOW THE STROKE TO DEFINE WHO YOU ARE.”
A bout six months after Katherine Ware had a stroke in 1996, she noticed that the small toes had begun to curl beneath her left foot. Wearing shoes became problematic and walking was painful. Her stroke physician referred her to a podiatrist, who identified her malady — a condition called “claw toe.”

Claw toe, and a similar condition called “hammertoe,”* is caused by an imbalance of muscles in the feet and toes. Brain damage during a stroke leaves survivors prone to neuromuscular imbalances. In the case of claw toe, muscles in the foot over-contract due to a neurological abnormality.

Because toe muscles are typically not very strong, the contracting muscle overpowers the muscles in the toe. This tightens the tendons, causing the joints of the smaller toes to buckle or curl in an unnatural way.

Claw toe most often strikes the stroke-side foot. Painful blisters may develop on the affected toes where their tips dig into the shoe. Added pressure from the imbalance may also cause calluses or corns to form on the ball of the foot. Claw toe also affects patients with joint diseases such as rheumatoid arthritis, cerebral palsy, nerve damage due to poor circulation, as with diabetes, and those confined to bed for a long period of time.

Claw toe is classified in two ways — “flexible” or “rigid” — based on the severity and progression of the condition. “Flexible claw toe” describes the earlier stages in which, as the name suggests, the toes are still flexible at the joint. For flexible claw toe, the American Academy of Orthopaedic Surgeons (AAOS), in conjunction with the American Orthopaedic Foot and Ankle Society, offers these suggestions for helping to correct the imbalance:

- Follow the instructions of your doctor and use a splint or athletic tape to reposition the toes.
- Avoid shoes with heels over two inches.
- Wear soft shoes with plenty of room for the toes.
- Give your toes a workout by using them to pick up small objects, such as marbles, or a crumpled towel.

*a toe-curling experience

by Heather Harper

* Claw toe and hammertoe are very similar conditions, differing in the muscles affected—flexor digitorum brevis and flexor digitorum longus respectively. For this reason, the terms “claw toe” and “hammertoe” are often used interchangeably in terms of treatment options.
Claw toe, and a similar condition called "hammertoe," is caused by an imbalance of muscles in the feet and toes. Brain damage during a stroke leaves survivors prone to neuromuscular imbalances. In the case of claw toe, muscles in the foot over-contract due to a neurological abnormality.

Several Stroke Connection Magazine readers have offered their own solutions to this problem. Stroke survivor Lillian Schwartz of Boca Raton, Florida, uses foam toe separators. Available at beauty supply stores for just a few cents, the separators are used by beauticians when giving pedicures. Schwartz recommends using two separators (one on top of the other) if your toes are long. James Pribish, a stroke survivor from New Castle, Delaware, uses a pair of gel insoles with tiny magnets embedded in them, which he says have greatly reduced the curling.

"Rigid claw toe" designates the later stages in which the toes are fixed in this unnatural position. As the tendons tighten and the deformity becomes fixed, fewer options are available. Non-surgical treatments are confined more to pain-management than to correction of the deformity. To minimize discomfort for rigid claw toe, the AAOS recommends trying specialized shoes "that have an extra 3/8" depth in the toe box" or asking a "shoe repair shop to stretch a small pocket in the toe box to accommodate [the toes]."

Katherine Ware recommends a different option: surgery. "I'd be on a cane if it weren't for the surgery," she said. The procedure involved cutting the tightened tendons. Other possible procedures include lengthening or repositioning tendons, or shortening the bone of the toe. Inserting a steel pin into the toe often corrects the deformity.

As with all surgeries, infection is a risk, and swelling and pain are common in the weeks following. Mrs. Ware described her surgery as "easy" with a "quick recovery." Although typically no tests are needed to identify claw toe, an X-ray will most likely be required if surgery is considered.

Botulinum toxin (Botox®), a complex protein byproduct of the bacterium famous for contaminating canned goods and homemade preserves, is another treatment option. Botulinum toxin has the highest toxicity of all known substances, so it seems odd that it has found its way to the forefront of medical technology. But the toxin, injected in tiny amounts at the site of the over- contracted muscle, has given relief.

