Stranger than Fiction
Reality beats survivor’s wildest dreams

Post-Stroke Depression
Treat It to Beat It

Taking Control
Managing post-stroke incontinence

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Survivor Gary Wilmart of Farmington, N.M., lives by the credo “where there’s a will, there’s a way.” Whether hunting, fishing, gardening or rafting through the Grand Canyon, Gary has made adaptation a way of life.

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I wish I could learn more about spasticity.
I wish there were tips for caregivers.
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I wish I could hear from others living with spasticity.
I wish there was more information about what to expect.

Explore your wishes at
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A stroke can disrupt the brain’s ability to send messages properly to the muscles, causing the muscles to contract and spasm, resulting in stiffness and pain. This condition is called spasticity.

SpasticityAnswers.com is dedicated to educating people affected by spasticity about the condition and its treatment options.

Find out more about spasticity • Learn about treatment options • Read stories from people living with spasticity • Get information for caregivers, and more!
Virtual reality and other video games led to significant improvement in arm strength following stroke and could provide an affordable, enjoyable and effective way to intensify treatment, according to research reported in Stroke: Journal of the American Heart Association.

Researchers analyzed seven observational and five randomized trials, representing a total of 195 patients, ages 26 to 88, who had had mild to moderate strokes. Each study investigated the effects of electronic games on upper arm strength and function.

In the observational studies, improvement in motor strength averaged almost 15 percent after virtual reality sessions. Survivors showed a 20 percent average improvement in motor function, or the ability to perform standard tasks. In the randomized clinical trials, patients who played virtual reality games showed a statistically significant 4.89 times higher chance of improvement in motor strength compared to those who got standard therapy.

“Virtual reality gaming therapy may provide an affordable, enjoyable and effective alternative to intensify treatment and promote motor recovery after stroke,” said Gustavo Saposnik, M.D., M.Sc., lead author of the study and director of the Stroke Outcomes Research Unit at St. Michael’s Hospital at the University of Toronto.

Recent research indicates the brain has a remarkable potential for remodeling because after injury it shows neuroplasticity, the ability to create new nerve cell connections. Those studies indicate that training designed to maximize the brain’s remodeling potential should be challenging, repetitive, task-specific, motivating and novel. All of those are qualities of video-gaming, especially virtual reality systems in which players interact with a multisensory simulated environment via a wireless controller and receive real-time feedback on their performance.

Advantages of virtual reality systems include:
- immediate positive reinforcement;
- multi-sensorial feedback, including vision, hearing and sensory perception;
- computer-assisted movement;
- simple graphics; and
- potential for modifiable speed that enables participation over a wide range of patients including those with a cognitive impairment.

Although treatment varied among studies, most patients played 20 to 30 hours during four to six weeks of therapy on one of several computer-based technology systems: three traditional video game systems (i.e., Glasstron, IREX®, PlayStation® Eye Toy®) and nine virtual reality systems (i.e., Virtual Teacher, CyberGlove, VR Motion, PneuGlove, Wii™).

The observational studies followed patients in treatment to monitor changes over time. The randomized trials – considered more scientifically rigorous – randomly assigned two groups of patients to get either standard or virtual reality therapy.

Some of the smaller studies added virtual reality or video gaming on top of conventional therapy, which may have skewed results for those who received more therapy. So far, there have been no large (more than 100 patients), randomized, controlled trials that compared the combination of virtual reality and conventional physical with occupational therapy to conventional treatment alone.
Stroke patients who received electrical brain stimulation (“e-stim”) coupled with swallowing exercises showed greater improvement in swallowing ability than patients who did not receive e-stim, according to a pilot study reported in Stroke: Journal of the American Heart Association.

Difficulty swallowing, known as dysphagia, is a common and serious stroke complication. It can lead to aspiration, when food or foreign matter accidentally enters the lungs causing pneumonia. Aspiration and aspiration pneumonia are common complications after stroke and can be deadly.

The non-invasive brain stimulation used in this study (Transcranial Direct Current Stimulation, or tDCS) uses a weak electrical current. It is transmitted via electrodes placed on the scalp, to increase activity in targeted areas of the brain. Researchers noted:

• Patients who received brain stimulation increased their ability to swallow by more than 2.5 points on a seven-point swallowing scale, compared to slightly more than one point among those who did not receive the treatment.
• Overall, swallowing ability improved by at least two points in 86 percent of patients receiving stimulation, and in 43 percent of those who did not.

“Further studies are warranted to refine this promising intervention by exploring effects of stimulation parameters, frequency of stimulation and timing of the intervention in improving swallowing functions in dysphagic-stroke patients,” researchers noted.

The study comprised 14 patients recruited from the inpatient stroke center at Beth Israel Deaconess Medical Center in Boston. All patients had suffered an ischemic stroke within the previous one to seven days. Participants were randomized so that some received tDCS to the brain regions that control swallowing while others received “sham stimulation.” Those receiving sham stimulation were prepped as if they are going to receive tDCS but did not.

Length of hospital stay in the family exercise group was an average 35 days compared to 40 days in the routine exercise group.

Researchers found statistically significant differences between FAME patients and routine care patients in eight measures of impairment and activity. For example, in the six-minute walk test, the routine group walked about 154 feet more after receiving therapy, while the FAME group walked about 538 feet more. Moreover, the FAME group survivors were significantly more integrated into their community at follow-up.

