Making Life Bigger than Aphasia

A new approach to a chronic communication challenge
Cover Story

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Sometimes the conventional approach to speech therapy does not cure aphasia, and survivors are left with a chronic disability. Given that, a group of speech therapists are developing the Life Participation Approach to Aphasia.

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Is this life after a stroke?

Did you know the extreme tightness that can appear in the upper limbs after a stroke can be a treatable condition? This condition—known as spasticity—can develop months after your stroke and is sometimes left untreated. Whether it’s difficulty buttoning your shirt or washing your hands, spasticity can turn the simplest everyday activities into the most complicated tasks. If you’re suffering from spasticity, help is out there. Talk to your doctor about your symptoms today. Relief is possible.

Visit MySpasticityAnswers.com to create a personalized doctor discussion guide.
Stroke caregivers are happier when they continue to enjoy their own hobbies and interests, according to new research in the American Heart Association journal Stroke.

Researchers used questionnaires to assess the well-being of 399 family members caring for a stroke survivor after a year. Most of the caregivers were women (69 percent) who were married to the person they were caring for (70 percent).

In a two-year follow-up, 80 of the caregivers completed the questionnaires again, and most of their answers remained similar to their initial responses.

Researchers found that the happiest caregivers were:

- older (average age 58) and in better physical health;
- maintaining their own hobbies and activities;
- providing higher levels of assistance to stroke survivors; and
- caring for someone with less cognitive impairment, memory problems or depression.

“I was most surprised that caregivers were happier when caring for a family member who survived a more severe stroke,” said Jill Cameron, Ph.D., lead author of the study and an associate professor in the Department of Occupational Science and Occupational Therapy in the Graduate Department of Rehabilitation Science at the University of Toronto. “But when a stroke is labeled mild, expectations are high and the issues are more subtle. That can cause more frustration because survivors of a mild stroke still have problems.”

Because stroke is a sudden event, survivors can often be home from the hospital just days or weeks afterwards, giving the family caregiver very little time to prepare.

“That might be one reason older caregivers are the most content,” Cameron said. “They’re more likely to be retired and less likely to have to juggle responsibilities of a job and children along with providing post-stroke care.”

Depression, cognitive issues and memory problems in the survivor had a negative impact on the well-being of the caregiver.

The caregiver’s attitude also impacts their happiness. If the caregiver feels they can handle taking care of their family member and that they will grow from the experience, and they continue to take part in activities that interest them, they are happier, she said.

Researchers said learning which factors led to more content caregivers will allow the healthcare system to make adjustments to better support stroke survivors and their families.

“If the family is doing better, that helps the patient do better,” Cameron said.
A new study by researchers at The Ohio State University Wexner Medical Center found that an interactive computer program designed as a rehabilitation biofeedback tool called ‘Embedded Arts’ is safe and well-tolerated by patients receiving occupational, recreational or physical therapy.

“The purpose of the system is to tap into artistic and creative neural pathways. Using real-time data from biophysical sensors, the program integrates creative process within rehabilitation therapies by transforming them into art,” said principal investigator Lise Worthen-Chaudhari, an assistant professor of physical medicine and rehabilitation and associate director of the Motion Analysis and Recovery Laboratory at Ohio State.

Movement of the body, measured by a motion sensor, was transformed into graphic art on a computer screen using custom software. Movement was detected in three dimensions and plotted in two dimensions on the computer screen as an abstract painting. The user could see the picture being drawn on the screen in real-time as they moved, or could view the composition at the end of their session.

“We know that these patients need to move their bodies to help them heal, and this is an artistic process to help people move more as part of their therapy. Movement is medicine,” Worthen-Chaudhari said. “We found that patients just go ‘in the zone’ and come up with designs that are really beautiful. This enables patients to create fun, individualized images that represent their personal healing.”

Digital “painting” created by an Embedded Arts participant; courtesy of Lise Worthen-Chaudhari

**e-ZINE BONUS:** Click to watch a video of survivors using Embedded Arts
I am a stroke survivor and I look normal! I had my first stroke at age 27 when I was undergoing a cerebral angiogram and the doctor went through an artery. I was misdiagnosed for three days and eventually learned that I lost my entire left cerebellum. As a nurse, I knew what happens when a stroke occurs, but what I learned as a survivor changed my life.

For a few months prior to the angiogram, I had been having severe headaches and vision loss. My doctor suspected I had vasculitis and needed the angiogram to prove it. I remember joking with the doctor and the staff when they were discussing the 1 percent chance of a stroke happening as a “side effect” from the angiogram. Be careful what you laugh about.

After the stroke, I had extreme dizziness, even when not moving. I felt like a chicken on a rotisserie. I couldn’t make sense of my symptoms and thought that I was going crazy. I was actually relieved to hear that I had had a stroke. I just figured I would do some rehabilitation and everything would return to normal. Even though I was told that I would not walk or work again, I knew I would prove the doctors wrong and walk to work one day.

What I didn’t realize is that stroke is a life-altering event. It affects me every day. I may no longer have the walker or foot brace, but trust me, on the inside there isn’t a day that goes by that I am not affected by my stroke.

By now I am used to the odd looks people give me when I say that I’ve had a stroke. I am not even mad. Well, of course I am but there is nothing I can do about it now. I have learned how to embrace and live with the new me. I try to maintain a positive attitude daily, but sometimes it is so overwhelming. I do my best and that is all I can ask of myself.

A good result from my stroke was meeting my husband in speech therapy. He was 20 when he had meningitis and encephalitis and was left paralyzed with the same “grim” future I was given. We instantly bonded and fell in love. We recently celebrated our fifth wedding anniversary. We laugh and wonder if we would have met if it weren’t for our brain injuries.

We wrote a book, “But You Look So Normal…” about our brain injuries, how we have lived and conquered them every day, and how we fell in love. We have even included a section on how to deal with people with brain injuries. We’ve also created a website, butyoulooksonormal.com and we have joined the board of the Head Trauma Support Project.