In order for a muscle to contract, it must receive a chemical signal (neurotransmitter) from a nerve ending. Botulinum toxin injections work by blocking the nerve endings. This keeps the neurotransmitters that signal the muscle to contract from reaching the nerve. The effects aren't usually noticed for five to 10 days and last only three to four months.

Although claw toe is not widely known, there is help for this painful condition. If your doctor doesn't know much about it, seek more help, and ask more questions.

Bob and Katherine Ware
hat use is a stroke? For two stroke survivors, the answer is “time.” After their strokes, Grace Ebersole of Chambersburg, Pennsylvania, and Bette Williams of Nashua, New Hampshire, found themselves with time on their hands.

When she was 72, Grace survived three strokes between Christmas and New Year’s Day 1998. Suddenly she had time on her hands and an opportunity. For many years she had wanted to write a book. “We are parents of a handicapped daughter who had a stroke at 18 months. The book I wanted to write is about how God worked in my life. As I look back I can see that God had a plan for me. Leroy and I were used to start a support group for the handicapped, and then a personal care home for them.”

But there had never been enough time to sit down and write. Every season was busy, and then came the holidays of 1998. “The work wasn’t taken away, I was taken away from the work so that I could write the book. This stroke gave me the time to write.”

As soon as she got home, still in a wheelchair, still paralyzed on her left side, she sat at the kitchen table and began writing, using notes she’d made earlier.

“It was so therapeutic for me. It gave purpose to my days when I could do little else. I am right handed, and the stroke had not affected that hand. Leroy did all the work, and I sat in the wheelchair at the table and wrote and wrote. Days flew by, I had no time for depressing thoughts with this creative task absorbing my mind.”

For about a year, Grace wrote longhand, on any paper she could find, until she was finished. The book *Chronicles of Grace* was published in June 2000 by Masthoff Press.

In 1986, Bette Williams was 63 when a right-hemisphere stroke left her with time to fill. Her therapist urged her to find something to replace all the physical things she could no longer do. “My husband Robert and I had restored five 200-year-old houses ourselves near our home in Hollis, New Hampshire, so as I recovered I wrote a book about them and the one we live in now.”

After a few rejections, Bette’s book was published by a Nashua, New Hampshire, publisher under the title *Old Homes That Made New Friends*. Bette, who writes on a computer, was just getting started.

Next she wrote and published a book of stories about 45 years of outdoors experiences called *Camping Is Not for Sissies*. And when we talked to her recently, she was compiling camping stories she’s received over the years into a book titled *Tales from Around the Campfire*. She was also taking a writing class in the seniors program at Rivier College in Nashua.
“When you have a stroke you feel stripped of many things,” says Grace. “I found it helps to think positively. I can’t peel a potato or tie my shoe, but I can read and write, two of my favorite pastimes. “What unused gift do you possess that has just been lying dormant within you, waiting to be expressed? I can’t tell you what that is, but I believe you will find it if you look for it. Writing, which I could never find time for before, gives me such fulfillment now. It gave me purpose. It makes me feel good about where I am in my life.”

Know the warning signs of stroke:

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

Call 9-1-1 IMMEDIATELY if you experience symptoms!

Time lost is brain lost!

Practice Writing

Everybody has a story to tell, but writers are different. They write theirs down. Here are some tips about putting pen to paper or fingers to keyboard.

✓ Do it for yourself and for your family. Don’t do it for publication. Just write a good story so your descendants can know where you came from.

✓ Start by journaling. Buy a cheap notebook and write three pages every day. If you don’t have anything to say, write, “I remember…” and see what comes out.

✓ Take a class. Sometimes it’s easier to start writing if you have assignments. Joining a class also gives you a built-in feedback loop so you can become a better writer.

✓ Find a sponsor. Having someone read your work gives you a purpose for writing it. A sponsor can be anyone who is willing to read what you write. Sponsors aren’t writing coaches. Their only job is to read.

✓ Share your stories with those you love and who love you.

Blogging

Blogs have become one of the fastest growing segments of the Internet. A “blog” is a sort of online diary. Blog is short for “Web log,” and it has been called a revolution in publishing. Anyone can create an online journal about any subject. Essentially, blogging allows you to publish your thoughts, opinions and musings without suffering an editor or being rejected by publishers. Blogs make it possible for thousands of authors to share their experience with others on the network.