Family members who participated in the exercise therapy said they were less stressed and more empowered as a result of doing something practical for their loved ones while they were in the hospital.

Your family’s involvement in your exercise therapy could significantly improve your function and recovery after stroke, according to a study in Stroke: Journal of the American Heart Association.

Researchers found that adding family-assisted exercise therapy to routine physical therapy improved motor function, balance, distance walked and ability to perform daily living activities. It also lowered the strain on the family member, who said participation lowered stress and was empowering.

The study involved 40 male and female stroke survivors, all Caucasian. Half received routine exercise therapy, while the others received the Family Mediated Exercise intervention (FAME) in addition to routine therapy.

Family members helped the survivor do exercises in 35-minute increments seven days per week for eight weeks to improve leg function. The exercises were simple enough to be done at the bedside, either at the hospital or at home. Exercise was tailored to each individual and modified weekly to reflect improvement. Researchers assessed the outcome of the two groups after the treatment period and at three-month follow-up.
My brother Pat sat patiently on a lonely metal folding chair, waiting to remove his sympathy smile and put on his everyday happy face. I was imagining my pureed peas as a hot sack of sliders. With my somewhat involuntary mind meandering a bit, I thought of the past and all the fun we had together.

When I returned to reality my aid was removing my bib. My brother stared, his eyes squinted with an intent look of encouragement, and with a combined effort we smiled. Somehow able to find some laughter, which, as always, became contagious and out of control. For the half dozen others at the feeding table, it was a moving kind of laughter that brought a puzzling kind of smile to their faces. For Pat and me, it was a stimulating way of communication that gave me the spirit and strength of character to take control and set out to regain my independence.

Laughter can be such a great tool; just a simple smile can contain a universal vocabulary as big as the universe itself. Devastating times can be very emotionally confusing. I try to remember that tears and laughter are so many times on opposite sides of the moment.

If I accepted my life the way it is instead of the way it could be then I’m living with no spirit, and without spirit there’s nothing but an unexplained emptiness. I needed to get out of that indescribable state of mind; this was the hand I was dealt and I had to play it.

As much as I wanted to turn back the hands of time and get a second chance to change the mistakes that were made leading to my stroke, I couldn’t. I could only move forward, so why should I lethargically tumble through life the way I was? Why not start playing the hand I was dealt?

Of course, I can fold any time I want. Sure, go ahead, game’s over. It’s easy, right? I’ve seen people accept defeat; it’s a sad sight. Defeat always seems to start with self-pity, “why me?” If I give self-pity a chance, it would certainly destroy me. Self-pity is the enemy, and if I let it sneak in, overpower me and join forces with something called depression, I’m done, finished. I’d be forced to fold and accept defeat.

Well, guess what? That’s not happening here. Who wants to lose? Not me. It’s good to win. Everybody wants to win. To be on the winning team is a great feeling. All I have to do is open my eyes and look around. It’s all right in front of me. Family, friends, all the great people here at Kessler Institute for Rehabilitation – that’s my winning team. I was so aware of my surroundings, my mind was so clear I could see that all I had to do was open my heart, let them in and there would be absolutely no room at the inn for sadness and despair. Don’t forget, winner takes all.

Keith McCormick, Survivor
Howell, N.J.
his spring I was one of thousands of students who put on a cap and gown and marched to *Pomp and Circumstance*, Op. 39, No. 1, commonly known as the Graduation March. At 33 I received my Ph.D. from the University of Nevada, Las Vegas.

The approach of this important day was a little surreal because of my recent stroke-related struggles. In September 2009, I was shocked by my stroke diagnosis, which was made after a seemingly too slow ambulance ride to the emergency room and a day in the hospital. I was just 31 years old, so it was easy to question how a blood clot had reached my cerebellum. I had kept myself in shape by running in four marathons.

I had been working full time as a legislative advocate at a law firm, advocating on behalf of clients’ interests at the Nevada Legislature. I enjoyed being active in the community through a gubernatorial appointment to the Nevada Commission on Post-Secondary Education and as a board member of St. Jude’s Ranch for Children, which provides a nurturing home for abused, abandoned and neglected children. In addition, I was a student working on my dissertation for a doctorate in Public Affairs.

After the stroke I found it difficult to walk, much less jog regularly. Instead of working and studying, I found it difficult to read or even use the computer for more than 10 minutes. It was just too difficult. And my busy lifestyle was overcome with extreme exhaustion; I couldn’t seem to do the simplest tasks. All the time my wonderful husband, Trevor, was truly an amazing caregiver.

Only a couple weeks before the stroke we had celebrated our one-year anniversary. After being released from the hospital, I, along with Trevor and my father-in-law, attended the annual Heart Walk in Las Vegas organized by the American Heart Association/American Stroke Association. Still very weak, I was placed in the survivor tent while Trevor went to find the event’s stroke adviser. The experience of connecting with other stroke survivors early in my recovery gave me hope and, more importantly, commonality with people who had shared a similar experience. Now I participate in our local Sharegivers Peer Visitor Program, where survivors who are 18 months or more into their recovery visit new survivors at the hospital to offer encouragement.