We marvel at how well we recovered but worry about the future. How will our brain injuries affect us? There is no way to know, but we have each other, remain positive and take one day at a time!

Kara Ellsworth Russo, Survivor
Sacramento, California
Confessions of the Lucky One

I am proud to call myself a stroke survivor. I survived a stroke in 1994 at age 51. The physical aspects of recuperating from that stroke were no easy task, but the mental deficits continue to be more difficult. Little did I know that my whole persona would change — I was no longer the “old Joe.” Because this drastic change meant surrendering much of my independence, it caused anger, bitterness and frustration. Learning to accept the cognitive deficit was the most difficult challenge.

For instance, before my stroke, I was in charge of our household finances. But after my stroke, I could no longer understand numbers. I have to depend on others to take care of my checkbook, to pay bills and look after finances. Surrendering this was extremely difficult, as it took a huge part of what I considered one of my major purposes. Looking back, if I had been willing to accept early on that I could no longer do numbers, it would have prevented a lot of frustration and anger.

After my stroke, I was still able to drive, which meant I could remain somewhat independent. However, I eventually lost my license because the doctors determined it was no longer safe for me to drive. I was enraged and blamed everyone else for this loss. I was unwilling to accept the loss of independence and continually tried to have my license reinstated, to no avail. Looking back, if I had accepted that situation, I could have saved myself a lot of time, money and frustration.

Perhaps the most important thing I’ve learned is the need to slow down. Having slowed down, I can appreciate my family, realizing there is nothing more important. I was so busy before my stroke that I missed many wonderful opportunities in my children’s lives.

After my stroke I was given a poem that I have reflected on when I felt like giving up:

DON’T QUIT
When things go wrong, as they sometimes will, When the road you’re trudging seems all uphill, When the funds are low and the debts are high, And you want to smile, but have to sigh, When care is pressing you down a bit, Rest if you must, But Don’t You Quit! Life is strange with its twists and turns, As every one of us sometimes learns, And many a failure turns about. Don’t give up though the pace seems slow, You may succeed with another blow! Success is failure turned inside out, The silver tint of the clouds of doubt, And you never can tell how close you are, It may be near when it seems so far. So stick to the fight when you’re hardest hit, It’s when things seem worse, That you MUST NOT QUIT!

Edgar A. Guest

I believe it was my faith and prayers that allowed me to eliminate my denial and embrace my challenges as the “new Joe.” I still face days that are dark and lonely, but I understand that denying things will not make it better or easier. I view my stroke as a blessing in disguise, which is why I call myself the Lucky One.

Joe Ganey, Survivor
Gainesville, Virginia
What’s the difference between one and a thousand? For Cory Weissman, it’s a whole new life.

It’s safe to say that Cory loves basketball. During his high school career, he scored more than 1,000 points for Jackson Memorial High School in Jackson Township, New Jersey. Only a handful of players have ever done that and his name was inscribed on the gym wall.

In the fall of 2008, he enrolled at Gettysburg College in Gettysburg, Pennsylvania, and joined the basketball team. As a freshman, he did not play much and didn’t score any points. After the season was over, he and a teammate were working out in the weight room when his left arm went numb. So did the left side of his face. An athletic trainer recognized the 19-year-old was probably having a stroke.

The trainer was right. Unbeknownst to Cory or anyone else, he had a brain AVM (arteriovenous malformation), and it burst. (For more on AVMs, see “Uncommon Causes of Stroke,” Spring 2014.) Doctors stopped the bleeding by pumping adhesive into the tangled, malformed blood vessels. Within two weeks he was in rehab, and even though he couldn’t walk, he was still thinking about basketball. His mother, Tina, is a physical therapist and knew that playing basketball would help his recovery, so she and his father Marc propped Cory up to shoot hoops on an outdoor patio at the rehab center.

“Before the stroke, my source of motivation was to become a better player,” Cory said. “Once I had the stroke, in my head, I was still a basketball player, so my motivation was to get back on the court. I never doubted I was going to do that.”
During the summer, he had surgery to remove the AVM that will keep him from ever fully controlling his left ankle and foot. As a result of the surgery, he also had seizures. He returned to campus in the fall, having already progressed from a wheelchair to a cane to walking very slowly, but – most importantly – on his own. He signed up to take a full load of classes, but the pace was too much, and he dropped two classes. He sat out his sophomore basketball season while he recovered, but rejoined the squad as a junior and practiced with the team.

By his senior year, Cory was putting on his No. 3 jersey and participating in pregame warm-ups, but he didn’t play and watched games from the bench. February 11, 2012 was Senior Day, the last home game of the season. His coach, Doug Petrie, named Cory the starting point guard. The opposing coach, Rob Nugent of Washington College, told his players not to make contact with Cory. Right after the tipoff, time would be called and Cory would go to the bench. Still, Cory was thrilled: “Once I got subbed out,” Cory said, “that was already the greatest day of my life.”

A gentle foul sent Cory to the line for two attempts. He went through his pre-shot free throw routine and shot, but the ball bounced off the rim. By then everyone in the gym was on their feet and cheering. Cory went through his routine again. Like any good shooter, he knew the result just by the feel. Swish!

When time expired, someone handed the ball to Coach Petrie, a souvenir of his 322nd victory at Gettysburg, putting him No. 1 on the school’s career list. Petrie gave the ball to Cory.

Then something amazing happened. The story spread quickly, boosted by a video shown on ESPN.

From there Hollywood got interested. “It all starts with taking the first step,” he said. “My first step was waking up in the hospital and saying I was going to get back on the court. If you don’t take that first step, you’ll never get anywhere.”

To other stroke survivors he has a different message: “You may have a disability, but you can use that to help other people. Your disability gives you a unique point of view. Because of that, you have the opportunity to help others.”

