Survivor in the Senate

Sen. Mark Kirk is putting a face on stroke in Washington, D.C.
Cover Story

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Sen. Mark Kirk, the junior Senator from Illinois, had a stroke in January 2012. He still has left-side weakness, but it has not stopped him from becoming an advocate for stroke families.

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Kara Kellerman of Pinckneyville, Ill., was 10 years old when her mother had a stroke. Little did the young daughter know that that event would set the course for her adult life.

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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.
Virtual reality hands” — controlled by stroke survivors’ thoughts — could help them recover use of their hands and arms, according to a small study presented at the American Heart Association’s Scientific Sessions 2013.

“Using a brain-computer interface, we’ve created an environment where people who may be too physically impaired to move can practice mental imagery to help regain use of their arms and hands,” said Alexander Doud, M.S., lead author.

Brain-computer interface technology can help tell if patients are activating regions of their brains in ways that have been linked to better recovery.

“During rehabilitation, usually a therapist will move the patient’s hand or arm in the desired direction while asking that patient to imagine they are making the movement,” said Doud, who was a Masters student at the University of Minnesota in Minneapolis when the study was conducted.

“In this practice space, the patients can control photorealistic hands by thinking about using their own hands without actually moving at all.”

The researchers tested the virtual system on six survivors who experienced impaired arm and hand movement. The patients viewed the stimulus using 3-D glasses to produce the illusion that they were seeing their own arms.

Patients achieved as high as 81 percent accuracy when using the virtual hands to reach out to a glass of tea or water. They improved their skills in as little as three, two-hour sessions.

“The system is created in a way that could allow it to be used to practice a wide variety of desired activities,” Doud said. “This can make it even more patient-specific and that leads to patient motivation.”

Though small, the study does prove the feasibility of this new approach becoming an affordable rehabilitation tool.

“This is an engaging system that encourages patients to practice using the areas of their brain that may have been damaged or weakened by their stroke, and the technology could be used along with commonly provided rehabilitation therapy for stroke,” Doud said.
Stroke deaths in the United States have declined dramatically in recent decades due to improved treatment and prevention, according to a scientific statement published in the American Heart Association journal Stroke.

The American Stroke Association commissioned the statement to discuss the reasons that stroke dropped from the third to fourth leading cause of death.

“The decline in stroke deaths is one of the greatest public health achievements of the 20th and 21st centuries,” said Daniel T. Lackland, Dr. P.H., chair of the statement writing committee and professor of epidemiology at the Medical University of South Carolina in Charleston, S.C. “The decline is real, not a statistical fluke or the result of more people dying of lung disease, the third leading cause of death.”

Public health efforts including lowering blood pressure and controlling hypertension that started in the 1970s have contributed greatly to the change, Lackland said.

Smoking cessation programs, improved control of diabetes and abnormal cholesterol levels, and better, faster treatment have also prevented strokes. Improved acute stroke care and treatment is associated with lower death rates.

“We can’t attribute these positive changes to any one or two specific actions or factors as many different prevention and treatment strategies had a positive impact,” Lackland said. “Policymakers now have evidence that the money spent on stroke research and programs aimed at stroke prevention and treatment have been spent wisely and lives have been saved.

“For the public, the effort you put into lowering your blood pressure, stopping smoking, controlling your cholesterol and diabetes, exercising and eating less salt has paid off.

“Although all groups showed improvement, there are still great racial and geographic disparities with stroke risks as well many people having strokes at young ages,” Lackland said. “We need to keep doing what works and to better target these programs to groups at higher risk.”

A New Alternative to Warfarin

A new drug not yet available in the United States was as effective in preventing strokes and safer than the blood-thinner warfarin in patients with atrial fibrillation, according to a clinical trial presented at the American Heart Association’s Scientific Sessions 2013.

The ENGAGE AF-TIMI 48 Trial included more than 21,000 a-fib patients in 1,400 hospitals in 46 countries. Participants were randomly assigned to receive a high dose of edoxaban at 60 milligrams (mg) per day, a low dose of edoxaban at 30 mg per day or warfarin.

Edoxaban performed as well as warfarin in preventing strokes, while significantly reducing the risk of bleeding and cardiovascular disease-related death.

- Compared with warfarin, major bleeding was 20 percent lower among patients taking the high dose of edoxaban and 53 percent lower among those taking the low dose.
- Compared with warfarin, the high dose of edoxaban was associated with a 14 percent reduction in cardiovascular death; the low dose was associated with a 15 percent reduction.

Instead of depleting the body’s clotting proteins like warfarin, edoxaban singles out one key clotting protein called Xa to prevent clots.

“Edoxaban is a more targeted, simpler approach to preventing blood clots,” said Robert P. Giugliano, M.D., lead author of the study and a researcher and physician at Brigham and Women’s Hospital in Boston.

Warfarin is the most common treatment for atrial fibrillation, or a-fib, an irregular heartbeat that can increase the risk for stroke. Determining the right dose of warfarin may require multiple blood tests; too much may increase the risk for bleeding and too little can increase the risk of blood clots.

Researchers will continue to study edoxaban’s side effects and determine which patient populations may benefit most. They will develop standards for monitoring dosing and determine how best to quickly reverse its effects if needed in an emergency.

“Atrial fibrillation is a common problem among the elderly, and as Americans live longer we need safer, yet effective treatments,” Giugliano said. “Once-daily edoxaban may be an important alternative to warfarin.”
I am a Hip-Hop musician and artist, so when I have a story to tell, my first impulse is to write a song. My song “Waiting for the Day” is a tribute to my father, Ronald Stephenson, Sr. It’s built around sharing our family’s experience with almost losing him during his stroke. It expresses my love for my dad, but I also hope it raises awareness about the impact strokes can have on an entire family. In the next few paragraphs, I will share the background behind the song, which you can listen to on YouTube at bit.ly/1i1Cn4H.