Now more than ever I appreciate this saying from William Arthur Ward: “The pessimist complains about the wind; the optimist expects it to change; the realist adjusts the sails.” As survivors, we may need to adjust our sails. Since strokes affect patients differently that adjustment will vary. My experience has been that a survivor needs to be aware of new-found limitations, patient with the progress of recovery, but also persistent in striving for goals, no matter how big or small. One of my initial triumphs was when I had the energy and balance to make myself a meal. As my cognitive skills began to improve, I was able to continue my doctorate studies. Now that I’ve graduated, I share my experience with the hope that other survivors won’t give up on their goals. As survivors we may need to adjust our sails, but we should enjoy the ride since there is so much life to live and so many dreams to achieve.

**Erin Russell, Survivor**

*Las Vegas*
I have taken two clichés to heart: One, don’t judge a book by its cover. And two, truth is stranger than fiction. These trite expressions have become truisms during my long and surreal journey.

It began in December 1993 when I started a job in academic services at a large, urban university. I had recently finished a marathon job at that same university, editing, ghostwriting, proofreading and desktop-publishing four textbooks in 18 months. The steady, predictable pace of a regular desk job was a welcome change, and it allowed me the time and energy to begin my graduate studies in educational psychology. After only a few months, I was on the fast track to bigger and better things.

Then, with no warning, life as I knew it ceased to exist. On Oct. 11, 1994, I had a massive brainstem stroke resulting in locked-in syndrome. I was paralyzed from head to toe. A machine breathed for me. I could only communicate by blinking my eyes.

My brain, however, was working fine. I was completely aware of everything around me. I remember it vividly and it haunts my dreams.

One description I’ve read calls this condition the closest thing to being buried alive. I saw it as the world’s smallest prison cell. The prognosis for people with locked-in syndrome is grim: Return of significant motor function is rare. My family was told to start looking at nursing homes. That is how my old life ended.

Over the next few months I defied my prognosis. This is how my new life began.

One month after the stroke, I started to move my head and my right hand. Two months post-stroke, I was standing with assistance, and the capability of making vocal sound was returning. Month three I spent relearning how to walk and talk – and I got to eat again (although I was not cleared to drink water until month four). Three months and two days post-stroke I was released from the hospital.

My body was no longer familiar to me. It felt like it belonged to someone else, despite the fact all the parts were in non-paralyzed, working order. My sister declared me a walking miracle.

A new life that looked much like my old one started to come together. Seven months after the stroke, I started driving again. A month later I celebrated the end of outpatient rehabilitation.

My return to graduate school came at the 11-month mark. I felt strong enough to make it to class most of the
time. Once I was in class, the conversation energized me, but sitting upright drained me, which created an odd balance that worked. Reading was the real challenge: My eyes had been able to track from one line of text to the next for only a few months.

In November 1995, 13 months after my stroke, I went back to work in a different area of the university. Instead of students and registration, I was working with payrolls and suppliers. That job had more physical demands than my previous position. Every day I was asked to do things that were beyond what I thought I could, or even things I knew weren’t safe for me. But I did them without question. Work pushed my limits, and that was good for me. My department became an unwitting accomplice in my recovery because I didn’t have it in me to talk back and refuse a task, even for my own good.

Four years later, I transferred back to the academic services job I had exchanged for a hospital bed. Back in graduate school, back in the same job, I was back to where I was when I got interrupted, right? Not exactly. I was different. My entire life was different. My resistance toward my new life was strong. I didn’t want to be different, so I learned to adapt. If I couldn’t actually be normal, I was going to do my best to blend in with the crowd.

During that first decade of my new life, I did a lot: I earned my master’s degree in educational psychology. I joined MENSA. I escaped an emotionally abusive husband. I located my birth family in 20 minutes on the Internet. I found a psychologist who specializes in brain-injury recovery. Seven stagnant years of trying to pretend to where I was when I got interrupted, right? Not exactly. I was different. My entire life was different. My resistance toward my new life was strong. I didn’t want to be different, so I learned to adapt. If I couldn’t actually be normal, I was going to do my best to blend in with the crowd.

Today my new life is defined by muscle problems, medications and energy limitations. Everything I do is a balancing act between those three things. If there is balance, I get to leave the house in the morning. I live with a jaw-closing disorder; a voice I still don’t recognize; a form of vertigo; generalized, left-side weakness; and a host of other problems, some big, some small. Also, there is the constant challenge presented by my pseudobulbar affect, another condition resulting from my stroke.

In medical language, pseudobulbar affect, also known as PBA, is a “pathological emotive display disorder.” The complexity of PBA reactions is nearly impossible to describe to its full extent. A common, simplified description of PBA reactions is “laugh at a funeral, cry at a circus.” My reactions are affected by my muscle/medication/energy balancing act. When I’m around other people, I’m far more likely to laugh than cry. Crying is pretty much reserved for my time alone — then I cry over everything, especially action/adventure movies and Stephen King novels.

I laugh a lot. Most of it is genuine – 90 percent, maybe more. Yet every day I will laugh at something longer than I want or harder than is warranted. Some laughter starts out real, then I lose control, and the laughter turns fake. I offend my own sensibilities by laughing at people and jokes I don’t find funny. I don’t do polite silence well; and the more I try to be quiet, the less likely it is I will be.

I love the Internet, email and instant messaging – I can laugh or cry like an idiot and it doesn’t interfere. I can express myself and converse as I wish. In type, I don’t have to measure my words by how much I can say before my lungs run out of air and my voice fails. I can laugh at my own jokes, usually starting before the punch line, and the effect is not lost. The freedom of electronic communication is wonderful. I get to be myself.