“1000 to 1: The Cory Weissman Story” features David Henrie (“How I Met Your Mother” and “Wizards of Waverly Place”) as Cory and Emmy Award-winner Beau Bridges as Coach Petrie. Most of the filming was done on the Gettysburg campus, with Cory sneaking in a cameo appearance. DVDs and digital downloads are available. An insert from the American Stroke Association explaining the warning signs of stroke and a public-service announcement about how to spot a stroke F.A.S.T. are included with the DVD.

Cory graduated from Gettysburg with a degree in health sciences. Now he lives in Los Angeles, where he is launching a career as a motivational speaker. Right now, while he’s learning his craft, he’s speaking for free to school kids.

His message to them is one he knows well. It’s about overcoming obstacles, whatever they may be.

“It all starts with taking the first step,” he said. “My first step was waking up in the hospital and saying I was going to get back on the court. If you don’t take that first step, you’ll never get anywhere.”

Cory Weissman

For more information, visit www.HomeHeartBeats.com
At some point during their recovery, stroke survivors and caregivers realize that life goes on and they have to fit into it. The world doesn’t reshape itself to fit their needs. Aphasia is a deficit that may have to be worked around, despite the best efforts of survivors and speech-language pathologists.
Conventional speech-language therapy focuses on improving language by practicing saying words and forming sentences, or trying to. That approach has served many survivors with aphasia. However, insurance reimbursement for speech-language therapy is limited to about two months, which is not enough. Even after therapy, some people with aphasia don’t fully recover language skills.

“Aphasia is often a ‘chronic’ disability in which language can improve, but does not recover,” said Nina Simmons-Mackie, Ph.D., professor of Communication Sciences & Disorders at Southeastern Louisiana University in Hammond. “This leaves the person with aphasia with a chronic communication disability. Chronic aphasia can make it difficult or impossible to participate in important daily life situations.” For many people with aphasia and their families, aphasia dominates their daily existence and becomes a barrier to getting on with life.

To improve the lives of survivors with aphasia, some speech-language pathologists have developed the “Life Participation Approach to Aphasia” (LPAA). “This form of service delivery differs substantially from more traditional aphasia management,” Simmons-Mackie said.

These programs emphasize group activities that allow survivors with aphasia to communicate and share their experiences with each other. The groups may be book clubs, exercise and yoga classes or theatre programs that are more enjoyable and entertaining than traditional speech therapy.

“The goal is to build confidence, skills and opportunities to get on with life in spite of aphasia, and at the same time practice communicating with other people,” Simmons-Mackie said. The Aphasia Institute in Toronto refers to this as “making Life bigger than Aphasia.”

A group of women who instituted LPAA programming at 13 centers around the country last year formed an umbrella organization called AphasiaAccess to provide continued support for those with aphasia. They collaborate to streamline the post-rehabilitation, long-term treatment process. (For a list of the centers visit StrokeAssociation.org/aphasia.) Although each center offers a different mix of programs, all emphasize interaction and participation. The AphasiaAccess website (AphasiaAccess.org) will be launched this fall.

Darlene Williamson, a member of AphasiaAccess, is the Executive Director of the Stroke Comeback Center in Vienna, Virginia, which offers more than three dozen groups each week. “Our groups focus on the four primary modalities of listening, speaking, reading and writing,” Williamson said. “We also have cognitively based groups, motor speech groups and technology groups.” They also have groups with a fitness component that work with balance, mobility, eye-hand coordination, and a yoga class. Because the center is located in town, members can practice their communications skills at nearby restaurants, shops or the bank. “Members of our center determine their goals and their focus and can create a customized rehabilitation program from among the groups we offer,” Williamson said.

“The goal of LPAA is to make life the focus and minimize the influence of aphasia,” Simmons-Mackie said. “Aphasia doesn’t go away, but life engagement becomes the focus.”

Research indicates that those who live successfully with aphasia engage in meaningful activities and interact with other people, coping positively with their disorder. “LPAA aims to focus explicitly on these goals, rather than assuming that improved language processing will automatically result in improved participation in life,” Simmons-Mackie said.

A key principle of LPAA is to have participants set an explicit goal of improving their participation in life. Another key element of LPAA is changing the environment around the person with aphasia, not only changing how the person with aphasia communicates. Simmons-Mackie likens it to trying to communicate in a foreign country without speaking the language. Native speakers can interact successfully by

“The goal of LPAA is to make life the focus and minimize the influence of aphasia.”

Nina Simmons-Mackie, Ph.D.

Darlene Williamson
Lisa Reynolds of Pecos, Texas, was 45 when she had a stroke in December 2003 that partially paralyzed her right side, impaired her vision and left her with expressive aphasia. She had traditional speech therapy for six months and then became a member of the Aphasia Center of West Texas (ACWT) in Midland. She attended programs five days a week for months, which required recruiting a pool of drivers to make the 200 mile round trip with her because she cannot drive.

Speaking with the mother of four, it is clear she still has aphasia, but it is equally clear she has confidence and enthusiasm for her life. She names off the classes she has taken – “computer lab, cooking, exercise, Bible study, current events where we talk about things over coffee, playing board games.” She has learned to write with her left hand and to maximize communication by asking others to ask her yes-no questions. Says her husband Randy, an attorney: “She is more confident, more independent. She is willing to talk to people, to go shopping.” He is obviously proud of his wife’s accomplishments.

When we talked, Lisa was returning to ACWT the next week. Even after 10 years of attending, she couldn’t wait: “I’m excited to see my friends but also getting something done. It gives so much more than speech improvement. It’s the overall balance that this brings into your life. It has so much to offer; it’s focused on speech but not just speaking.”

“A stroke turns entire families upside down,” Randy adds. “ACWT does a great job addressing issues that affect the survivor directly, but it also provides assistance to the survivor by providing much needed resources to the survivor’s caregivers and family.”
When talking to Bob Mayer, 55, of Tenafly, New Jersey, it is obvious he has aphasia, but what he clearly doesn't have is fear or reticence. He may search for words, but he doesn't search for the confidence to speak. After an ischemic stroke at age 40, he says “the symbol system broke down.” Bob has been coming to the Adler Aphasia Center (AAC) in Maywood, New Jersey, four days a week for 10 years.