For more on blogging, type blog into your favorite search engine, and you will quickly find all the information you need to become a blogger.
Daily Renewal for Caregivers

Caregiving takes energy. Spend a little time every day renewing your energy before you become drained; that way you have a reserve to work from.

Renewal means balancing personal needs and the demands of caregiving so you have time and energy for yourself. Renewal helps prevent burnout.

Here are a few suggestions:

• Go on a retreat. This could be a weekend or an afternoon where you distance yourself from caregiving and just relax.

• Set aside personal time every day for energizing activities like exercise, meditation, prayer and play. As little as five or 10 minutes spent this way can help.

• Engage in renewal activities in the midst of your caregiving responsibilities, such as deep breathing, prayer, consciously appreciating the moment or finding humor in a situation.

Keep It Simple

Conscious breathing is something you can do anywhere. Deliberately taking a breath helps you restore yourself physically, mentally, emotionally and spiritually.

When you are upset, your breathing is shallow, restricted and fast, but when you are calm, it is deeper, slower and more relaxed. When you practice deep, steady breathing, you can release emotional tension and calm your mind.

Try breathing consciously and deeply when you are on hold on the telephone, when things are getting tense, when sitting at a red light or standing in line.

Renew Your Commitment

In the midst of a hectic day, it is easy to lose sight of what inspires you to be a caregiver. Remember why you do this work. Ask yourself, “Why do I do this?” Make a list of your reasons.

Revisiting those reasons may provide you with the energy you need to be a more inspired and committed caregiver. Or your answers might spark you to see the deeper reasons for working as a caregiver, or to see your role as a gift to yourself.

Join a caregiver support group. Ask other caregivers what keeps them going.

When things get tough, remind yourself about the contributions you make each day that improve your survivor’s quality of life.

Keep a Gratitude Journal

Each day write down three to five things for which you are grateful. You’ll be making an inventory of all that you have, instead of what you don’t have. Find a convenient time to do this, like bedtime. Some people find the evening meal a good time to involve family members in this practice.

Remember, the most important thing is to energize yourself before you become depleted.

Adapted from Running on Plenty at Work: Renewal Strategies for Individuals, by Krista Kurth, Ph.D. and Suzanne Adele Schmidt, Ph.D. For a list of quick renewal tips from this book, contact us at 1-888-4STROKE (478-7653).
While some stroke survivors are fortunate enough to have a trusted caregiver or family member to manage finances, others may need to seek outside help to keep money matters in proper order. Many are seeking the assistance of Daily Money Managers (DMM). This growing field is made up of professionals available to help seniors and persons with disabilities navigate a variety of basic financial services.

What Do Daily Money Managers Do?

According to the American Association for Daily Money Managers (AADMM), “Daily Money Managers provide personal business assistance to clients who have difficulty managing their personal monetary affairs. The services meet a continuum of needs, from organizing and keeping track of financial and medical insurance papers, to assisting with check writing and maintaining bank accounts.” Some services include:

- Bill-paying, including calls to payees regarding incorrect bills and preparation of checks for clients to sign
- Balancing checkbooks and maintaining bank records
- Preparing and delivering bank deposits
- Organizing tax documents and other paperwork
- Negotiating with creditors
- Deciphering medical insurance papers and verifying proper processing of claims
- General organization assistance
- Providing referrals to legal, tax and investment professionals

However valuable these services may be, it is important to note that a DMM should not replace your accountant, lawyer or other financial advisors. DMMs do not have power of attorney and they are not meant to take the place of other counsel.

Who Needs a DMM?

Since many survivors have communication challenges, it may be helpful to have a trusted ally to aid in financial tasks. Caregivers with little time and few resources may need to seek outside help as well. Daily Money Managers ease the burden of detailed financial tasks without the restrictions of full guardianship.

Questions to Ask

Since there is no current national regulation of the DMM industry, it is important to do a full background check on anyone who has access to your finances. To help with this process, ADMM lists some important questions to keep in mind.

- Is the DMM willing to involve another person, such as a lawyer, accountant or family member?
- Some DMMs offer a free initial consultation — ask in advance.
- Is the DMM insured?
- With which local organizations are they affiliated?
- Always ask for references and check them.
- How does the DMM bill for their work?
- What will the services of the DMM cost and what are the common billing methods?