A lot of effort goes into fighting to control my PBA reactions in everyday life. This struggle is often evident in my voice. I will turn away from people, close my eyes or avert my gaze during conversation, or change the subject out of the blue – all attempts to maintain control.

My giggly-girl appearance has me boxed into an image that isn’t quite me. My potential is lost beneath a demeanor I can’t control. PBA is the bane of my existence. It is also my greatest blessing. I have chronic depression, but it is nearly impossible to be depressed when I’m laughing. This makes PBA an almost instant depression cure, albeit a temporary one. Like I said, never judge a book by its cover — especially this one — things are rarely what they seem.

If I could spend the rest of my life telling everyone related to the medical community how to treat brain-injury patients as human beings, it would be a life well spent. In my dreams there is a book, a documentary, a website, a few speaking engagements … a lot of speaking engagements. What is really in my future? No clue. But I’ll tell you when something happens. You’ll just have to wait until I stop laughing.
I had a stroke in January 2001 at age 57, and in my experience, recovery is a life-long commitment. It requires determination and hard work. There will almost certainly be failures and setbacks, but never give up. Set realistic goals and work toward them. Once the insurance gave out, I continued on my own rehab and you can too.

By Gary Willmart, Survivor
Farmington, N.M.
The computer as a recovery tool

My computer and the Internet allow me to stay connected with family and friends as well as do research on stroke. The computer also allows me to continue writing, which is part of my therapy, and to find adaptive equipment so I can continue doing the things I need for daily living and pursuing my hobbies.

For example, hunting and fishing were my twin passions in life before the stroke, and I was determined to keep doing them. But it took research and work to discover how. I typed with one finger on my right hand, and it often required many corrections and took a lot more time to finish things. But so what – that is why there are backspace and delete keys!

Exercise: A big part in my recovery

Every day weather permitted I walked, adding a little distance each time. Two of my dogs joined me, and they looked forward to our daily walk as much as I did. We gradually worked up to a mile each day. The days I couldn’t walk because of weather, I rode my stationary bike. I would put on a DVD and pedal away. A recumbent stationary bike was easier for me to get on and off alone. An adjustable strap keeps my impaired leg on the pedal. I also purchased an adult trike to ride in my neighborhood.

Planning ahead

I have learned to plan and multitask to save effort. If I was going to a storage shed to get something, was there anything that needed to be returned? I could take it back, get what I needed and save myself a trip.

I now make lists on my computer for each trip we take. It causes me to think things through, step by step, so I don’t forget something. I found that planning is an important part of a project or adventure for me. It is good mental exercise, and I am contributing to the success of the endeavor.

One-handed in a two-handed world

Remember, although you may only have the use of one hand, it has five fingers. Use them all.

I wanted to become part of the daily household routine, to be able to help with chores to take some of the load off Barb, my wife and caregiver, who did so much for me. I started running the vacuum; we bought a new one that I could maneuver more easily.

Although it takes me longer, I do laundry, fill the dishwasher and put clean dishes away. I stop and rest often, finding I don’t have the stamina I had prior to the stroke. Yes, it probably isn’t done as well as Barb would do it, but at least she doesn’t have to do everything. Doing these things feels like a victory on the road to independence.

We made many changes to our house to make it safer and easier for me. For instance, we removed throw rugs and installed grab bars in the bathrooms and shower. We replaced the toilets with higher ones that are easier to get on and off. At first, when I suggested something I wanted to do, the response was often “you can’t do that.” To which I responded, “Don’t tell me that; help me figure out how I can.” My motto became “where there’s a will, there’s a way.”
If I wanted to do some cooking, I initially had two problems: opening a can one-handed with a can opener and slicing something. I did some research and found an electric can opener designed for one-handed use and solved that problem. A cutting board with a locking adjustable clamp and prongs to pin stuff while I sliced was another useful tool, as was a one-handed chopper and mincer for vegetables.

Our yard needed to be landscaped, so I became the planner. I was determined to be part of the actual doing as well. I’m here to say you can dig a hole for a tree one-handed, it just takes longer.

To start the lawnmower and keep it running, I use a bungee cord to hold the kill-switch lever down. I can then pull the starter cord, engage the self-propel lever and off I go, one-handed!

To move materials around the yard, I got a garden wagon I can pull one-handed and a wheelbarrow that has two front wheels, which makes it less prone to tipping. We put a two-inch PVC pipe across the handles so I can lift the wheelbarrow one-handed.

Driving again

Because I was unable to drive initially, that became a goal to get some independence back. The stroke had caused severe left-side neglect and affected my peripheral vision. About six months after the stroke, the eye doctor said my vision was OK and the neurologist said I could drive again. He did recommend that I avoid heavy traffic. Since we live in a rural area, I started on our dirt roads. I find that I need to concentrate when I drive, never taking my eyes off the road for even a second because I tend to go where I’m looking. Now I can drive to town by myself for appointments or shopping. To make it easier to turn the steering wheel with just my right hand, we put a spinner knob on the steering wheel. It works great for me. Since turn signals are on the left side, I made a low-cost lever that attaches to the turn signal and crosses over to the right side. I can activate the turn signal now using the fingers on my right hand, keeping my hand on the steering wheel.