In that time, he has participated in all the center’s four dozen classes, which change each semester as members ask for new things. “My favorite is drama club. We ad lib a lot of lines,” he said laughing. “We can’t remember everything.” The drama group produces a condensed version of a Broadway musical each August.

“Being in group helps — you realize we’re all in this together,” he said. “It adds quality of life. Builds confidence. Gives peer support.”

Bob participates in a jewelry-making group called Something Special. Each Friday, members sell their creations at retirement center gift shops. Their jewelry sales in four years have raised more than $150,000 for AAC. “Plus it (working in the gift shops) builds self-esteem and teaches others about aphasia,” Bob said.

“People know stroke, but they don’t know about aphasia.”

AAC members educate first responders and medical residents in their community about aphasia and how to interact with people who have it.

“I’ve come here for 10 years and people are down at first but their whole attitude changes because they are talking and interacting, even if just with gestures. Amazing the changes that you see. I pay a small fee to come here and it’s well worth the money. Being part of AAC is where I want to come for recovery. It’s happy, lots of hope and help here.”

Thoughts of a Founding Mother

Everything about my father’s identity, how he saw himself and how others viewed him, came to a crashing halt following his stroke and aphasia. It would be months of heartache, frustration and hopelessness before I heard Aura Kagan, Ph.D., explain the Life Participation Approach to Aphasia. I felt my whole body relax, knowing I had finally found a plausible, on-going and life-affirming model of service for my dad and others like him. Now, I’ve had the honor of watching hundreds of survivors enter the doors of the Aphasia Center of West Texas. Over and over, I’ve witnessed how they grab the lifeline of friendship, communication strategies and empowerment the Life Participation Approach provides.

I jumped at the chance to be a “founding mother” of the AphasiaAccess network because I want the LPAA model of service to spring up in cities across North America. From the moment someone enters a hospital on a gurney to ordering coffee at the local coffee shop, I want people with aphasia to find healthcare professionals, business owners and community leaders who know how to make life accessible again. AphasiaAccess will be the go-to resource to learn exactly how to do that.

Kathryn Shelley  |  Founder; Marketing & Development Director
Aphasia Center of West Texas
Stroke is one of the most common causes of disability and the No. 4 killer, but many people don’t know it kills more women than men. Of the 6.8 million Americans who have survived a stroke, 3.8 million are female. Mostly, this is because stroke increases with age. Seventy-five percent of strokes occur in people over 65 – and women live longer than men. The lifetime risk of stroke for those between 55 and 75 is 20 percent for women and 17 percent for men.

By 2030 almost a fifth of Americans will be over age 65, and the majority will be women. This has profound implications for our society. For example, stroke is the third leading cause of death for women while it ranks fifth for men. Because stroke occurs later in life for women, they are less likely to recover fully and return home to live independently, and thus they are more likely to be institutionalized. These demographics indicate there will be approximately 200,000 more women than men living with the effects of stroke.

But age is not the only reason women have increased risk of stroke. Some risks are because of their gender. For this reason, the American Heart Association/American Stroke Association recently published “Guidelines for the Prevention of Stroke in Women.”

“Emerging data suggest that men and women have a different expression and different incidence of disease,” says Louise McCullough, M.D., professor of neurology and neuroscience at the University of Connecticut Health Center and The Stroke Center at Hartford Hospital, and a co-author of the guidelines. “The original [stroke prevention] guidelines didn’t take into account some of the factors that are unique to women — pregnancy and pregnancy complications being examples — but also that women have poorer recovery from stroke. Women have higher rates of recurrent stroke. A lot of that is related to age.”

The guidelines review risk factors unique to women or that affect women differently and try to determine if there is a need for a stroke-risk score for women using female-specific factors such as pregnancy and menopause.

High Blood Pressure

Hypertension is the leading modifiable cause of stroke, and because women live longer, it affects them more than men. While women have lower blood pressure for most of their lives, this changes as they go through menopause. About 75 percent of women over age 60 have high blood pressure.

Inga Tuveson of Ocean City, Maryland, had never been a big believer in doctors and medicine, even after she was diagnosed with high blood pressure. “My mother dabbled
Survivor Inga Tuvesson with her daughter Tia

in the new age arts,” says Tia, her daughter. “She attended heal-your-life workshops and read positive-thinking books.” Inga felt she didn’t need to take her medicine at the prescribed times and only took it when she felt bad. Then seven years ago Inga had a stroke at age 73. Today she still lives with the deficits caused by her stroke – aphasia, limited vision and right side weakness.

“So much for the power of positive thinking,” says Tia. “Now she is very much regimented about taking her blood pressure and other meds on time. In fact, she reminds my father about them sometimes.”

“Treating hypertension is paramount, and that’s true for both women and men,” McCullough says. “Often people don’t realize that even mild hypertension is a risk because hypertension often doesn’t have any symptoms. Patients come in with a blood pressure of 160 or 170, and they feel just fine, but I put them on a medicine that makes them tired or gives them a cough or is expensive. There are multiple reasons why people aren’t compliant, but it’s exceptionally important to treat hypertension.”

Pregnancy, Preeclampsia & Eclampsia

Pregnant women are at greater risk of stroke than women who are not pregnant (34/100,000 compared to 21/100,000). One reason is preeclampsia, a complication marked by increased blood pressure and protein in the urine. There are no symptoms, so the condition can only be diagnosed by a doctor. If left untreated, preeclampsia can become eclampsia, which involves seizures and is very dangerous.

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However, the danger from this complication does not end with birth. “We know that women who have had preeclampsia have double the stroke risk of women who didn’t have preeclampsia, even 40 years later,” McCullough says. In addition, there is evidence from a Taiwanese study that not only does the woman have a high risk for stroke but her offspring may have increased risk, too. “There’s something that goes awry in the maternal-fetal unit through the placenta,” McCullough says. “Nobody knows exactly why, but it causes this significant hypertensive response and probably causes damage to the blood vessels that is long-lasting.”

