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1-888-4STROKE (1-888-478-7653) StrokeAssociation.org
Thank you for your wonderful magazine. On Thanksgiving night 2003, my beloved husband of 42 years had a stroke. He died 18 hours later, leaving all who loved him with a hole in our hearts. I read your magazine cover to end, and strange as it may seem, it brings me comfort.

*Helen Yorgan, Stroke Family Member*
*Seattle, Washington*

---

Last year my father had a stroke and as a result has dysphagia. I heard about a procedure called Vital Stim Therapy that offered electrical stimulation to treat swallowing disorders. I sent information to the director of my father’s nursing home and his physician. Neither had heard about this procedure and were not interested in pursuing it. Could you do a study and article on Vital Stim Therapy for the benefit of stroke patients?

*Linda O’Hara, Stroke Family Member*
*Darien, Connecticut*

Editor’s Note: For professional opinions about electrical stimulation and dysphagia, visit www.asha.org and search for “electrical stimulation.” There are several articles available to the public.

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This past summer, my daddy fell one morning and was unable to get up. He was confused, disoriented and unable to walk. At the hospital, it was determined that he’d had a massive stroke.

After 34 days in ICU, my sweet daddy passed away from heart failure. Those days in the hospital with him were the saddest but most educational of my life.

Now I realize that I was very uneducated about stroke and heart disease. Even though it can’t help my daddy, I am now very inquisitive about the causes and prevention of stroke.

A month after his passing, I began receiving *Stroke Connection Magazine*. It is very informational and educational. I hope I can help others by being better educated.

*Teresa Hutton, Stroke Family Member*
*Anniston, Alabama*

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I would like to address the question of why caregivers don’t ask for help brought up in “The Impact of Caregiving on Caregivers” (Nov/Dec ’03).

Both my parents had minor strokes, enough to make them goofy but not incapacitated. Things got really rough when my mother was incapacitated for two months after surgery.

I sent an SOS to the family that I needed help — something I rarely do. The response was pretty much “No, you don’t.” One sister did come, six weeks later. She had previous social engagements. When I told another sister I had put in 12-hour days for 60 straight days, she said, “We didn’t know you’d been working 12-hour days.” Why didn’t they know — I was eager to tell anyone.

The offers of help I do get now aren’t for what I need. I’d give anything to hear someone say, “How can I help? What do you need?”

*E.E. Hawks, Caregiver*
*Oregon*

---

I am a survivor of three TIAs and reborn from cardiac arrest. I have three Bibles to help me through: 1) the Holy Bible, 2) my daily journal and 3) *Stroke Connection Magazine*. I have received it since 2002. Last month my aide threw them away accidentally. Please send me some replacements.

One day I will write an article about me. I was writing a book, but because of short-term memory problems and what I call “cookie moments,” I have not continued it. Boy, a stroke is a mother.

*Muriel Atkinson, Survivor*
*Coram, New York*

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We Want To Hear From You

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| fax: | 214-706-5231 |
| e-mail: | strokeconnection@heart.org |

*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.*
Ignore Daily Aspirin, Triple Your Stroke Risk

Ischemic stroke survivors who stopped taking their daily prescribed aspirin tripled their risk of having another stroke within the month, according to a study presented at the American Stroke Association’s 30th International Stroke Conference.

Aspirin, the most frequently prescribed medication to prevent another ischemic stroke or heart attack, requires regular scheduled use, said Patrik Michel, M.D., co-author of the study and director of the acute stroke unit at Lausanne University Hospital in Lausanne, Switzerland.

Michel urged caution in interpreting what the research indicates. “Although the absolute risk of suffering a substantial stroke during a short period of aspirin discontinuation is probably not very high, this difference is meaningful, and patients and physicians should be informed about this potential risk,” Michel said.

“More research is needed to determine the exact risk of another stroke when aspirin use is discontinued.”

Electrical Stimulation Holds Rehab Benefits

A preliminary study pointed to the possibility that electrically stimulating part of the brain’s surface layer aids recovery of arm and hand function after an ischemic stroke, according to researchers.

The group that received both rehabilitation and electrical stimulation through an implanted device tended to show more improvement than those who were treated with rehabilitation alone, after four weeks of follow-up. Researchers concluded that electrical stimulation is safe and effective in aiding recovery.

Exercise Lowers BP for Survivors

Resistance exercise training (RET), consisting of recumbent stepping, stretching and repetitions of basic resistance exercises, significantly reduced blood pressure measurements for 11 moderately impaired stroke survivors.

The Kansas University Medical Center study measured blood pressure in three categories: resting systolic, diastolic and average arterial pressure. After seven weeks of twice-a-week, 20-minute activity sessions, measurements in all three categories dropped. The study’s authors suggested further study of RET as a nonpharmacological therapy in managing hypertension in stroke survivors.
Freedom to choose where, when and how to explore life is the aspiration of virtually every American. For many persons with physical disabilities and special transportation needs, having choices to fit their individual needs provides a rewarding experience. Ford Mobility Motoring offers valuable financial and practical assistance, including reimbursement for the exact amount of vehicle adaptations, up to $1,000 on adaptive equipment and up to $200 on alerting devices, lumbar support and running boards.*

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**In memory of Christopher Reeve.**

The Christopher Reeve Paralysis Foundation (CRPF) is committed to funding research that develops treatments and cures for paralysis caused by spinal cord injury and other central nervous system disorders. The Foundation also vigorously works to improve the quality of life for people living with disabilities through its grants program, Paralysis Resource Center and advocacy efforts.

*Total reimbursement is not to exceed $1,000. Options available for factory installation are not considered eligible under the terms of the program.
After Stroke, Visual Therapy Can Restore Some Vision

Visual Restoration Therapy (VRT) can help patients regain some vision after losing it during a stroke, according to research presented at the American Stroke Association’s 30th International Stroke Conference. VRT is a system for identifying and stimulating regions in the visual field that are only partly impaired by stroke or trauma. By compelling the patient to use the impaired areas, the process strengthens the nerve activity in those regions and helps restore some visual function. Typically, the training is done in two 30-minute sessions per day at home in front of a computer-based device.

The study found that VRT is effective in most patients for whom some vision remains, and that the greater the area of residual vision, the better the outcome of the therapy.

“This is the first technique stroke patients can use to improve their vision,” said Bernhard Sabel, Ph.D., professor of medical physiology at Otto-von-Guericke University in Magdeburg, Germany. “This study found that the effect of therapy lasts well after therapy stops and indicates that extended training tends to further improve results.”

Have you or someone you know suffered a stroke?

Select stroke centers nationwide are seeking individuals who have suffered a stroke (even if your stroke was many months or years ago) that has caused weakness in one hand and/or arm to participate in an investigational research study.

Stroke survivors are currently being enrolled at centers in Chicago, Detroit and Cincinnati. Expansion beyond these initial cities may occur later this year.

All costs related to the study and rehabilitation (including local transportation) will be covered for those who qualify.

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Looking Up To My Daughter

I will never take anything for granted ever again!” My 33-year-old daughter Lesley has said that many times since her stroke in January 2003. She had collapsed at a friend’s house with a terrible headache. One hour later she was life-flighted to a hospital in Kansas City.

We live 2 1/2 hours away, and you can imagine the things that raced through my mind during that drive. The reports we were getting by cell phone were terrifying.

We arrived just after she’d been taken to surgery. When the neurosurgeon came out 4 1/2 hours later, he gave us devastating news: “It’s really bad, and I can’t offer you much hope. She had an aneurysm in her cerebellum, and the blood hit her brain stem with the force of a baseball bat. It doesn’t look good.”

Lesley was in a coma for nine weeks and locked in for many more. We hesitated to allow her two-year-old son Nicholas to see her. Finally, in March we brought him, and oh, what a beautiful, tender moment. I had dressed her in her own clothes and put her favorite perfume on her. She looked like she was sleeping. He came in the room, climbed up on the bed and just lay on top of her without moving. Periodically he would raise his head and just stare at her, then lay his head back down on her shoulder. All the nurses were there and there wasn’t a dry eye in the room.