Pushing my envelope

In May 2002 we did an eight-day raft trip through the Grand Canyon. There were 28 of us on two motorized rafts. When I saw those rafts at the launch, they were so big and high I wondered how I was going to get on and off. Two big guys solved that problem when they simply picked me up and put me in the raft. Going through the rapids, seeing the beautiful scenery and sleeping on a beach each night was a wonderful experience. We said we departed the launch site as 28 strangers and finished the trip 228 miles later as a family of 28. I discovered that people are more than willing to help you fulfill
your dreams. Where there’s a will, there’s a way.

Another big adventure happened in May 2006, when Barb, her sister and I did an overnight mule ride into the Grand Canyon. As on the raft trip, two big guys lifted me into and out of the saddle. I wanted to see the canyon again in a different way and prove to myself that I could do it in spite of my disabilities. When we stopped for lunch, the two men lifted me off the mule. As they put me back on afterward, one of them commented that he wasn’t sure I could make it. I thought, “I’m going to prove to you and myself that I can do it.”

Almost six hours after starting down, we crossed the Colorado River on a bridge and reached the Bright Angel Lodge where we would spend the night. I was lifted from the saddle and carried to a seat. I was so saddle sore, I couldn’t move for a few minutes. Back at the rim the next day, I was still so saddle sore I could barely walk. But I was proud of myself. I must say it was probably the hardest physical thing I have ever done. I told Barb, “That was the trip of a lifetime – once in a lifetime.” We now have certificates hanging on the wall, certifying that we are master mule skinners. Each time I see them, I relive that adventure in my mind.

Adapting and conquering hobbies

Woodworking and gardening were hobbies I wanted to continue. To continue vegetable gardening, I designed a 12-foot wide, 18-foot long, 2-foot high, above-ground garden plot, using 6-by-6 timbers. Soil was trucked in to fill it. I can sit on the walls to work or climb into the garden using the steps at one end. I designed and built (with Barb’s help) three flower beds out of landscape timbers. It is so rewarding to see the bright flowers, knowing I made it happen through determination and hard work.

I plan the garden each year, and Barb plants the seeds and lays out the drip watering system. We both reap the benefit of many fresh vegetables. And I get the benefit of therapy by working in the garden.

To continue my woodworking, I needed Barb’s help to be able to use many of the power tools safely. Barb had never done woodworking, so I was her instructor, teaching her how to use tools like a router, which requires two hands. With more Internet research, I found a tool called a Rotozip that does the same things and can be used one handed. Barb would trace the pattern on the wood and I would cut it out. We worked as a team, making yard shadows, birdhouses, wind chimes — all sorts of stuff.

Barb also played an important role in my being able to continue hunting and fishing. She made an important discovery the first time we went to shoot one of my rifles: I couldn’t see through the scope using my right eye. Since I had been left-handed all my life, my left eye still tried to dominate, so I would move my head over to try and use the left eye to sight. Barb suggested I put a patch over my left eye. It worked, and now I wear the patch to hunt and shoot. I also have to wear an AFO in my left boot, or my weakened ankle will turn over on uneven terrain.

I had another problem with my old Winchester rifle, which weighed 11 pounds and was too heavy to carry and impossible to hold steady one-handed. The Internet helped again: I found out that Remington Arms makes titanium rifles that weighed 5 pounds. Using that gun and a tripod, I have harvested numerous trophies since my stroke. I no longer hunt alone, going with friends or a guide for safety, and honestly it’s more fun to share the experience with others.

Next I tried my hand at fishing. Prior to my stroke, I had been a professional fly-fishing guide and instructor. I wanted to continue fly fishing but (continued on page 14)
I wish I could learn more about spasticity.
I wish there were tips for caregivers.
I wish I could find the support I need.
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I wish there was more information about what to expect.

Explore your wishes at
SpasticityAnswers.com

A stroke can disrupt the brain’s ability to send messages properly to the muscles, causing the muscles to contract and spasm, resulting in stiffness and pain. This condition is called spasticity.

SpasticityAnswers.com is dedicated to educating people affected by spasticity about the condition and its treatment options.

Create your Wish List Discussion Guide to help prepare to talk to your doctor.

Find out more about spasticity • Learn about treatment options • Read stories from people living with spasticity • Get information for caregivers, and more!
needed adaptive equipment to do it. On the Internet Barb found a reel made in Italy that I could use one-handed. Since purchasing it, I have caught some very large trout.

Deep-sea fishing involved a different problem that was solved with special fighting belts that hold the rod and reel so I can fight the fish one-handed. Since getting these belts, I have been able to land marlin, sailfish, tuna and other big fish. Fishing trips to Costa Rica, Mexico and Alaska have proven the value of this equipment and allowed me to continue a sport I love.

**Giving back**

In keeping with my commitment to educate others about stroke and recovery, I have been going to my local college twice a year to talk to the physical therapy students and let them practice on me. I’m usually the first actual survivor they have worked with. It is rewarding to me, because it helps the students become better therapists when they graduate. I have also enlisted a few other survivors to attend, benefiting them and the students.

I volunteer in the New Mexico Adopt-A-Highway program. Barb and I are responsible for cleaning up two miles. It is good exercise for me and allows us to contribute to our community. I also volunteer two days a week at our local hospital and serve Sunday dinner at the homeless mission several times a year.

**Recovery is a lifelong job**

As a stroke survivor, progress often comes in small steps, with hard work and determination. I had always been an avid reader and still am. I normally finish a book in a couple of days. Reading keeps the brain active and is stimulating, both good therapies.