Hypertension during pregnancy, even if not associated with preeclampsia, needs to be treated because “the fetus can develop what we call ‘intrauterine growth retardation,’” McCullough says. Pregnant women with high blood pressure should be started on medication. Although there are some drugs, such as ACE inhibitors, that should be avoided, there are many safe medications listed in the guidelines. “The complication of developing eclampsia or having severe hypertension is a higher risk than taking medication.” Women should be screened for hypertension before trying to get pregnant.

A history of miscarriages also appears to increase stroke risk. Although it has not been well studied, this may relate to undiagnosed clotting disorders. “These disorders put women at risk of clots, whether deep vein thrombosis in the legs or pulmonary emboli from the lungs,” McCullough says. “We
Women are at higher risk of stroke primarily because stroke risk increases with age, and women live longer than men.

know that there are a lot of these clotting risk factors and that these can cause miscarriages. If women have recurrent miscarriages, that should be a red flag there might have been a thrombosis (clot) that caused the miscarriage.”

Women with recurrent miscarriages are at much higher risk for stroke and should be treated, typically with an anticoagulant such as aspirin, McCullough says.

Overall, clotting disorders such as antiphospholipid syndrome, are more common in women. “This may be related to estrogen because estrogen can sometimes cause clots as well,” McCullough says.

Oral Contraceptives (OC)

Oral contraceptives, which typically contain estrogen, are another risk factor unique to women. Although in isolation, OCs may not increase risk, when women taking them smoke or have hypertension, migraines or high cholesterol, it certainly increases their risk of stroke. Each of these factors adds to a woman’s risk, and that risk profile builds up. That is what happened to Toni Amick of Columbia, South Carolina, who had a stroke when she was 26 years old. A blood test after her stroke showed that she had two blood disorders. “However, I was also taking birth control pills and smoking,” she says. “This combination caused me to have a stroke.” She no longer takes contraceptives nor smokes and takes a blood thinner every day.

The guidelines suggest that women planning to take OCs should be screened for hypertension and treated if they have it. Any other risk factors should also be treated aggressively, and of course, they should not smoke.

Atrial Fibrillation (AFib)

AFib is the most common heart arrhythmia, and its irregular heartbeats allow blood to pool and clot. As a result, clots can be pumped into the brain, causing strokes. According to McCullough, this type of stroke, called embolic stroke, is generally larger, more debilitating and more deadly.

AFib increases ischemic stroke risk by as much as five times. Non-Hispanic whites have the highest prevalence of AFib compared to blacks, Hispanic whites, Asians or other ethnic groups. Although an equal number of men and women have AFib, it increases with age, so women represent about 60 percent of AFib patients over age 75. That means that elderly women have the highest risk for embolic stroke.

“AFib doesn’t always give you symptoms,” McCullough says. “You may not be short of breath; you may not feel your heart racing. So we often send those women home with what we call a loop monitor that should pick up AFib. Especially if a woman is over 75 and she comes in with a stroke that looks like it’s embolic but she’s not in AFib at that moment, I will send her home with a loop monitor to look for AFib.”

The standard treatment for AFib is blood thinners, but this can present a dilemma in treating older women. “Sometimes we are very hesitant to put elderly women on anticoagulants, especially if they’re living alone and at risk for falling because that can be a complication,” says McCullough. “Obviously, if you’re on a blood thinner and you live alone and you fall, that could be disastrous. But elderly women are at highest risk for AFib, so it’s kind of a Catch-22.”

Migraine with Aura

Migraine headaches are a common disorder, and most do not cause strokes. However, there is some increased risk (1.5 times) of both ischemic stroke and intracerebral hemorrhage that accompanies migraine with aura. The “aura” refers to a variety of symptoms – blind spots, zigzag patterns, prickly feelings on the skin, flashing lights – that happen 5 to 30 minutes before the headache begins. Women with this disorder have stroke about four times more often than men. Women who have this type of migraine and also smoke or take oral contraceptives have seven times the risk of stroke as women without these risks. “If a woman has migraine, she should take medicine to prevent it,” McCullough says, “but she should also stop smoking and stop taking birth control pills in order to lower her stroke risk.”
Obesity

Experts estimate that 86 percent of Americans will be overweight or obese by 2030. While this is a problem for both sexes, obesity affects women more than men (35 percent compared to 32 percent).

Postmenopausal women are more likely to have abdominal obesity, which is more strongly associated with insulin resistance, high cholesterol, diabetes and cardiovascular disease than other body fat distributions.

Obesity is a risk factor for stroke. Obesity, defined as a body mass index (BMI) of 30 or more, increases the risk of stroke after considering other factors such as age, physical activity, smoking, alcohol consumption, diabetes and hypertension. The larger your waist circumference, the greater the chance for stroke.

“Obesity increases risk for men and women, probably because it interacts with other risk factors, like metabolic syndrome, especially in the 45 to 55-year-old age groups,” McCullough says. (Metabolic syndrome is a group of risk factors that increases the risk of diabetes, heart disease and stroke.) “If you have obesity, you’re more likely to have other problems, including diabetes or cholesterol issues, and those all increase risk. That’s why these guidelines recommend, and this is the same for men, to follow a Mediterranean-type diet or DASH diet – low in saturated fat, lots of fruits and vegetables. And be more active.”

The Takeaway

Women are at higher risk of stroke primarily because stroke risk increases with age, and women live longer than men. Older women can reduce their risk by being screened for AFib and being treated with blood thinners, but this strategy is not without risk.

As for younger women, stroke is rare. However, pregnancy increases risk, especially for women who develop preeclampsia. Oral contraceptives also increase risk slightly. However, this risk rises dramatically if oral contraceptive use is combined with smoking and other risk factors.