One rehab doctor told us we should just find a nursing home because she would never get any better. At the next place, a female doctor said, “She deserves better than we can give her here” and recommended a rehab hospital in Columbia, Mo.

When admitted there in April, the only movement she could make on command was moving her fingertip. Within one day, they had her communicating through eye movement on a yes/no board. Six months after the stroke, she said her first word, “mooooovie.” That was a beautiful sound.

She came home in October, and I felt like a new mother bringing home her child. I was scared to death, what if she choked and aspirated?

One year after her stroke, Lesley hosted a TGIA (“Thank God I’m Alive”) party. For several hours friends and family celebrated the first anniversary of her “new” life. At the end, the neurosurgeon called. He got choked up, and the conversation ended with Lesley saying, “Thank you for saving my life.”

Lesley has had therapy 3-to-5 days a week for the past 18 months. She cannot walk, eats mostly pureed food and gets her liquid intake through a feeding tube. Everyone who meets her tells her that she is inspiring. She says, “I don’t like it when people say that because it puts pressure on me.”

She designs beautiful jewelry, and her caregiver and I make it. She picks out the beads at bead shows, then we come home and pour them on the table. She selects certain ones, reclines in her wheelchair and tells us which beads to put where. Recently she was one of 24 artists invited to exhibit in an art show in Kansas City, and her jewelry sold well.

Several times a week she attends the American Stroke Foundation center in Overland Park, Kan. They have classes and a wellness center free for stroke survivors and their families. Whenever we get frustrated, we just say, “On January 20, 2003 we would have given anything to have this problem, so suck it up!”

Donna Rieman, Proud Mother and Part-time Caregiver
Carl Junction, Missouri
YOU DON’T WANT ANOTHER HEART ATTACK OR ANOTHER STROKE TO SNEAK UP ON YOU.

PLAVIX HELPS KEEP BLOOD PLATELETS FROM STICKING TOGETHER AND FORMING CLOTS, WHICH HELPS PROTECT YOU FROM ANOTHER HEART ATTACK OR STROKE.

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Please see important product information on the following page.

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WITH PLAVIX

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**INDICATIONS AND USAGE:** PLAVIX® (clopidogrel bisulfate) is indicated for the reduction of thrombotic events as follows:

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**WARNINGS:**

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  For patients with unstable angina or non-ST-segment elevated myocardial infarction (NSTEMI), PLAVIX has been studied in combination with aspirin to reduce the incidence of death, MI, or stroke compared to aspirin alone. In patients with acute coronary syndrome (unstable angina or NSTEMI) treated with aspirin, PLAVIX reduced the risk of death, MI, or stroke by 31% (7.5% vs 11.1%)

**CONtraindications:**

- The use of PLAVIX is contraindicated in patients with a hypersensitivity to the drug substance or any component of the product, and those who are to be managed with percutaneous coronary intervention (with or without stent) or CABG. PLAVIX has been shown to decrease the incidence of death, MI, or stroke as the rate of the combined end point of coronary-vascular death, MI, or stroke in patients who had previously experienced at least one of these events.

**CONTRAINdICATIONS:**

- The use of PLAVIX is contraindicated in patients who are taking cerivastatin (Baycol™)

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cardiovascular accident, but “strokes.” Well, this “head” marched right out of that beauty shop in Fort Worth, and this “stroke” decided while lying flat on my back, unable to walk out of there or anywhere else right then, I would never again be reduced to just a thing — never allow myself to be defined by that stroke.

I am/and always will be a child of God, a woman, mother, grandmother, daughter, sister, aunt, niece and friend. I am a teacher, a student, a reader, a writer, a homemaker, a museum member, a symphony supporter, a taxpayer, an astute political analyst and committed voter, a shopper, a traveler, and a connoisseur.

I’m a singer, dancer, actress, and fashionista. Sometimes I’m Princess Di, Martha Stewart, Wonder Woman and Dear Abby.

I am also a good and brave citizen. Soon after I left the hospital I attended the trial of the man who had robbed me at gunpoint two years before. I was a star witness. Afterward, I looked him in the eye and said good luck to him, as he got ready to board a southbound bus to serve 15 years in prison for his crime. Recently, I was re-elected president of the board of directors of a rural water utility in East Texas. It’s my fourth term. The other six directors are conservative, successful, outspoken men.

At the beginning of this year I bought a two-year planning calendar, and I fully intend to fill up all 730 days.

To survive and prosper in this strange new world, I had to reconsider every behavior that had served me for six decades and figure out what would get me what I needed and wanted for the rest of my life. The result was a set of guidelines I now refer to as My Eight Simple Rules For Getting Along in the Normal World after Stroke.

(continued)
Donna’s 8 Rules

1. Be Positive.
2. Don’t Complain.
3. Anticipate Ignorance.
5. Ask For Help When Necessary.
6. Keep a Sense of Humor and Find or Make the Fun. Remember, things could have turned out much worse, so remember No. 7:
   Finally, and possibly most important:

These eight rules are my daily goals — where I’ve set the bar for myself. Certainly, there are times when the whole world crashes around me, but most days, I follow them, and they get me what I want and need.

Donna Isaacs, Survivor • Tyler, Texas
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I have always appreciated a challenge. Tell me I can’t do something and I’ll do it or die. That attitude has served me well during some tough times, but never so well as in the spring of 2003.

On April 1, at age 75, I suffered an intracerebral hemorrhage that completely paralyzed my right side. Six weeks before, I had fallen from a ladder and shattered the tibia in my left leg as well as my left forearm. As a result, I lay completely helpless in a hospital bed, a virtual quadriplegic!

Shortly after my release from ICU, I was introduced to my wheelchair. It was hate at first sight. I resolved that — unlike my Uncle Johnny — I would not allow that contraption to take away my legs. Uncle Johnny had suffered a similarly paralyzing stroke as a young man. He spent the next 30 years a prisoner of that set of wheels.

When he died in his 50s, his withered legs were “frozen” into L-shapes, the result of years in a seated position. They had to break his knees to fit his body into a casket.

With that haunting image branded on my mind, I was determined not to become addicted to a rolling chair. When I began intensive physical therapy at a unique rehab facility called Easy Street, I kept remembering the words of my neurosurgeon: “The brain can be retrained.”

A blood clot in my leg temporarily interrupted my physical therapy, but I doggedly persisted. I was determined to regain the use of my legs. After four weeks, I refused the chair and insisted on trying a rolling walker.

At first, it seemed hopeless. Two therapists couldn’t hold me upright. My legs were like rubber. But day-by-day, week-by-week, I gradually grew stronger and more confident. Finally, by the fourth week, I begged, “Let me try it by myself.”

They reluctantly agreed and held their breath as I struck out on my own. It wasn’t pretty, I staggered and stumbled like a toddler taking his first steps. But it was a start. The next week, I was discharged from Easy Street and transferred to the Tyler Center in Anniston, Ala. There I spent a full year learning to walk again.

When I was discharged in May 2004, I could walk pretty well with a cane but still had a severe foot drop and balance problem. If I stumbled and fell, I couldn’t get up without help.

The grass grows fast, come springtime in Alabama. I soon learned that I could mow my own lawn by hanging onto the handle of a push mower. Not only did it save a little money, it also strengthened my still-weak legs.

One hot day in July, my son Tom and his wife Judy noticed me sweating and struggling with the mower. When I stopped to rest, Tom said, “Dad, we’ve been trying to figure out why in the world you insist on using that old push mower when you have a brand new self-propelled Snapper in the garage.”

Without thinking, I shot back, “Too easy. No challenge.”

Judy grinned as she playfully punched her husband. “Told ya,” she said smugly.

Jack Zorn, Survivor
Lineville, Alabama
The EZ Does It Bath Transfer System has been designed by engineers and caregivers that have first-hand experience with the bathing needs of physically challenged individuals. Whether you desire independence or require assistance in bathing, our chair will fit your needs. If you need a shower chair for everyday use or need a solution for bathing when you travel, the EZ Does It Bath Transfer System is truly the only chair that will give you this option.