My left leg stays stiff, so I tend to swing it. My walking isn’t pretty, but, like Larry the Cable Guy, “I git ’er done.” Even now, 10 years after my stroke, I’m trying to improve my walking. As I said, recovery is a lifelong job and gains can be made years after a stroke.

I have made lifestyle changes to reduce my chances of another stroke. Several years ago I stopped drinking alcohol because it was becoming a problem for me. I have learned to eat healthier and lost 30 pounds in 2008. My 2009 goal was to quit smoking (for the third time in my life). I gave it up in April that year and have been cigarette-free ever since.

Here’s my advice to survivors: Never give up. If at first you don’t succeed, keep trying. But please think safety all the time; don’t let your impulses get the better of you. My desire to get things done immediately has gotten me into trouble and even resulted in injury. I learned patience, waiting for someone to help me with the things I could not do by myself or do safely alone.

I have also learned to see the humor in things and laugh at myself when things don’t go as planned. I plan on making progress even after all these years, and you can too, no matter how recently or long ago your stroke happened.

None of this would be possible for me without the support and encouragement of Barb, my best friend and caregiver. I look at each day as a gift, thank God for it and try to do my best that day. Like I said, where there’s a will, there’s a way.

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**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

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— Bill, Age 74
Post-stroke depression is a perfect example of adding insult to injury. Studies indicate 40 to 60 percent of survivors experience depression during the first year after stroke. In some cases, the depression is a direct result of the injury. Until recently it was thought to be associated primarily with left-hemisphere strokes, but current evidence indicates it is not hemisphere-specific.

**TYPES OF DEPRESSION**

There are three types of depression. The first is often referred to as minor depression or depressive symptomology. “This early type of depression happens in the acute stage and is likely a result of the biochemical changes caused by the stroke,” said Dr. Loran Vocaturo, a rehabilitation psychologist and director of neuropsychology at Kessler Institute for Rehabilitation in New Jersey.

Later, when survivors begin to understand how the stroke may change their lives, they may experience reactive depression. “We usually see this in the acute rehabilitation phase,” said Dr. Vocaturo.

Then there is major depression or clinical depression. This may set in after survivors return to their communities and try to participate in activities they did before the stroke. “That’s when they get an appreciation for how their impairment affects their lives and interferes with what they were doing before,” Dr. Vocaturo said. “Most patients can learn to live with a certain level of physical impairment. However, fatigue and communication impairment are what really get in the way of people living their lives.” Survivors often run out of energy: They might be willing to do certain things, but their bodies don’t cooperate. The more that happens, the more likely they are to become depressed.

Survivors with depression will fit into this minor-to-major spectrum differently depending on when (and if) the depression is identified and treated, where the stroke occurred in the brain and how it has affected their abilities.

**TREATMENT**

Failing to treat post-stroke depression prolongs the misery. Depression may have long-lasting consequences because it can keep people from fully engaging in their rehab program at the time it is typically most effective. “It interferes with motivation so survivors don’t participate in rehab and don’t reach their full.
potential,” Dr. Vocaturo said. Depressed patients stay in the hospital longer and have higher mortality and suicide rates.

The good news is that post-stroke depression responds well to treatment. Studies indicate that a combination of three approaches works best:

1) Psychotherapy, such as motivational enhancement therapy, an early intervention intended to engage survivors in treatment and improve their motivation for rehab.

2) Cognitive behavioral therapy, a form of psychotherapy based on the idea that the way survivors think about things affects how they feel and what they do.

3) Drug therapy, including anti-depressants as well as psycho-stimulants or cognitive enhancers, which help with the emotional flatness and decreased arousal that survivors often have.

“Most anti-depressants are well tolerated, and any side effects are generally short-lived,” said Dr. Vocaturo. “The benefits far outweigh the problems.” The mix of therapies is determined by the severity of symptoms and is designed to address each survivor’s particular emotional, cognitive and behavioral functioning.

OVERALL IMPROVEMENTS

Treating depression doesn’t just affect a survivor’s mood. Attention, concentration and memory problems often improve as well. Cognitive problems that are a result of the stroke may require cognitive rehab to teach compensatory strategies for survivors’ cognitive deficits. (Cognitive deficits include learning and memory problems as well as challenges in executive function such as organization, judgment, planning, abstract reasoning, inhibition and mental flexibility.) “When survivors try to play by pre-strokes rules, they get tripped up because their brains aren’t functioning that way anymore,” said Dr. Vocaturo. “Cognitive rehab helps patients organize their lives to help them do the things that their brains are not doing naturally. That way they can reach their full potential.”

Sometimes survivors put off treatment for depression because they fear there is a stigma attached to any mental health diagnosis. “In general we’ve done a lot better in validating survivors’ depression. People are more willing to use drug therapy and that helps,” Dr. Vocaturo said. (continued)
KNOWLEDGE IS HELPFUL

Just understanding the connection between stroke and depression can benefit survivors and caregivers. It helps them realize that it is not a matter of will. “When I explain to patients that these are symptoms of the stroke and that many people have them, it’s like a huge burden is lifted,” Dr. Vocaturo said. “They think they are the only ones struggling because they don’t understand the relationship between stroke and depression. The more we can educate people and make them sensitive to what is going on, the more willing they are to accept treatment.” (See “Overcoming Depression; Finding Purpose” on page 17.)