Uncontrolled high blood pressure poses the greatest risk for women of all ages. There are lifestyle changes that may reduce blood pressure, but if they don’t work, women should consider taking medication to bring their blood pressure under control.

There are effective lifestyle interventions for many of these problems. “They’re the same for men and women and it’s exactly what you expect,” McCullough says. “It’s not rocket science. If you smoke, stop. If you’re overweight, lose weight. If you are sedentary, try to be physically active and follow a diet that is low in saturated and trans fats, sodium (salt) and added sugars. Treat hypertension. If you have high cholesterol, oftentimes that’s genetic, and we’re finding that’s a risk and that requires treatment with medications. Treat the things that we know are risk factors for stroke.”

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Although stroke effects are unpredictable, mood disorders such as depression, anxiety and pseudo-bulbar affect (PBA) are fairly common. We talked to neuropsychologist Dawn Giuffre, Ph.D., of Medstar National Rehabilitation Hospital, about these common post-stroke conditions.

Researchers are actively investigating if certain kinds of strokes or strokes in certain areas of the brain produce mood disorders. So far, studies suggest that simply having a stroke increases the risk of either anxiety or depression, or having both. Research indicates that PBA is more common in survivors of brainstem stroke, but it can occur in strokes in other areas.

Depression affects between one- and two-thirds of stroke survivors. It’s characterized by feelings of overarching sadness, lack of pleasure in activities that were previously enjoyed, or changes in eating and sleeping patterns. For more information, visit StrokeAssociation.org/depression.

By contrast, anxiety occurs when a survivor focuses on worries and concerns. “They go over them again and again in their minds but without necessarily reaching a conclusion,” Giuffre said. Anxiety affects about 20 percent of survivors.

PBA is characterized by a mismatch between feelings and expression – laughing at a funeral, crying at a joke. PBA hasn’t been investigated as much as depression or anxiety, but it’s not uncommon, impacting 28 to 52 percent of stroke survivors, according to studies.

Mood disorders significantly alter the lives of survivors and their families. Because crying or a lack of emotions characterize the disorders, it’s best to identify them accurately and receive treatment based on a psychological assessment. A mental health professional talks with the survivor to determine their internal state of mind and their behavior.

According to Giuffre, it is not uncommon for survivors to experience all three mood disorders. “Patients experience many things when they are going through recovery,” Giuffre said. “And they experience different things at different points. With PBA, if it is going to happen, it usually occurs in the acute phases of a stroke because it is a symptom of the neurological changes that occurred as a result of the stroke.”

Any of the disorders can cause a lot of post-stroke suffering, so one is not worse than another. The severity of symptoms is what matters – “mild PBA would be less likely to have a continual impact on someone’s day-to-day ability to participate in life, whereas severe PBA could really have an impact.”

The good news is that treatment is available. For depression and anxiety, one of the best treatments is counseling or therapy with a licensed mental health practitioner. “We’ve learned through research that cognitive behavioral therapy or solution-focused or problem-focused therapies tend to be quite useful for patients with depression and anxiety,” Giuffre said. “Some other types of counseling methods such as mindfulness therapy, attitude and commitment therapy and interpersonal therapy have been shown to be useful.”

However, the majority of research has been done in people who have not had a stroke. But in general, problem-based and behavioral therapies seem to be useful for patients with stroke. “There are also medications for depression and anxiety that research indicates can be useful, particularly if combined with therapy or counseling.”
Both medication and counseling are typically covered by insurance.

Although there isn’t much research about counseling and talk therapy’s effect on PBA, a new medication, Nuedexta™, was recently approved to treat it. The drug is covered by many insurance plans, although there is not yet a generic form. (For more on this, see “A Social Disability,” January/February 2012.)

Nutrition often affects anxiety and depression. “Nutrition is not necessarily the biggest factor in recovery, but we have certainly learned that poor nutrition can make either condition worse,” Giuffre said. Poor nutrition can lead to additional health conditions or make people not feel well day-to-day, both of which may worsen psychological symptoms.

Physical activity, on the other hand, can ease the effect of mood disorders, although there’s a lack of research on how nutrition and exercise affect PBA.

Giuffre advises caregivers to get their loved ones assessed so they can be treated. If they are reluctant to see a mental health professional, they might be willing to see a pastor, priest or rabbi. Sometimes a trusted medical doctor can write a prescription for an antidepressant or encourage a reluctant survivor to seek counseling.

“When people develop depression and anxiety or PBA that is so intense that it makes them feel depressed, it is important to seek treatment,” Giuffre said. “Not just to improve how they feel in their day-to-day life, but also to insure that they are not feeling so depressed or worried that they skip their medications or fail to pay attention to their diet or miss doctor appointments.”

Different Types of Therapy

SOLUTION FOCUSED THERAPY (SFT) — As the name suggests, SFT is future-focused, goal-directed and centers on solutions, rather than on the problems that bring individuals to seek therapy. It is also called Solution Focused Brief Therapy and Solution Building Practice Therapy.

PROBLEM SOLVING THERAPY (PST) — PST is a brief psychological intervention, or “talking therapy,” usually provided over a series of between four and eight sessions with a therapist. During these sessions the therapist and individual collaborate to identify problems in the person’s life. The therapist teaches the person a structured approach to solving these problems, and a focus on improving their general approach to problems.

COGNITIVE BEHAVIORAL THERAPY (CBT) — CBT focuses on examining the relationships between thoughts, feelings and behavior. By exploring patterns of thinking that lead to self-destructive actions and the beliefs that direct these thoughts, people can modify their patterns of thinking to improve coping. In CBT the therapist and individual actively work together to help recovery.

ATTITUDE AND COMMITMENT THERAPY (ACT) — ACT (also known as Acceptance and Commitment Therapy) is a comprehensive theory of language and cognition that is an offshoot of behavior analysis. ACT teaches people to “just notice,” accept and embrace their thoughts, feelings, sensations, memories and other private events, especially those that were previously unwanted, rather than trying to better control them, as in CBT.