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The Biomove 3000 - formerly Curamove 3000 - uses technology proven to be very beneficial for regaining muscle control after stroke.
W

hile his wife is at a committee meeting, Jerry sits in his wheelchair in front of his computer screen. He reads a story about woodworking, his favorite hobby, displayed on the screen. When he finishes the article, he reads some questions about the paragraph. Jerry types in his answers, and the computer flashes a green light to let him know that he was correct.

Edward views a computer screen showing a picture of his favorite flower — a rose. He struggles to say the name of the flower aloud. He then presses a button on the computer, and it says, “The name begins with the ‘r’ sound.” Edward then says, “Rose!” And the computer records his speech.

Alice walks to her local convenience store. She approaches the counter and presses a button on a bracelet she wears around her wrist. A prepared computer voice says to the cashier, “I’d like a lottery ticket, please.” The clerk smiles and asks, “Which game did you want?” Alice presses a second button on her talking wrist bracelet and a message says, “The Quick Pick.” The clerk hands her a lottery ticket and Alice waves goodbye.

Marilyn is making an entry into her computer journal about her life since her stroke. She’s hoping to publish it one day. When she finishes typing a page, she clicks the mouse. The computer reads her page back to her, highlighting the text as it reads. Marilyn looks and listens carefully to pick up any errors in word choice, grammar or spelling.

John is struggling to compose an e-mail message to his daughter at college. Writing his daughter about a trip to a flea market, he finds he can’t think how to spell “antiques.” He types in the letters: “a-n-t-i.” As he types each letter, he looks up to the screen. Finally, after typing the letter “i”, he sees the word “antique” appear on the list of possible word choices. “That’s the word I’m looking for!” he thinks, and he clicks on it to include it in his e-mail.

All of these stroke survivors are taking advantage of computer technology to help them improve their lives after stroke. Jerry and Edward are using computers to do home-based therapy activities to improve specific language skills. Alice, Marilyn and John are using computers to help them participate more fully in their daily life activities.

As computer technology has become more efficient and less costly, an increasing variety of hardware and software options are available that can help people recovering from stroke. A set of options called “computer-based treatment systems” consists of a regular desktop or laptop computer equipped with specialized software programs. The software programs may be used by the client
independently or may be used as an adjunct to weekly therapy sessions with a speech-language pathologist or other rehabilitation professional.

The software provides more opportunities for survivors to practice therapy tasks that will help them improve specific language or cognitive skills, such as reading comprehension or attention.

Other computerized options, called “augmentative and alternative communication systems,” help people with speech or language disorders function better in daily life. These systems may look like portable “talking boxes” or may consist of software that is used on a desktop or laptop computer. Augmentative and alternative communication systems can enhance the speech and writing of people with significant speech and language difficulties.

Research demonstrates that specific problems may be improved with computerized treatment approaches. For example, computerized reading treatment has been shown to improve the language performance of survivors with aphasia on reading tasks that were not computer based. In addition, a symbol-based communication system, in combination with a daily training program, has been shown to improve natural language production in people with severe aphasia. Certainly, many people report benefits that come from “exercising” their brain and practicing skills on a daily basis with the nonjudgmental, immediate feedback a computer can provide.

To find out whether you might benefit from a computer-based treatment system, you need first to determine your particular goals. A speech-language pathologist can help you define goals and identify appropriate software tools. It is possible to find programs designed to help with auditory comprehension, reading comprehension, writing, word-finding and cognitive skills, such as attention, memory and problem solving. Many Web sites contain lists of vendors who sell software programs geared toward people recovering from stroke.

If you are interested in using computers to help you write and talk, a wide variety of alternative communication options exist, ranging from voice-output devices that come in many shapes and sizes, to word-prediction software that “guesses” what you are trying to type, to programs that read the text on the screen out loud.

Alternative communication systems may also be called “speech-generating devices” and are covered by Medicare and many other insurance providers. In order to obtain one, you must be evaluated by a speech-language pathologist, who will help you identify which system is appropriate for you. Unlike communication systems, computer-based treatment systems are usually not covered by insurance. Many software companies have trial periods or demonstration pages that allow you to see software programs before you purchase them.
Imagine if stroke were twice as common in your community, if instead of one person in your family with a stroke, there were two, or more. Imagine if stroke had arrived in your life 10 years earlier. For blacks in the Stroke Belt states of the southeast United States, this is often the reality, but statistics don’t convey the cost in lives disrupted, finances ruined and families strained. Perhaps the stories of three African American survivors from the Stroke Belt — Ron Thomas, Louise Strozier and Trecolia Bussey — can illustrate realities that numbers miss.
Without his knowing it, a stroke was in Ron Thomas’s future because stroke, high blood pressure and diabetes were part of his past. His maternal grandmother’s sister had died of a stroke, and his mother has high blood pressure, heart problems and diabetes. All of these are risk factors that occur at a higher incidence among African Americans than whites.

Ron was only 44 when he had a stroke during the Fourth of July weekend last summer. His home, Columbia, S.C., is close to the heart of the Stroke Belt (see “Stroke Belt,” page 20). African Americans in these states have among the highest stroke rates in the world; they also have strokes about a decade earlier than any other group.

As with so many people, Ron didn’t know the warning signs of stroke, despite having worked for a large chain of rehab hospitals for 16 years. That’s why when cutting his front lawn tired him so much that he couldn’t mow the back, he thought he’d just rest and go back out. “But the feeling didn’t leave so I went to bed,” he said. “As soon as I lay down, my head started hurting so bad I couldn’t go to sleep. Later my wife Jeanette was awakened by my moaning.”

When she turned on the light, she could see his face was drooping and called an ambulance and he was rushed to a hospital. “The doctor told me I had had a mild stroke,” Ron said.

Ron was determined to get back to work, and after a week in the hospital following his stroke, he went directly to rehab. “My right side was completely paralyzed, and my mouth was crooked,” he said. “I couldn’t hear it, but my wife said I also slurried my speech.”

He spent three weeks in rehab and then had therapy every day during August and September. “I didn’t want to be dependent. Besides, I have bills to pay and I needed to get back to work.”

Through his determination and that of his therapists, Ron regained some of the use of his right side. Then, in October, he passed his driving test and returned to his old job only three months after his stroke. “My hand has come back pretty well, but I still have more work to do on my leg,” he said. “Sometimes my right leg doesn’t want to do what I want it to do. I can’t walk far, I get exhausted pretty quick. I still go to therapy before I come to work three days a week.

“I was able to come back so fast because I have a lot of faith. It took a lot of determination, and that has to do with spirituality.”

“I was able to come back so fast because I have a lot of faith. It took a lot of determination, and that has to do with spirituality.”
Louise Strozier knows the warning signs of stroke now, but when she experienced a stroke in 1999, she thought she was having an allergic reaction to a new breakfast cereal.

First, she had a sharp pain in her leg while walking on a treadmill at her wellness center in Atlanta, Ga. Then her speech became slurred and she was swallowing large amounts of saliva. She never considered it might be a stroke. “After all, only older people suffered strokes,” she said.

She was 57, but she had had high blood pressure for 25 years, and she had been diagnosed with diabetes in 1985.

Still thinking it was an allergic reaction, she had her husband Franklin take her to Wal-Mart to get some Benadryl. “I didn’t feel bad at the time, I was just having trouble with my speech,” she said. “Later my daughter Theresa called. When she heard me speak, she asked what was wrong.”

She didn’t buy her mother’s allergy explanation and called back first thing the next morning. Louise’s speech had not improved, and Theresa insisted she go to the doctor. “After examining me, he said I’d had a full-blown stroke and he was going to put me in the hospital for further tests. I had an MRI to assess the damage, but my speech was my only problem. I didn’t feel any pain.” She was discharged the next morning.

“When I came home, I was in a trance. I realized I could have died and started going into depression. I couldn’t drive and that really depressed me,” she said. She did get her driver’s license back four months later, but she continued to receive speech and cognitive therapy for two years.

“They were training my undamaged neurons to do the work of the injured ones. I had to read a lot, and I had a lot of trouble writing. I was such a crybaby because I couldn’t do all the things I had done before. I had neuro-psychotherapy where I worked with a neurologist and a psychologist to overcome the depression.”