Dr. Vocaturo emphasized that social support is part of treatment that is equally as important as assessment and therapies. According to research, social support is the prime predictor of how survivors adjust long-term to disability and depression. “I think you want to do two things with social support: keep the survivor connected as much as possible to who they were before; and develop a network of survivors who understand the challenges,” Dr. Vocaturo said. “I’m an advocate for stroke support groups for both survivors and caregivers.”

Although post-stroke depression is common, it responds well to treatment. If you suspect your survivor is struggling with it, don’t wait for him or her to get better without treatment. Assessment should come right away, because untreated depression can have critical consequences later on.

Prozac May Aid Rehab

In a small French study reported in the *Lancet*, fluoxetine (Prozac) had a positive effect on the rehabilitation of ischemic stroke survivors with paralysis or muscle weakness. Fluoxetine is usually prescribed as an anti-depressant. At the beginning of the research, all 118 survivors scored 55 or below on a common movement scale in which 100 is normal. During the study, survivors were given fluoxetine or a placebo for three months, starting 5-10 days after their strokes. Those who got fluoxetine showed greater improvements (34 points on average) in their movement than patients receiving placebos. Those receiving fluoxetine were more likely to be able to carry out the usual activities of daily living independently after three months. Although this study is the largest of its kind to date, even larger studies will be needed to confirm its findings, and to determine whether the effects last after the drug is discontinued.
Taking Control

Incontinence, a general term for problems going to the bathroom due to a lack of bodily control, is a delicate subject. It’s also a very real problem for stroke survivors, many of whom face embarrassment, further health risks or delays returning home after stroke because of it. According to the Copenhagen Stroke Study, about half of all survivors are diagnosed with bowel or bladder incontinence in the acute phase.

The good news is that six months later, only 20 still had urinary incontinence and 10 percent had bowel incontinence.

How stroke affects control

Stroke can affect the nerves and pathways that control continence. When these systems are working properly, the bladder and the rectum can sense when they become full and communicate that sensation to the brain. Then the brain either holds back the release of waste or allows it. People who are cognitively impaired and can no longer recognize those sensations cannot allow the sphincters to relax and open. This can be further complicated if the sphincter muscles are too loose and can’t keep themselves closed; or if they can’t open and empty because they are too tight.

“In my experience, incontinence is one of the most distressing things survivors experience,” said Deborah Stockdale, a rehab nurse at Genesis Regional Rehabilitation Center in Davenport, Iowa. “It is the primary reason for discharge to a facility instead of home because of the burden of care it adds to an elderly spouse or because there is no caregiver at home. To survivors, it is a huge embarrassment and affects their willingness to participate in the world outside the home.” It also may contribute to the risk of falls, as survivors, for fear of having an accident, don’t wait for assistance to the bathroom. If not managed correctly, incontinence also contributes to skin breakdown.

Categories of incontinence

**Functional incontinence** occurs when paralysis, weakness or lack of mobility make it difficult, if not impossible, to independently get into the bathroom, deal with clothes, transfer to the toilet and handle hygiene.

**Stress incontinence** occurs when a survivor increases the pressure in the abdomen by coughing, laughing or picking up a heavy object. This puts more pressure on the bladder, making it impossible for the already weakened muscles to close the bladder. In the general population, this type of incontinence is more common in women because childbirth weakens many of the muscles involved.

**Urge incontinence** occurs when the bladder goes into spasm before someone gets to the toilet. This happens because the bladder has become more sensitized to
filling with urine and the survivor gets a sudden urge to empty the bladder even when it’s not full. Stroke is not the only cause of this. Other contributors include foods that irritate the bladder (spicy foods, caffeinated or carbonated drinks, alcohol and artificial sweeteners), concentrated urine from not drinking enough water and urinary tract infections.

Other contributors to incontinence, such as lack of estrogen or an enlarged prostate, may be worsened by a stroke.

**What can be done**

First of all, incontinence can be a side effect of some drugs, so investigate that possibility and talk with your doctor about alternative medications. Treatments and management are determined by the type of incontinence. Stress incontinence is treated with more frequent toileting, standing up from the toilet then sitting and trying to go again, and avoiding spicy foods and caffeine. “Survivors should drink more in the morning than in the evening to decrease nocturnal incontinence, as well as wear incontinence garments,” Stockdale said.

Such garments include adult incontinent briefs. They can hold large volumes of urine in special fibers or gels that are built into the material. The material next to the skin allows fluids to pass through so the skin stays dry while the fluids are trapped in the next layer. A waterproof outer covering stops leakage.

Urge incontinence can be managed with medication and bladder training, the goal being to go to the bathroom every two hours during the day.

Functional incontinence improves with overall physical improvement from occupational and physical therapy. It can be treated by identifying the problem and addressing it. For example, if a man needs to stand at the toilet to go, but gets his clothes wet with urine when he does, he can use a container-type urinal while standing at the toilet.

Generally speaking, if the survivor can’t get to the toilet fast enough, or misses it or spills urine, keep a diary to learn the pattern and plan accordingly. “Most survivors regain control, but ongoing urinary incontinence is best managed by controlling fluid intake, maintaining a toileting schedule and incontinence garments,” Stockdale said. “Bowel incontinence is somewhat easier to regain, if stools are formed, because we can take advantage of normal reflexes involved in defecation.”