INTERPERSONAL THERAPY (IT) — IT focuses on the interpersonal relationships of the depressed person by improving the way they communicate and relate to others to treat their depression. Techniques used in interpersonal therapy help the person identify their emotion and where it is coming from; express their emotions in a healthy way; and deal with emotional baggage from unresolved issues from past relationships.

MINDFULNESS THERAPY (MT) (also called Mindfulness-Based Cognitive Therapy) — MT is designed to help those who suffer repeated bouts of depression and chronic unhappiness. It combines the ideas of cognitive therapy with meditative practices and attitudes based on cultivating mindfulness. Its goal is to become acquainted with the mental states that often characterize mood disorders while learning to develop a new relationship to them.

Rina Terry | SURVIVOR

Rina Terry of Cordova, Maryland, had a stroke in 2005 when she was 38 years old – the result of a blood clot slipping through a hole in her heart. The stroke left her with a useless left arm and what she termed “invisible wounds” in a May/June 2010 article. In the four years since, those wounds have not healed. “I have always worked, but now I can’t,” she said. “In my brain, I think of myself as how I was pre-stroke, and I can’t understand why I haven’t gotten better.”

A few years post-stroke Rina was having suicidal thoughts, which prompted her to see a psychologist who put her on anti-depressants: “I can feel the difference.” She will soon begin counseling. “I hope with the new therapist to talk about a plan for getting past the stroke. I feel stuck between a rock and a hard place.”
THE ORANGE

Recently, I presented a one-handed cooking demonstration that was unlike any I had done before. Instead of presenting to a support group, I was asked to present my “One Hand Can Cook!” demonstration to inpatients at a rehab facility. It was a small group of survivors, some of whom still had that post-stroke, deer-in-the-headlights look. You may recognize the look on your own face in the mirror.

Unexpectedly, meeting this group of freshmen survivors opened up a floodgate of memories and emotions that I had not accessed since my stroke 19 years ago. Talking to one of the gentlemen, I remembered a particular day, actually, a particular meal tray that was set in front of me. At first glance, there was nothing surprising or problematic on the tray, that is, if it had been the week before. Not until I reached for the orange did I think, “What am I supposed to do with this? Don’t they know I only have one hand that works?” I admit, at that point, I wasn’t up to the challenge of peeling an orange with one hand. I rolled myself out of the dining room frustrated and without having enjoyed the luscious-looking orange.

In hindsight, there is one take-away lesson there. First and foremost, ask for help when you need it. Not asking for help was my loss. As a proud and fiercely independent person asking for help was more than difficult. Whenever I did, usually when the frustration was too much to bear any longer, I felt like a part of me was dying. NOT! Most everyone I’ve ever asked for help, friend or stranger, has been gracious and accommodating to a fault. There is no shame in asking for help when you need it. We learn through trial and error what we can safely do for or by ourselves. Knowing when it is safer and smarter to ask for help is an invaluable step toward living life re-abled rather than disabled.

Regarding peeling an orange — there exists a very inexpensive, small, plastic gadget called a Round Citrus Peeler (Fig. 1) that makes peeling citrus quite possible, even with only one functional hand. Of course, it was made for two-handed peeling, but I use it in a way that suits my needs, as I do with many tools in many situations. I simply slide the ring over the thumb of my less functional hand with the cutting point facing up (Fig. 2). With that hand resting on a table or in my lap, plastic point up, I slowly turn the orange as I drag it along the sharp plastic point (Fig. 3), with enough pressure to pierce its skin. Repeat at numerous locations on the fruit’s surface. I also pierce a circle around the stem end. Then holding the orange in my “good” hand and using my weak hand as a “backstop,” I can loosen and remove the skin of the orange and joyfully devour what I had denied myself that day in rehab, before I had learned to ask for help.

Fig. 2: Slide the peeler over the thumb of the affected hand. Fig. 3: Turn the orange over the peeler with the unaffected hand.

Fig.1: Round Citrus Peeler

e-ZINE BONUS: Visit our Tips for Daily Living Library at StrokeAssociation.org/tips for more great kitchen tips from Roseanna. Share your own video, audio or written tips with us while you’re there!
Managing Caregiver Expectations: Recovery

Most people choose the role of family caregiver with little or no knowledge of what they’re getting into. Stroke is a sudden occurrence that requires many decisions to be made very quickly. Often loved ones come home relying on their caregivers to have the answers about their care and recovery. This is challenging and adds stress to a life-changing role that was taken on without warning. I have found journaling very helpful and wanted to share tips about recovery via journaling, in a series of articles on managing expectations about recovery.

About two and a half years after becoming a caregiver to my mom, who survived a stroke, I realized I had built up resentment towards family, friends and even my mom for not meeting my expectations — expectations I hadn’t consciously realized I’d set. I noticed that I had begun a slow, steady path towards depression. I wasn’t sleeping, had difficulty concentrating and was getting headaches several times a week. I knew I needed to do something for myself, to continue to care for my mom and help her recover.

Counseling led me to therapeutic writing. I use my journal to manage the stress and emotions that can come from caregiving. With the right tools, a journal can be both a safe confidant and a way to manage expectations.

Let’s begin slowly with a 5-minute exercise. Find a quiet place where you will be undisturbed for several minutes. I found a good time for me was when Mom went to bed or while she was watching her favorite show.

Below are three partial sentences; pick one to begin the process and write for 5 minutes, setting a timer. When it goes off, finish your sentence and put down your pen. Read what you wrote and then write for 2 to 3 minutes more, beginning with “I am surprised by…” or “I didn’t realize that…” This is a very telling part of the process. We will use this “a-ha” moment in the next exercise.

Here are your sentence starters:

I thought that _______________ (the stroke survivor) would have begun _______________.

Recovery means ________________________.

If I don’t ____________________ every day, _______________ (the stroke survivor) will _________________________________.

Don’t forget to add the 2-3 minute follow-up mentioned above.