That’s when Louise joined the Emory Stroke Support Group. “It is so beneficial for survivors to join a support group,” she said. “There I bonded with other survivors, and I learned that along with physical healing, there’s a process of mental healing and allowing yourself to grieve for what is lost. Most important, I learned that stroke isn’t a death sentence.”

In the support group, Louise learned about the American Stroke Association Peer Visitor Program. “That really raised my awareness about the importance of knowing the warning signs. It also gave me the opportunity to assist others who had recently had a stroke,” she said. “God gave me a vision to reach out and share with others.”

Community support — doctors, nurses, family, therapists, the stroke group — had played a big part in her recovery, and she wanted to recreate that for others. She had retired as the regional director for a community-based organization and put those skills to work organizing the Love and Courage Stroke and Heart Disease Survivors program. “This is a community program, not based at a hospital,” she said. “We started our first support group in 2003. We had 30 members, and it’s exceeded our expectations. We’ll soon be expanding to several other locations in Atlanta.”
A Tale of a Risk Factor
Out of Control

PROFILE: TRECOLIA BUSSEY

Trecolia Bussey had just turned 50 when she got the bad news: her blood pressure was high. She started on medication right away, and at the re-check two weeks later, the doctor changed the prescription. “But I didn’t have time to get the new one before I left town,” she said.

At the time, Trecolia was a director in Mary Kay Cosmetics, and she was heading for Dallas for a weekend seminar. “Through the weekend, everything was fine,” she said, “but I woke up with a bad headache on Tuesday morning. I thought my hair must be pulled too tight, so I took off my scarf and the headache stopped.” Her relief was short-lived.

As Trecolia was about to climb the steps at the convention center, “I felt the strength drain out of my right side. Eventually I climbed them, and my husband Richard and I found our seats. As I spoke to the lady on my left, I realized my speech was slurred,” she said. “I couldn’t take notes though I could understand the speaker.

“We sat through a second class, but I was more and more disoriented. It was like I was there but not there. I finally said, ‘Baby, take me back to the hotel. I don’t feel right.’”

Instead Richard took her to the first aid station in the convention center. There an attendant took Trecolia’s blood pressure. “She said, ‘Wow! I must have made a mistake. You try it,’ to the other girl.” When the second attendant took it, she got the same reading: 220/140.

They called an ambulance, and by the time Trecolia got to the hospital, her right side was numb, but a CT scan turned up nothing. Richard insisted she be given an MRI. That image showed that she had had a brainstem stroke.

By the next morning her right side was completely paralyzed. She stayed in Dallas a week while arrangements were made to fly back home to Raleigh, N.C., where she stayed another week in the hospital followed by two weeks at a rehab hospital.

Despite her doctor’s predictions that she would get nothing back, Trecolia now has mobility on her right side, though she walks with a limp. It’s been almost three years since the stroke, and she hasn’t returned to work. “I’m working on me, trying to get my strength back. My faith in God has been the driving force for my recovery,” she said. “After a stroke, it’s like being a baby again. I work out at the wellness center three or four days a week and I do range-of-motion exercises in the water. I was always an exerciser. The doctor said that’s what helped me during the stroke, otherwise it would have been more severe.

“I lost valuable time because I didn’t know the warning signs. I never thought stroke could happen to me. I wasted about four hours because I never considered I might be having a stroke. I thought it was eventually going to go away.”
African American Stroke & Risk Factor Facts

Fact: The age-adjusted stroke death rate for African Americans is almost 1.5 times that of whites (76.3/100,000 to 54.2/100,000).

Fact: Blacks have almost twice the risk of first-ever stroke compared with whites.

Fact: Stroke kills over six percent of the over 290,000 blacks who die each year.

Fact: The overall death rate for stroke was 56.2/100,000. Death rates for blacks were 81.7 for males, 71.8 for females.

Fact: The rate and prevalence of high blood pressure among African Americans is among the highest in the world. Compared with whites, blacks are more likely to develop HBP earlier in life, and their average blood pressures are much higher.

Fact: Among blacks or African Americans age 18 and older, 27.0 percent of men smoke and 18.5 percent of women smoke.

Fact: In 1999–2000, 86 percent of non-Hispanic black children ages 4–11 had cotinine in their blood. Cotinine is an indicator of secondhand smoke exposure.

Fact: Among non-Hispanic black adults age 20 and older, the following are overweight or obese (BMI of 25.0 kg/m² and higher): 62.9 percent of men and 77.2 percent of women.

Fact: The rate of diabetes for non-Hispanic blacks is almost twice that for non-Hispanic whites. In the total population age 20 and older, 7.2 percent of men and 6.3 percent of women have physician-diagnosed diabetes. Among blacks, the prevalence is 10.3 percent for men and 12.6 percent for women. Diabetes increases the relative risk of stroke by as much as 3 times.

Fact: In 2000 the prevalence of any self-reported cardiovascular condition among blacks with diabetes age 35 and older was 31.4 percent for men and 34.0 percent for women.

Fact: The 2002 overall death rate from diabetes mellitus was 25.4. Death rates for blacks were 49.4 for males and 48.6 for females.

Fact: Among non-Hispanic black adults age 18 and older, 45.1 percent of men and 55.1 percent of women report no leisure-time physical activity.

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Stroke can happen to anyone, but people in the “Stroke Belt” states of the Old South have them more often than people in other states. The rates are higher for both whites and blacks, but African Americans as a group have a higher incidence of strokes than Caucasians.

Not only are the rates higher, but stroke happens to people earlier in the Southeastern states. For instance, the average age for stroke in white men in South Carolina is 55 — 10 years earlier than for white men in Minnesota. For black men, the average age for stroke is 45, fully two decades earlier than white Midwesterners.

In addition to more and earlier strokes, the Stroke Belt region has a high prevalence of high blood pressure and low numbers for control of this risk factor. Only about 20 percent of white men with blood pressure problems have them under control; the rate for African Americans is even lower, 13 percent.

African Americans and Caucasians in the region also have a higher prevalence of the risk factors obesity, lack of physical activity and diabetes than either group has in other states.
When you’re 22 and about to graduate from college, a ski weekend with friends should be nothing short of a great time. For me, that could not have been farther from the truth. It was March 1997, in New Hampshire, and all we needed was “one last run.” But when I started down the mountain, I saw a bright yellow light, felt an overwhelming sense of nausea and dizziness, as well as a blinding pain in my head.

Stopping to regroup, I figured I was fine. I continued down the mountain until my left leg completely gave out and I collapsed.

I thought nothing of it at first but became concerned when I kept attempting to stand up and couldn’t. Nervously I told a friend that I felt like I was having an aneurysm, but I didn’t expect that to be the case. A passerby noticed my situation and stopped to help.

When this kind stranger asked if I was all right, I said, “I have no idea what’s wrong, but I can’t stand up.” The words sounded all garbled, and I panicked. He recognized something was dreadfully wrong and flagged down a ski patrolman.

Then there was a toboggan ride to the infirmary, where they kept asking me to smile. “Why am I doing this?” I thought. “I know I have a great smile, but is now the time to look at it?” They explained that they were comparing symmetry to see if my face was drooping. They thought it might be Bell’s Palsy.

Then they had me touch each finger to my thumb one at a time to test my dexterity. This became my official “self-exam” over the next few days.

I was taken to a local hospital where I was given a CT scan. On a scale from 1 to 10, my headache was now a 10. Something was wrong, but nothing turned up on the CT scan. The doctor thought it must be a complicated migraine and gave me an injection to help the pain. When I was still in pain a few hours later, my parents decided to take me to a larger hospital.

Although I was able to walk to the car, my left leg began tingling on the trip and my left arm went numb. My dad exited at the next blue “H” sign.

When they realized they could not help me, they told me I was hysterical. We left for the original hospital, where they gave me a spinal tap. My headache had subsided to a 5, and the spinal tap showed nothing. Movement was returning to my left arm and hand.

These things convinced the doctors I could leave the emergency room. They prescribed Advil for the headache, which was now uncomfortable but bearable. I also drank lots of coffee because caffeine helps replace spinal fluid.