How much do they cost?

Many senior centers and programs throughout the U.S. have trained volunteers that provide basic financial services free of charge. However, most DMMs charge fees. Services are usually billed on an hourly basis ranging from $25 to $65 per hour. Check with your local Area Agency on Aging or the AARP (202-434-6276 or www.aarpmmmp.org) to see what these organizations offer. Sometimes reduced fees or free services are provided for low-income clients.

(See resources on the next page.)
Resources

American Association of Money Managers
You can contact the American Association of Daily Money Managers to find Daily Money Manager services in most areas of the country. Their Web site provides questions to ask before hiring a money manager. You can also ask a trusted family member, friend, lawyer, accountant or doctor to refer you. Your local government, senior center or Area Agency on Aging may also be able to direct you to these types of services.

www.aadmm.com
P.O. Box 8857
Gaithersburg, MD 20898-8857
Phone: 301-593-5462
Fax: 301-668-5760
e-mail: info@AADMM.com

Stroke SAFE
This support and awareness Web site offers online support groups plus educational articles about locked-in syndrome, thalamic pain and other stroke subjects. You can link to stroke information sites as well as product catalogues for stroke survivors and other people with disabilities. You can download a free, 42-page stroke caregiver handbook.

www.strokesafe.org

American Stroke Association
1-888-4-STROKE (478-7653)
Fax: (214) 706-5231

National Family Caregivers Association
Voice: (800) 896-3650
Fax: (301) 942-2302
www.nfcacares.org

Americans with Disabilities Act (ADA)
Voice: (800) 514-0301
TTY: (800) 514-0383
www.usdoj.gov/crt/ada/adahom1.htm

National Aphasia Association
Voice: (800) 922-4622
Fax: (410) 729-5724
www.aphasia.org

National Rehabilitation Information Center (NARIC)
(800) 346-2742
www.naric.com

Friends on the Web

Barbara Dean Schacker
www.strokefamily.org

Rob Evan Hughes
www.pathcommand.com/hughes/rob.html

StrokeHelp.com
www.strokehelp.com
PLAVIX®
clopidogrel bisulfate tablets

BREAST SUMMARY—Please see package insert for full prescribing information.

INDICATIONS AND USAGE: PLAVIX (clopidogrel bisulfate) is indicated for the reduction of thrombotic events following percutaneous coronary intervention (PCI).

Recent MI, Recent Stroke or Established Peripheral Arterial Disease

For patients with acute coronary syndrome (unstable angina or non-Q-wave myocardial infarction [MI]), established peripheral arterial disease, or stroke, PLAVIX has been shown to reduce the rate of a composite endpoint of non-fatal MI, stroke, or death in the presence of non-fatal MI, stroke, or death in the presence of clinical evidence of ischemia.

PLAVIX is indicated for the prevention of atherothrombotic events in patients with a recent MI, stroke, or transient ischemic attack (TIA), and is indicated for the prevention of atherothrombotic events in patients with a recent MI, stroke, or TIA in the presence of clinical evidence of ischemia.

CONTINUATIONS: The use of PLAVIX is contraindicated in patients with a hypersensitivity to the drug substance or any component of the product, such as the preservatives. In such patients, the use of such preservatives may result in anaphylactic or other allergic reactions.

ADVERSE REACTIONS: The occurrence of adverse reactions was 0.7% for PLAVIX and 0.3% for placebo. In the CURE trial, the incidence of patients withdrawing because of skin and appendage disorders adverse reactions was 0.7% for PLAVIX and 0.3% for placebo. In the CURE trial, the incidence of patients withdrawing because of skin and appendage disorders adverse reactions was 0.7% for PLAVIX and 0.3% for placebo.

Adverse events occurring ≥ 1% of patients on PLAVIX in the CAPRIE controlled clinical trial are shown below regardless of relationship to PLAVIX.