**Skin care**

Protecting the skin is important for people with incontinence, said rehab nurse Denise Howell of St. Charles Hospital and Rehabilitation in Port Jefferson, N.Y. “Stool is much more damaging than urine because it contains digestive enzymes that can literally digest the skin if it is not protected,” she said.

Soiling should never be cleaned up with soap and water. “Skin has an acid mantle that protects it, and soap destroys that,” Howell said. “Use a special skin cleanser called a ‘perineal cleanser’ that protects the acid mantle and restores the skin’s natural oils.”

After cleaning, apply a moisture-barrier ointment to prevent further moisture-associated skin damage. Your pharmacy or surgical supply store should have these products.

If a man is urine incontinent, he has the option of using what’s known as a “condom” or “Texas catheter” to contain the urine. This device fits over the penis and has a tube that is connected to a urine storage bag. The adhesive that holds the condom in place lasts only a day, so it must be changed every 24 hours. The urine storage bag can either be a large bedside drainage bag or a smaller “leg bag” strapped to the leg so it is less visible.

Incontinence is a vexing problem, but for most survivors it stops. If it does persist, there are training programs and supplies that can help, and there are therapists that specialize in treating this condition. Ask your doctor or therapist for a referral.

For more information on incontinence, visit the National Association for Continence at nafc.org.

**Making It Easier to Go**

- Use Velcro fasteners so clothes are easy to open.
- Modify the bathroom so a wheelchair or walker can easily fit through the doorway.
- Install grab bars next to the toilet for use during transfers.
- Install a bidet for perineal hygiene.
- Use a bedside commode for nighttime toileting.
Nowadays it seems everyone waiting for a train on the subway platform is held captive by their cell phones, accomplishing momentous tasks like “Farmville,” “Rock Band” and “Angry Birds.”

You’ll find me hanging at the news stand. Why? Well, I don’t own a cell phone. Not just because Keith Richards says using one is like sticking your head in a microwave — although if Keith says something is bad for you I’d tend to listen. Truth is there’s a kind of James Dean, rebellious, impracticality about not owning one that I identify with.

I play a game too, but mine doesn’t require an app or monthly payment. This rebel without a cell phone takes headlines from women’s publications (like “Allure”) and mentally superimposes them on men’s magazines (like “Road & Track”) to see if they still make sense. “Cellulite Is Not a Crime!” Nah. “If You Change Your Face Will Hubby Notice?” Nope. “Get Rid of Muffin Top — 7 Belly Blasting Tips!” Nada. “Get the Body You Love!” Hmm, maybe. If aliens beamed down and read these articles they’d think all we humans care about is appearance. Bingo! “OK Rich, tell ET what he’s won.”

I never gave much thought to my looks until I was shipped off to prep school. It was 1963 and I was 13. Being Lebanese-American my skin color is what J. Crew would call khaki, hence my nickname “Twilight.” My other nickname “Brillo-head” was due to my curly hair. Every guy at the time had a Beatles haircut. I tried one too, but I ended up looking more like a Chia Pet.

Still, it took me by surprise when Mr. Lawton, my Ancient History teacher, asked me to stand up in the middle of a lecture. He proceeded to announce, “If you want to know what a Phoenician looked like take a gander at Mr. Kawie here.” (So much for blending.) Then there was American Literature. On my first day Mr. Bower did what a lot of people do to someone they assume doesn’t understand English. He brought his face uncomfortably close to mine and spoke loudly, over annunciating each word (like that’s going to break the language barrier), “AAR-YOO-THEE-EX-CHANGE-STOO-DENT-FRUM-GAAM-BE-AH?” (Now I’m Gambian?)

At Christmas break even a kitchen worker got in on the act. He asked me to bring back stamps from my country. “Hate to break it to you Mr. Secretary General, Springfield, Massachusetts doesn’t have it’s own stamp.”

So let’s jump ahead to the mother of all appearance changes: Stroke. Mine affected my whole left side and while I survived prep school, a major attitude adjustment was required to become acclimated to my new body. If someone looked at me cross-eyed I’d go all Muhammad Ali on them. I’d float like a cinder block, but I figured I could verbally sting like a bee. “What are you lookin’ at pal? Take a picture. It’ll last longer.” (OK, maybe it was more stings like a Pee-wee Herman.)

Then, the other day, when I was in CVS, a 6-year-old asked bluntly, “Hey mister, d’you have an accident?” “Yes, I did.” I said. “You OK now?” “Yeah, I feel good...really good.” That’s when I knew I was healed. Not cured, but healed. There’s a difference.

On the way home I found myself humming the Ray Charles cover of that old Hank Snow hit “I’m Movin’ On.” Funny how these things pop into our heads.
At the age of 47 and on the cusp of the breakthrough that is every artist’s dream, the comedian John Kawie suffered a devastating stroke which he thought would derail his career…and life. With the sardonic wit that landed him gigs as a writer/contributor for comedians such as Bill Maher, Dennis Miller, and David Brenner, John focused on his experiences with the stroke and created BRAIN FREEZE, a hysterical, poignant, and affirmative journey through the bumpy road to recovery and beyond. Recorded live at the Gotham Comedy Club in New York City in front of a rollicking full house, BRAIN FREEZE is sure to delight those who know just how healthy a laugh can be – and to help teach us all that (to quote John) life is indeed at the curb!

A portion of the proceeds go to the American Stroke Association*