Three days later, I woke up with my left leg tingling and when I walked, my left foot was dragging. My condition deteriorated through the day, and around dinnertime my parents took me back to the hospital. By the time we got there, I couldn’t walk and was having difficulty touching fingers to thumb.
Seeing my condition worsening, a nurse rushed me to a doctor. I collapsed in the examination room, and the doctor ordered an emergency MRI. That image indicated a massive stroke in the right frontal lobe caused by a right carotid dissection, which had occluded.

A slew of surgeries followed. A team of 12 doctors drilled a bolt into my skull to track intracranial pressure. They positioned electrodes to determine the amount of damage to my swollen brain. To relieve the pressure, they removed the right half of my skull and stored it in my abdomen.

In a third surgery, three-quarters of the affected lobe was removed because it was causing too much pressure on the brain stem. Without a skull, I had to wear a helmet to protect my brain. Then an abscess developed in the remaining healthy part of my brain, and drains were inserted — another extensive procedure. The antibiotics used to treat the staph infection in my brain were so strong that my kidneys failed, leading to the threat of heart failure as well. I was unable to eat because of constant vomiting due to the kidney failure, and my weight dropped to 75 pounds.

In February 1998, doctors replaced my skull. It was so liberating to be relieved of that helmet. However, because of the staph infection, the skull fragment had been in my abdomen a year longer than expected. It had shrunk and no longer fit correctly.

This became quite painful, and as recently as May 2003, I had another surgery to secure the “bone flap” to my skull with tighter fittings. Doctors also put in a plastic insert to give my face a more symmetrical look.

The doctors told me I would never walk again because the part of the brain responsible for my left arm and leg had been injured, but I didn’t believe them. I had been a nationally ranked artistic roller skater just a few years before, so it was hard to hear that I would not move again.

In the hospital the physical therapist worked with range of motion on my leg and arm even though there was no sensation in either. I am very grateful for this.

About two months into recovery, I was so determined to move my lifeless leg one day that I channeled all my energy into where I thought my leg was — and before my eyes, I lifted my left leg up onto the bed. We worked with that limited bit of movement, until with the aid of an AFO and a quad cane, I could take steps.

The quad cane became a straight cane after weekly workouts at home.
I also took up quilting, which was very visually stimulating. When I had the field of vision exam again, there were signs of improvement. I continued my vision quest and eventually regained back enough range of sight (160 degrees) to get my driver’s license back. With that newfound freedom, I really felt like my old self again. A week later, I bought a new VW Beetle. I was doing things for myself again!

I have tried not to let this setback change my life course. I love to travel and have tackled the hilly terrain of England and Scotland.

When my nephews were learning to play baseball, they were very patient with me as I retrieved the ball at my slower pace. They didn’t realize how this helped me regain my balance. Now they tell me how far I have come!

Actually, without the support and encouragement of my amazing family, there is no way I would be where I am now. I am so lucky to have a family willing to do anything to see me well.

Recently I’ve been designing jewelry, definitely not something the doctors would have expected. I have hosted a few jewelry parties, so it has been successful!

From this experience I have learned that the brain is a mysterious machine. No one person knows its capacity or limits. There were many times I could have given up because of the doctors’ dreary predictions.

However, we each know our own bodies and limits better than anyone. So we can’t limit ourselves to what someone tells us it says in a textbook. We’re all still learning and discovering, most of all when we are striving to overcome the impossible!

with a physical therapist using weights and stationary bike riding, plus swimming. I also went for acupuncture treatments to increase circulation and spark my remaining brain to take over for the lost portion.

Due to these treatments, I can now walk without a cane. In fact, I was able to walk through commencement at Clarkson University, although a year later than scheduled. It really felt like an achievement.

I also wanted to get into biology, my college major. My speech therapist brought in some college textbooks, and I started from chapter one, relearning a tricky subject. After a few chapters I realized the knowledge had not been lost and contacted my boss from a summer internship at a world-renowned molecular biology lab. He offered me the opportunity to see just how much I remembered and if I still enjoyed biology.

I started as a part-time volunteer, but for the past six years, I have been a full-time employee in the protein sequencing and mass spectrometry lab.

Although the feeling was returning to my leg and walking was possible again, I still had another major challenge to conquer: a complete left field cut in my vision. I had difficulty finding things to the left or tracking the lines back to the left when reading.

A neuro-ophthalmologist told me not to expect to recover that vision, but I was determined. So I found activities that would challenge me to regain that sight.

I dived into word search puzzles, which forced me to be aware of scanning the left side of the puzzle.

I read the paper and did matching games on the computer that forced me to pay attention to the left side of the screen.

Top: Shelley with her sister Linda, her mother Fran and sister Kathy
Bottom: Shelley and her nieces and nephews
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When I received the news of my father’s stroke two years ago, I began wrestling with a bundle of emotions ranging from anger to despair. I quickly made travel plans, and I soon found myself sitting in a hospital room in Atlanta, Ga. There I saw a broken man, partially paralyzed and barely able to speak. The person lying in the hospital bed before me was a fragment of the brawny man I call “Daddy.” Seeing my father emotionally and physically broken only intensified my internal turmoil. As the months passed, fear and helplessness set in.

I have always known that there is a history of stroke in my family, but seeing my father’s wounded condition made my family medical history eminently relevant. Suddenly it resonated within me that I am at risk of having a stroke.

I began to feel afraid for my father’s health and my own. My father had experienced an aneurysm as a child and survived with minimal damage, however his recent stroke left a permanent mark on him. When my mother suggested that I participate in the Train To End Stroke (TTES) program, I was ready to listen, but initially I was leery of participating. I doubted both my ability to meet the fundraising goals and my ability to prepare my “couch potato” body to complete a full or half marathon.

After attending several training sessions in Rock Creek Park with the Washington, D.C., team, I determined that participating would allow me to proactively address my fears and emotions regarding stroke and my father’s condition.

My mother and I decided we would join TTES together, and we collaborated to develop a game plan to raise money to meet our fundraising goals. I was still concerned about my ability to meet my physical goal, so I took a leap of faith and placed my body and mind in motion.

My mother and I made a deal: We would train and fund raise together, and if either of us had to drop out, the other would take over all fundraising activities. We kicked off our fundraising efforts with a brainstorming session, which led us to create a newsletter to share our experience with family and friends.

Our first newsletter created a “buzz,” and we began receiving donations in our mailbox almost daily. In our second newsletter, we sold advertising space and announced that my mother had broken her foot, ending her marathon training. I continued to train on my own, and my mother focused on supporting me in my fundraising efforts despite her injury.
With my training in full swing, my trainer began modifying my diet, and I saw major improvements in my general health. I discovered I was allergic to something in dairy products, and when I removed dairy from my diet, and all my hay fever symptoms, which had plagued me for years, disappeared. For the first time since I was 10 years old, I was able to breathe clearly.

Slowly but surely, I was able to tick off miles without blinking, and after six weeks, I could already see that completing a 26.2 mile marathon was possible. I also began losing weight, reducing my risk of stroke. So with my mother’s aid and the support of my family and friends, I began the final push to get my body ready, and I stepped up my fundraising efforts.

My uncle, a family friend and my mother braved the cold and snow during December to help me distribute literature on the dangers of stroke, while asking for donations at a local mall and Wal-Mart. I also spent two days wrapping Christmas presents and distributing bookmarks with information on stroke at Border’s bookstore for donations.

During each of these fundraising activities, I was moved by the stories so many people whose lives have been touched by stroke told me as they made donations. That experience gave me even more motivation for my training, realizing the prevalence of stroke. It made me aware of the need to educate people on the warning signs of stroke.

When marathon day finally arrived this past January, I was able to look around me and feel the support of the new friendships developed during my training process. I also developed a new appreciation for fitness, providing me with a positive vehicle for managing my health and stress.

Most of all, completing the marathon in Bermuda last June allowed me to honor my father and other family members who’d had strokes, and to heal my emotional wounds. Crossing the finish line that day was an emotional, mental and physical triumph that I will always treasure.

We all shared a bond developed by providing love and support for one another when we felt we couldn’t push our bodies any further.

At this moment I realized that this was the most emotionally healing experience I could have chosen to abate my emotional turmoil over my father’s condition and fears about my own health. Most importantly, I knew I had empowered myself to reduce my own risk for stroke, while helping future victims of this disease. Crossing the finish line that day was an emotional, mental and physical triumph that I will always treasure.