Adverse Events Occurring ≥ 2% of Patients in CAPRIE

Body System

Incidence % (% Discontinuation)

Event

PLAVIX (n=3649)

Aspirin (n=3654)

P-value

Body as a Whole—general disorders

Fever 2.2 2.2 0.73

Other body as a whole disorders

Urinary tract infection 3.6 (0.1) 3.9 (0.2)

Hematologic and lymphatic disorders

Agranulocytosis 0.8 (0.1) 0.8 (<0.1)

Infections and infestations

Dermatitis herpetiformis 3.1 (0.1) 3.1 (0.1)

Drug/Laboratory Test Interactions

None known.

Carcinogenesis, Mutagenesis, Impairment of Fertility: There was no evidence of tumorigenicity when administered for 78 weeks to mice and 104 weeks to rats at doses up to 77 mg/kg per day, which afforded plasma exposures ~25 times the dose in humans at the recommended human dose. In mice and rats, increased incidences of benign and malignant neoplasms, mainly lymphoid and hematopoietic neoplasms, were observed at the high dose levels. However, these were rarely severe (PLAVIX=0.2% and aspirin=0.1%). In the CURE trial, the incidence of diarrhea for patients receiving PLAVIX was 1.1% compared to 0.8% in the placebo group. In the CAPRIE trial, the incidence of diarrhea for patients receiving PLAVIX was 1.1% compared to 1.0% in the placebo group. In the CURE trial, the incidence of patients withdrawing because of skin and appendage disorders adverse reactions was 0.7% for PLAVIX and 0.3% for placebo.

Adverse events occurring ≥ 2% of patients on PLAVIX in the CURE controlled clinical trial are shown below regardless of relationship to PLAVIX. In the CURE trial, the incidence of these gastrointestinal events for patients receiving PLAVIX was 11.7% compared to 13.2% for those receiving aspirin + placebo. In the CURE trial, the incidence of gastric or duodenal ulcers was 0.2% for PLAVIX and 0.6% for aspirin. In the CURE trial the incidence of gastrointestinal adverse reactions was 3.2% for PLAVIX and 3.7% for aspirin. In the CURE trial, the incidence of patients withdrawing because of gastrointestinal adverse reactions was 0.5% for PLAVIX compared to 0.8% for aspirin + placebo. In the CURE trial, the incidence of the patients withdrawing because of gastrointestinal adverse reactions was 0.5% for PLAVIX compared to 0.8% for aspirin + placebo.

Adverse events occurring ≥ 2% of patients on PLAVIX in the CURE controlled clinical trial are shown below regardless of relationship to PLAVIX. The median duration of therapy was 50 months, with a maximum of 3 years.

Incidence of these gastrointestinal events for patients receiving PLAVIX was 11.7% compared to 13.2% for those receiving placebo + aspirin. In the CURE trial, the incidence of patients withdrawing because of gastrointestinal adverse reactions was 3.2% for PLAVIX and 3.7% for aspirin. In the CURE trial, the incidence of the patients withdrawing because of gastrointestinal adverse reactions was 0.5% for PLAVIX compared to 0.8% for aspirin + placebo. In the CURE trial, the incidence of the patients withdrawing because of gastrointestinal adverse reactions was 0.5% for PLAVIX compared to 0.8% for aspirin + placebo.

Adverse events occurring ≥ 2% of patients on PLAVIX in the CURE controlled clinical trial are shown below regardless of relationship to PLAVIX. The median duration of therapy was 50 months, with a maximum of 3 years.

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For most, heart attack or stroke is caused when platelets form clots that block the flow of blood to the heart or brain. Think aspirin and your other medications alone are enough? Adding PLAVIX could help protect you against a future heart attack or stroke.

PLAVIX and your other medications work in different ways. Adding PLAVIX can go beyond your current treatment. Prescription PLAVIX, taken with aspirin, plays its own role in keeping platelets from sticking together and forming clots—which helps keep blood flowing.

Talk to your doctor about PLAVIX. For more information, visit www.plavix.com or call 1-800-300-3501.

Add more protection against heart attack or stroke

IMPORTANT INFORMATION: If you have a medical condition that causes bleeding, such as stomach ulcer, you shouldn’t use PLAVIX. The risk of bleeding may increase with PLAVIX, and when you take PLAVIX with certain other medicines, including aspirin. Review your medicines with your doctor to minimize this risk. Additional rare, but serious, side effects could occur.

Please see important product information on the following page.