After the journal exercise, what did you learn about your feelings concerning recovery? Are there ways you can adapt your expectations to be more in line with your loved one’s current stage of recovery and how fast it’s moving?

The next exercise is designed to help you identify new ways to think about the recovery process. Look back at your two minute follow-up and find the a-ha. Write a description of what the process might look like considering your a-ha realization. My a-ha moment was recognizing that I had expected my mom to be back to normal in a year. A year after her stroke, when she had not met my expectation, I had no idea how to continue. After writing about how to allow recovery to take as long as it needed, I was in a better place not to be disappointed because it was slow going.

I hope these exercises can help you in your journey. I look forward to sharing more techniques about managing expectations around family and friends in the next article.
Tips for using a journal:

- Find the type of book you prefer to use; for example, a spiral notebook or a journal with bound pages.
- Get a pen that is comfortable to use.
- Never edit yourself; misspelled words can hold a key.
- Always set a time limit. The limit will depend upon the technique (from 5 to 30 minutes).
- MOST important: When your time is up, put down your pen. Read what you wrote, then write for two more minutes beginning with: “I am surprised by...” or “I didn’t realize that...” This is where the real a-ha moment will happen. I recommend that you use this awareness to write the next day, and keep writing until you feel you have resolved your topic or issue before you move to the next one.

About the author...

Lori Ramos Cavallo became a caregiver at age 43 when her mother, Lupe, had an ischemic stroke in July 2001 at the age of 75. At the time, Lori was living in Denver and her mother was in California. Lupe’s husband, Lori’s stepfather, was too ill to become Lupe’s caregiver, so Lori moved to California in order to take on that job. Because of the level of commitment, which she likens to joining the military, caregiving became her whole life. After Lupe’s husband died in 2003, Lori moved her mother to Denver and took care of her until Lupe’s death in July 2009. Continuing the military analogy, she wrote in her blog: “I too am left with the wounds from combat against the effects of a ‘brain attack’ that took my mom’s independence. Most family caregivers like me are left with both mental and physical scars from our time of service. I have begun my journey back into the ‘civilian population,’ and I am reaching out to other caregivers through my website carepartnersresource.com. My hope is to heal my battle scars by teaching others the successful strategies I learned during my tour of duty.”
Fourteen days into my stroke — and 21 days after my wedding — I was sitting on my hospital bed contemplating a future of AFO’s, wheelchairs and Velcro. My new body may have needed the first two, but at 47 I wasn’t about to trade in my favorite Jack Purcells for a pair of Velcro-strapped sneakers that all but screamed “reverse mortgage.” So I decided to sharpen my one-handed shoelace tying technique.

In the middle of attempting to unravel yet another tangled rat’s nest I heard a determined rap on my door. A stout, strange woman stormed into the room like a human microburst. Discombobulated, she pulled her worn, hemp bag across her body, plopped down in the chair opposite me, and with no introduction or preamble, leaned forward and asked, “Mr. Kawie, are you able to have an erection, and more importantly, have you had one lately?”

Now, anyone requesting that information had better be wearing a white coat with a stethoscope around their neck. When I responded, “And you would be...?” she revealed she was St. Vincent’s resident psychologist. Her concern seemed to me like dropping a turkey and making sure that the pop-up thermometer’s okay. But she wanted an answer so I said, “All systems go...Houston we have no problem.” With that she took a booklet from her bag, deposited it on my lap, and disappeared.

I peeked at the title — “Sex After Stroke.” Oh goodie, something else to worry about. It might as well have said, “No Way You’re Having Sex After Stroke.” Is this the next shoe that drops? Is stroke the clown car of debilities, where just when you think you’ve seen every problem there’s always one more rearing its hideous, painted face ready to jump out and spritz you with a seltzer bottle?

The cover was divided into four quadrants each showing huggy, happy couples who looked anything but disabled. However two of the guys creepily resembled Richard Simmons and Dan Quayle. (Talk about a cold shower.) I turned the page and glanced at the Table of Contents. Fear of this, fear of that, fear of things I never feared before. I was overwhelmed with everything I wouldn’t be able to do. So I did what my younger self would have done with a Playboy magazine — skip to the pictures. Only in this case they were simplistic line drawings reminiscent of a DIY Ikea manual illustrating various positions. It was a veritable, disabled Kama Sutra attempting to do for wheelchairs what my hormone-enhanced teenage mind did for the back seat of a ’57 Chevy. If erotica was the objective, it wasn’t working. Still, I was impressed they came up with so many. Personally, I could only imagine three:

- **Fig 1. Me on the bottom**
- **Fig 2. Me on the bottom**
- **Fig 3. Me on the bottom**

The rest of the day was what I now call the “Afternoon of Mixed Epiphanies.” One minute I’m a helpless stroke survivor never to experience intimacy again — and the next I’m thinking maybe all is not lost, because, in a way, stroke is like starting over. I remembered when I was a kid my libido’s built-in GPS guided me. It may have taken me the long way around, but it always got me where I wanted to go. Eventually, with a little practice, I got the hang of it. Like trying to tie a sneaker one handed, but way more enjoyable.

**Editor’s Note:** Despite John’s light-hearted take on the issue of sex and intimacy after stroke, we know it can be a difficult subject for people to broach with their doctor and often with each other. If you’d like a more serious take on the topic, visit our March/April 2009 issue of Stroke Connection online or request information by calling 1-888-478-7653 or emailing strokeconnection@heart.org.
Could you have symptoms of spasticity?

Did you know the extreme tightness that can appear in the upper limbs after a stroke can be a treatable condition? This condition—known as spasticity—can develop months after your stroke and is sometimes left untreated. Whether it's difficulty buttoning your shirt or washing your hands, spasticity can turn the simplest everyday activities into the most complicated tasks. If you're suffering from spasticity, help is out there. Talk to your doctor about your symptoms today. Relief is possible.

Visit MySpasticityAnswers.com to create a personalized doctor discussion guide.