My participation in TTES brought so many positive experiences into my life. My eating habits and general health were improved significantly. Learning of my dairy allergy allowed me to leave behind a regimen of drugs and inhalers. I also developed a new appreciation for fitness, providing me with a positive vehicle for managing my health and stress.

Most of all, completing the marathon in Bermuda last June allowed me to honor my father and other family members who’d had strokes, and to heal my emotional wounds.
hen Doris, age 71, arrived home from a shopping trip, she opened the kitchen door and saw her husband Fred sitting in the recliner in the den. When he moaned instead of greeting her she rushed to him and found him slumped to his left.

“Fred, speak to me!” Doris demanded. He groaned, but no words came out.

Doris immediately dialed 9-1-1 and described Fred’s symptoms to the dispatcher. In a few minutes, paramedics and emergency medical technicians (EMTs) arrived at the house. One examined Fred using the Cincinnati Stroke Scale (see “Stroke Alert,” p. 31) while another checked his breathing and started him on oxygen.

They asked Doris what time she noticed his symptoms and about his medical history.

Next they checked his glucose and started an EKG to detect any heart problems. Soon Fred was in the ambulance, with Doris at his side, headed to the local hospital, the site of a primary stroke center. While starting Fred on a saline IV and checking his blood pressure, the team alerted the hospital by phone that a 73-year-old man with stroke symptoms was on the way.

All of the prescribed steps for prehospital stroke care had been taken.

After Fred was wheeled into the emergency department (ED), the EMTs shared their information on the patient’s symptoms and condition with ED physicians. Fred was immediately prepared for a CT scan so physicians could determine what kind of stroke he was having and how to treat it.
Only 21 minutes had passed from the time Doris entered the house until Fred arrived in the ED. Preparing Fred for a CT scan, performing it and interpreting it took an hour, bringing the elapsed time to less than an hour and a half for him to be ready to receive the clotbuster tPA. The maximum time allowed from the onset of symptoms to receiving the tPA is three hours. He was off to a good start.

Even with today’s advances in EMS training and the use of tPA, acute stroke events don’t always unfold like clockwork. The case of Fred and Doris is an ideal, although fictitious, scenario in prehospital stroke care.

Why should stroke survivors care about how the EMS system works? Because many have had intimate interactions with EMS — and may have them again.

**It Wasn’t Always Like That**

To understand how far prehospital stroke care has come, consider what was done for stroke patients before the FDA approved tPA in June 1996.

“Before tPA, emergency personnel could wait about an hour to respond to a stroke call,” said Dr. Charles Sand, M.D., an emergency physician at St. Joseph’s Hospital, a primary stroke center (by Brain Attack Coalition standards) in Tampa, Fla. “Stroke was no more an emergency than someone with a hurt arm or a diabetic who had run out of medicine.”

It seems unthinkable now, but it made sense at the time. “There was not much you could do about a stroke,” Dr. Sand said. “You got to it when you could. In the ED, they would just sit around and wait for their CT scan, which could take many hours, and just make sure nothing bad is going on, like a bleed in the brain, and then ship them off to the nursing home.”

Stroke treatment is different today because of tPA. “Time is the critical factor now,” said Todd J. Crocco, M.D., assistant professor and director of Clinical Research, Department of Emergency Medicine, West Virginia School of Medicine, in Morgantown. “A well-rehearsed 9-1-1 system is required today so EMS can provide the highest level of care as soon as possible.”

Even if the patient or a bystander doesn’t recognize the stroke warning signs, 9-1-1 dispatchers and EMS personnel should be able to. This detection phase is the first of four links in the Stroke Chain of Survival. After Detection, the other three links are Dispatch, Delivery and Door (see “Chain of Survival” at right).
Training Is Key

One of the challenges in creating a strong system of stroke care is making sure EMS personnel recognize the warning signs.

“Having a system in place where EMS personnel can rapidly and efficiently evaluate a patient for a potential stroke was, and remains, a critical issue,” said Dr. Crocco, a member of the Stroke Subcommittee of the American Heart Association’s Emergency Cardiovascular Care Committee. “With good training, EMS personnel can do this, and they can do it very well.”

One system doing it well is the Hillsborough County Fire Rescue in Tampa. “All of our paramedics and EMTs are trained that this is an urgent matter now, whereas 10 years ago it was not considered a true emergency,” said David Travis, chief of the rescue division.

In Hillsborough County, Stroke Alert forms became a major tool when new procedures for stroke calls were adopted in 1999. As EMS began using the form, identification of stroke symptoms improved greatly. Hospitals were notified of a stroke alert quickly and were better prepared to act, keeping more patients within the three-hour window.

WHERE YOU’RE TAKEN MATTERS

“Another challenge in the chain is getting the patient to the most appropriate hospital. Assuring that the hospital can treat the stroke patient as an emergency is second in importance only to the sense of urgency by EMS,” Travis said. Those two factors — EMS’s quick action and a hospital’s ability to start treatment quickly — are the major differences in how stroke patients are handled today.

Florida is the first state to pass a law that mandates a transport protocol for stroke patients, requiring the use of the Stroke Alert forms and taking patients to the closest appropriate hospital. Other states are considering such a law.

Even though hospitals with primary stroke centers are the preferred place to take stroke patients, many other hospitals provide excellent care and treatment.

The American Stroke Association and the Brain Attack Coalition have established recommendations for hospitals to set up primary stroke centers.

The first component of a stroke center is a team to treat acute stroke, including a physician with experience in diagnosing and treating stroke. Treatment must follow written procedures to streamline and speed up diagnosis and treatment of stroke patients.

Other stroke center requirements include a specially trained emergency staff, the ability to perform brain-imaging studies, a stroke unit for patient monitoring and continuous medical education for the staff.

Setting New Standards

Hospitals that receive certification as primary stroke centers from the Joint Commission of Accreditation of Healthcare Organizations (JCAHO) must measure up in three main areas: compliance with national standards, effectively following Brain Attack Coalition stroke center recommendations and clinical guidelines, and meeting performance standards.

The certification program is a year old, and as of February 2005, JCAHO had approved 88 primary stroke centers with more applications to process. For a listing of
primary stroke centers, visit StrokeAssociation.org and click on “Find a JCAHO Primary Stroke Center.” Or you can call (630) 792-5800.

Some hospitals also are pushing the three-hour window to four hours with advances in surgical procedures. Intracerebral thrombolitics involves inserting a catheter into the brain to deliver the clot-busting drug, instead of using the standard IV method. In neurovascular surgery, devices can be used to open blood vessels to restore blood flow to the brain.

“The EMS system is gearing up, and the hospital system is gearing up,” said Dr. Sand, who serves on the American Stroke Association’s Advisory Committee. “We’re really in our infancy in acute stroke care. The main thing right now is to get the system improved and for EMS to take [the patient] to the right place.”

Swift action by the professionals, however, can only do so much if they don’t get to the patient in time. “Before tPA, and after tPA, the average Mr. and Mrs. American still don’t recognize the signs and symptoms of a stroke as rapidly as we need them to,” Dr. Crocco said. All stroke survivors and their families should know the warning signs listed on this page and in every issue of Stroke Connection Magazine.

Travis, the chief of rescue operations at Hillsborough County Fire Rescue in Tampa, agrees that knowing the warning signs is the best starting point for the public. Anyone with symptoms should call 9-1-1 immediately. “A lot of times the onset happens and people are not really sure what is going on. The sooner they call us, the sooner we can get them into the system.”

When EMTs are dispatched in Florida, they use the Cincinnati Stroke Scale as part of their Stroke Alert report. It provides quick identification of symptoms.

Cincinnati Stroke Scale (FAST)

F (FACE) Facial Droop: Have patient smile or show teeth. (Look for asymmetry)
Normal: Both sides of the face move equally or not at all.
Abnormal: One side of the patient’s face droops.

A (ARM) Motor Weakness: Arm drift (close eyes, extend arms, palms up)
Normal: Arms remain extended equally, or drift equally or do not move at all.
Abnormal: One arm drifts down when compared with the other.

S (SPEECH) “You can’t teach an old dog new tricks.” (repeat phrase)
Normal: Phrase is repeated clearly and correctly.
Abnormal: Words are slurred (dysarthria) or abnormal (aphasia) or none.

T (TIME) TIME LAST SEEN NORMAL

The FAST test has proven remarkably effective at predicting stroke, and not just for EMTs. Like knowing the warning signs, it is another helpful tool that stroke families can use to reduce the time to treatment, because time lost is brain lost.

KNOW... THE WARNING SIGNS OF STROKE!

• Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
• Sudden confusion, trouble speaking or understanding
• Sudden trouble seeing in one or both eyes
• Sudden trouble walking, dizziness, loss of balance or coordination
• Sudden, severe headache with no known cause
I was a very gifted athlete for over 30 years. In grade school, the other kids called me “First Pick” because of my sporting prowess. I was successful in multiple sports in high school and college and fared well recreationally at everything I attempted. I took up golf and was down to an 8 handicap. All of that ended in September 2000 when I had a stroke. I was 33.

I had a consultation with Dr. Robert Spetzler, a widely respected neurosurgeon in the area of arteriovenous malformation. We were to meet in Phoenix, a mecca for golfers. My desire to rekindle some flicker of physical ability led me to take a golf lesson.

Within minutes I had ripped a hole in my finger for which a first aid kit would prove useless and which the ER treated like a third-degree burn. I had torn through all layers of skin because I couldn’t secure the club with my affected hand. But even more painful was the hole in my confidence at the loss of my complex motor skills.

Disheartened by my attempt at golf, I embarked on a day trip to Grand Canyon. The trip to northern Arizona helped me put my physical failures in a different perspective.

I recalled the initial period after my stroke when I found out that I had only a 50/50 chance of surviving the craniotomy. I reflected on three months confined to a wheelchair and nurses assisting every move as my once athletic body converted to a helpless rag doll unable to do anything for itself.

When I was finally strong enough to undergo very low impact physical training, I had to do everything from a seated or lying position. Watching others doing exercises on their feet, I envied them, wondering if I would ever get that opportunity. When I was eventually able to stand, I consistently fell due to poor balance. And when I tried...
to walk, I was only upright because of the application of countless assistive devices and the multitude of personnel manipulating my limbs. I felt hopeless.

Powerless to control my own body, I remember thinking, ‘This is not me. I am an observer in the shell of a physical body.’ I felt like a marionette whose movements others controlled. At age 33, walking had suddenly become a skill I would have to learn, as if I had never done it effortlessly. And there was not an inkling that I would regain this ability.

Certain of my life goals directly exploited my physical gifts. I had been planning a trip to climb Mt. Kilimanjaro. That all changed when I woke up one day paralyzed and had to struggle to become a biped again.

As the tour bus arrived at the lodge on the Canyon’s South Rim, I struggled to lift myself out of the seat and promptly fell in the aisle. Eventually, I exited and shuffled slowly with the mass of people. We followed our guide around the building in anticipation of a spectacular view.

Things were going well until my cane slipped. I looked down and noticed that the terrain had changed from the paved path of the tourist-lodge area to loose rock. It was the legendary red rock of the world’s seventh natural wonder.

I proceeded to the rim, and the heat from a blazing Arizona sun pushed a stiff breeze as I leaned on the guardrail and looked across the 25-mile expanse. The sun painted the landscape from a limitless palette as the colors changed every second.

While the sun was using one of the world’s natural wonders as its canvas for an art project, I had an epiphany. I realized that while stroke takes so much away from all of us who survive, it also leaves us with something. Most importantly, we have our lives and, in my case, some cognitive and gross motor function. I understood these were my new gifts, two very generous ones if you consider the alternatives.

I am making the most of them. I am head of a local stroke support group and I hope to return to work full-time. I go to a personal trainer twice a week. I focus on what I have been left with instead of what was taken away.

Nothing good comes from stroke. No one’s abilities are enhanced by having their brain tissue destroyed. The only way to learn anything from this trauma is by exploiting the least negative aspect of an event that could have taken your life. If you are a survivor, you are gifted, and all of us must make the most of our second chance. We must appreciate the least negative side of a very unfair coin.

It is difficult to accept my two lives, the first with a body and brain able to coordinate complex movements and the second where I cannot hold a fork, much less a golf club. But in my new life, I have done the impossible. The quantum leap I have made from a helpless patient in the ICU to walking along the Grand Canyon on my own two feet was a bigger thrill than anything I ever accomplished in sports.

And most importantly, the stroke is only a part of me. It does not define who I am. Knowing who you are is the greatest gift one can receive. This trauma has helped me become the person I am now. I do not allow it ever to play first string. It will be forever relegated to “riding the bench,” something I have never been accustomed to.

As survivors, we must not subscribe to old adages like “maximum return of function ends after 18 months.” If that were true, I’d have only seen the Grand Canyon in a picture book while bedridden.

When I was investigating the trip to Mt. Kilimanjaro, I discovered that mountaineering skills are not required. One can walk on a guided trek to the summit. I wonder if the rock is red there, too? 
When Tami Layne-Voorhis’ son experienced a stroke at birth, she had nowhere to turn. She stumbled through the darkness of learning how to care for her son for six years until, as a new employee of the American Heart Association, she learned about the American Stroke Association and started to work at the Stroke Family Warmline there.

The Warmline is a team of four people who answer calls from stroke survivors and their families, providing support and helpful information or just a listening ear. Although everyone at the ASA’s national call center is qualified to answer questions about stroke, the Warmline team members have some particularly special experience: Either they are stroke survivors themselves or have a family member who is.

“I love the concept of helping other people through the darkness, even if it is just a little bit of light,” Tami says.

When another team member, Dan Rodriguez, went to work for the American Heart Association and saw the people across the room handling stroke calls, he knew he had to do it, too. He had been through two frightening experiences when his wife had strokes. After applying for an open position with the Warmline, he was accepted.

He remembers a call from a young woman, 18 years old, crying in a hospital hallway, gripped by fear and uncertainty while her grandmother lay in a coma after a massive stroke. “I could tell this was an important moment for her. She had never come so close to the passageway to death.”

Even though he explained to her scenarios of what could happen to her grandmother, including death, Dan was able to calm the young woman down and encourage her to latch onto hope.

After a Stroke

The Stroke Family Warmline

Whether you’ve already experienced a stroke or are doing all you can to reduce your risk, the American Stroke Association and American Heart Association have the resources you need to support you. Here are just a few:

**Learn and Live Quiz**

Reducing risk factors is important whether you’ve had a stroke or not. Use your personal power and take control of everything you can.

Getting advice on how to reduce risk is easy with the American Heart Association’s Learn and Live Quiz. You can take the quiz at www.americanheart.org in less than 5 minutes and receive immediate feedback. The quiz provides a summary of the factors that raise stroke risk. Based on your answers, the site recommends actions you can take to keep your risk as low as possible.

Taking the Learn and Live Quiz will get you a free book — the *American Heart Association’s Learn and Live Recipes* cookbook. Just save the results of your quiz on the Web site and register. Be sure to include your mailing address on the registration form.
volunteer, which eventually led to a full-time position.

Norman’s own recovery plays a big part in what he tells people who call. “I get to let people know that there is life after stroke.”

Emily Springer, the fourth person on the team, was exposed to stroke as a teenager when her grandfather had a stroke that left him unable to speak or walk. She likes to point out material in Stroke Connection Magazine that answers questions for families that call the Warmline.

One of her favorite experiences has been helping a family whose niece, a dialysis patient, was participating in the Train To End Stroke marathon at Walt Disney World. Emily found a spot where the family could see her run without buying a ticket to the park and reassured them that medical personnel would be available along the entire route.

The runner finished the marathon without incident. “It was exciting to be a part of a customer’s positive experience with Train To End Stroke,” Emily says.

Call 1-888-4-STROKE (1-888-478-7653) to reach the Warmline.

**Stroke Support Group Registry**

Stroke support groups can be a wonderful way to connect with others who’ve had similar experiences, socialize and learn more about the recovery process. Approximately 1,800 stroke support groups are registered with the ASA. During meetings, group members – stroke survivors, family members, friends, caregivers and others – share information, fellowship and hope as they help each other face and overcome the challenges of recovery.

If you are looking for a stroke support group, you can call 1-888-4-STROKE (1-888-478-7653) to find out if there are any groups registered in your area. You can also visit www.strokeassociation.org/strokegroup to enter your ZIP code and search for groups near you.

If there is no stroke support group in your area, we’ve got information and helpful resources for how to start one. Write StrokeAssociation.org or call 1-888-4-STROKE (1-888-478-7653).

**Stroke Connection Magazine**

Stroke Connection became free to individual subscribers in 2001. If you have other family members or friends who are experiencing stroke, please let them know that Stroke Connection is free, published six times a year, and is filled with inspirational stories from stroke survivors and family caregivers. We’ll continue to strive to make Stroke Connection your best resource for practical ideas for daily living, helpful information on avoiding another stroke, and news from the world of medical research and public policy.

To get a free subscription to Stroke Connection Magazine, call 1-888-4-STROKE, e-mail strokeconnection@heart.org or subscribe online at www.StrokeAssociation.org.

These are just a few of the resources available through the American Stroke Association and the American Heart Association. Visit our Web sites at StrokeAssociation.org and AmericanHeart.org for more information and tools to
Books about Stroke

Stoke and the Family: A New Guide
by Joel Stein, M.D.
Harvard University Press; Cambridge, Mass., and London, England

Joel Stein shows the many faces of stroke and the people it strikes in this comprehensive guide to making sense of the confusing variety of diagnoses and treatment options for stroke. He goes on to explore the challenges that the recovering stroke patient and recovering family will face during a long recuperation with an uncertain outcome.

The Long Gray Tunnel: A True Story of Crisis, Spirit, and Recovery
by Bert Wall
Sunbelt Eakin Press
A division of Sunbelt Media, Inc.
Austin, Texas
ISBN 1-57168-751-3

Fifth-generation Texan Bert Wall narrates a tale of his own hemorrhagic stroke and an amazing inner journey he takes while in a coma, hanging on to life by his fingernails. Along the way, he’s led by three guides, all childhood friends, who escort him not only through the mysteries of the afterlife, but through his miraculous recovery and the many challenges he faces as he learns the basic tasks of living anew.

Brain Attack: Danger, Chaos, Opportunity, Empowerment
by Paulina Perez with Marsha Rehns
Cutting Edge Press
A division of Perez Enterprises, Inc.
Johnson, Vermont 05656
ISBN 0-9641159-5-6

As a health care worker and lecturer on health care issues, Polly Perez kept a very busy schedule until December 1998, when a stroke interrupted her morning — and her life. From there, she embarked upon a long process of recovery, eventually regaining her abilities and career in spite of her condition. In this intimate journal, Perez recounts the inspiring story of her often-difficult recovery, and the rich rewards she shared with family, friends and colleagues along the way.

Long-Term Care: How to Plan & Pay for It
by Attorney Joseph L. Matthews
Nolo
Berkeley, Calif. 94710
ISBN 1-4133-0139-8

Now in its fifth edition, this authoritative guide to navigating the difficult course of planning for long-term care covers everything you need to know in plain English. Matthews takes a straightforward, nuts-and-bolts approach to explaining the options, pitfalls and planning essentials for making the right choices in long-term care. The new edition adds a chapter on scams and fraudulent practices that target the elderly.
**PLAVIX® clopidogrel bisulfate tablets**

**BRIEF SUMMARY** — Please see package insert for full prescribing information.

**INDICATIONS AND USAGE:** PLAVIX (clopidogrel bisulfate) is indicated for the reduction of thrombotic events as follows:

- **Acute Coronary Syndrome**

For patients with a history of recent myocardial infarction (MI), recent stroke, or established peripheral arterial disease, PLAVIX has been shown to decrease the rate of a combined end point of cardiovascular death, MI, or stroke, and to decrease the rate of a combined end point of cardiovascular death, MI, stroke, or thrombotic stroke (see Warnings).

**Acute Coronary Syndrome**

- **For patients with an acute coronary syndrome (unstable angina, non-Q wave MI) including patients who are to be managed medically**

  - PLAVIX has been shown to decrease the rate of a combined end point of cardiovascular death, MI, or stroke and to decrease the rate of a combined end point of cardiovascular death, MI, stroke, or thrombotic stroke (see Warnings).

- **For patients with a history of recent myocardial infarction (MI), recent stroke, or established peripheral arterial disease**

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**Contraindications**:

The use of PLAVIX is contraindicated in patients with a hypersensitivity to the drug substance or any component of the product, and in patients with active internal bleeding, and in patients who are at risk of increased bleeding. More than one component of internal hemorrhage may be needed before the patient is hemorrhaged. PLAVIX should be used with caution in patients who have lesions with a propensity to bleed (such as ulcers). Drugs that might reduce such lesions should be used with caution in patients taking PLAVIX. Use in Heavily Impaired Patients: Experience is limited in patients with severe hepatic disease, who may have bleeding diatheses. PLAVIX should be used with caution in this population. In one heavily impaired Patients: Experience is limited in severe renal impairment. PLAVIX should be used with caution in patients with chronic renal failure.

**Warnings**:

**Thrombocytopenia, thrombocytopenic purpura (TTP)**: TTP has been reported rarely following use of PLAVIX, sometimes after a short (<2 weeks) treatment. TTP is a serious condition requiring prompt treatment. It is characterized by thrombocytopenia, microangiopathic hemolytic anemia (reticulocytosis, schistocytes, fragmented red blood cells), and fever. TTP is not associated with an increase in platelet count, and should be suspected in the differential diagnosis of the unexplained patient with unexplained fever and a decrease in the platelet count. Clotting factors may be diminished. TTP has been associated with sepsis, septic thrombosis, and thrombotic microangiopathy. In TTP, diagnosis is usually made by exclusion. PLAVIX, aspirin, and sulfonamides should be used with caution in patients with a potential for increased bleeding (see Contraindications).

**Thrombotic thrombocytopenic purpura (TTP)**: TTP has been reported rarely following use of PLAVIX, sometimes after a short (<2 weeks) treatment. TTP is a serious condition requiring prompt treatment. It is characterized by thrombocytopenia, microangiopathic hemolytic anemia (reticulocytosis, schistocytes, fragmented red blood cells), and fever. TTP is not associated with an increase in platelet count, and should be suspected in the differential diagnosis of the unexplained patient with unexplained fever and a decrease in the platelet count. Clotting factors may be diminished. TTP has been associated with sepsis, septic thrombosis, and thrombotic microangiopathy. In TTP, diagnosis is usually made by exclusion. PLAVIX, aspirin, and sulfonamides should be used with caution in patients with a potential for increased bleeding (see Contraindications).

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YOU DON’T WANT ANOTHER HEART ATTACK OR ANOTHER STROKE TO SNEAK UP ON YOU.

PLAVIX HELPS KEEP BLOOD PLATELETS FROM STICKING TOGETHER AND FORMING CLOTS, WHICH HELPS PROTECT YOU FROM ANOTHER HEART ATTACK OR STROKE.

If you’ve had a heart attack or stroke, the last thing you need is another one sneaking up on you. PLAVIX may help. PLAVIX is a prescription medication for people who have had a recent heart attack or recent stroke, or who have poor circulation in the legs, causing pain.

PLAVIX OFFERS PROTECTION.

PLAVIX is proven to help keep blood platelets from sticking together and forming clots, which helps keep your blood flowing. This can help protect you from another heart attack or stroke.

IMPORTANT INFORMATION: If you have a medical condition that is causing bleeding, such as a stomach ulcer, you should not use PLAVIX. Side effects include itching, rash, diarrhea, and bruising. Additional rare, but serious, side effects could occur.

Please see important product information on the inside page.

TALK TO YOUR DOCTOR ABOUT PLAVIX.

For more information, visit www.plavix.com or call 1-877-700-0701.

Plavix®
(clopidogrel bisulfate) 75mg tablets
PROVEN TO HELP PROTECT FROM ANOTHER HEART ATTACK OR STROKE