In January 2001, I received a phone call from a family friend that changed my life. The family friend told me my dad, who was home alone, called him because he had lost feeling on his left side and fallen. The friend had called 9-1-1. I left work and headed to my dad’s house, speeding the whole way. After calling 9-1-1 on my mobile, and confirming an ambulance was on its way, I called my dad. He answered the phone, but he was so distraught he didn’t recognize me. I was terrified.

The ambulance arrived before I did, and my dad crawled down the stairs to open the door for the emergency personnel who took him to the hospital. At the hospital, my mother and I were told that my dad had suffered an extremely severe stroke. Although he was 50 at the time, the doctors said the stroke was of a degree more likely to be suffered by an 80 year old. Two days after the stroke, the doctors advised my mother and me not to visit him in ICU. They said that the brain swelling and damage was so bad that he was not going to make it, and that we wouldn’t want to see him in the unconscious state he was in. His death seemed imminent.

Surrounded by friends and family, my mom and I waited for the phone call. Every time the phone rang, we expected the end. If I slept, I would hear phones ringing in my sleep. Thankfully, the phone call we were expecting never came. My dad eventually woke up, and thanks in no small part to my mother’s unbelievable sacrifice and support, he is still living as I write this, nearly 13 years later. Still, as other stroke families know, the effects of a stroke are long-lasting and life-altering. Ever intelligent and confident, my dad had worked his way up to executive positions at prominent companies and later operated a successful small business. He was my childhood playmate, and he is still my model for manhood and strength. These days, along with his investment advice, he encourages me to exercise and maintain a healthy diet. I am thankful he is still with me to see me publicly use my music and this article to say how proud I am of him.

R.S. (Ronald Stephenson Jr.)
Atlanta
Moving From the Minors to the Majors

Sometimes you strike out more times than you hit a home run. Life is about handling the strikeouts — adjusting your strategy after each pitch, adjusting your swing after a strike and being ready for the next pitch. As you move from one league to another, there’s a period of adjustment to be made — each league has its own challenges and skill sets. You’ve got to handle them all.

In February 2012, I suffered an intracerebral hemorrhage, and I moved from one league to another. I thought I had been demoted, moving from the majors to the minors, but I have since found out I was wrong. I was actually promoted, moving from the minors to the majors — that other league was a piece of cake. This post-stroke league is no cakewalk.

To succeed in this league requires determination, unbound energy and constant practice. It’s filled with challenges and requires you to have full confidence in yourself and your abilities. You need to have the flexibility and the physical and mental toughness to step up your game after each pitch and always be ready for the next. You have to be flexible enough to make the needed adjustments, even if you have never seen that type of pitch before. I have found you have to have vigor and passion to succeed, and an attitude to never quit.

Remember Babe Ruth? He is famous for his 714 career home runs. But did you know that he struck out 1,330 times in that same career? He could have taken the easy route and quit after so many strikeouts, but he didn’t. Instead, at his next opportunity, he walked to the plate with more determination and faced the next pitcher with vigor, going for his next home run. In 1927, Babe Ruth broke the record for most home runs in a single season (60), but he also struck out 89 times that year.

I haven’t broken any records yet, but I’m still swinging every day in my personal life. My lack of record breaking isn’t because I lack desire or determination — that is definitely in me. I just need to get up to bat more often. Perhaps this year I will break my own personal records for my most home runs and most strikeouts. Both will be great records because they mean I have not quit but am willing and ready to get back to the plate, to face the next pitch and swing for my next home run.

J. Williamson Moses, Survivor
San Antonio, Texas
A Survivor in the Senate

By Jon Caswell

Stroke survivors do not always return to work. Even when they do, it's safe to say that they are not welcomed back by the Vice President of the United States. Not so for Mark Kirk, the junior senator from Illinois.

In January 2012 Sen. Kirk had experienced dizziness and felt numbness in his left arm and leg on a Saturday morning and checked himself into the hospital near his home in Chicago. He was given anticoagulant therapy when imaging tests revealed a dissected carotid artery. When his vision blurred and his left side continued to tingle, he was transferred to Northwestern Memorial Hospital, a primary stroke center, in case surgery was necessary. That was a good call as surgery was required when the dissected artery blocked the blood flow to his brain on January 27th. About a week later, he woke up in the intensive care unit following two surgeries, including a craniotomy, to relieve the swelling in his brain. “I remember thinking that someone was sharing a bed with me, not realizing that it was my own leg,” he said in an interview with Stroke Connection. He vaguely remembered a Super Bowl party the ICU staff had and the smell of the food they brought.

A few days later he was transferred to the Rehabilitation Institute of Chicago. There he dreamed that three angels visited him and asked him to go with them, but “I said no because I knew where I was, on the ninth floor of the RIC, and why I was there — to begin a long, difficult recovery from an ischemic stroke,” he recalled in an interview with the Washington Post.

That realization came before he had actually begun the hard work of rehab with a therapist he appreciatively calls a tyrant. At first he couldn’t even sit up in bed, his whole left side weak and unresponsive. His glass-half-empty attitude was on full display. He credits his therapy team’s relentless glass-half-full attitude and belief in him as pivotal in his recovery. He participated in an 11-week intensive gait rehabilitation trial using a treadmill and harness. “I struggled with the fact my brain was no longer communicating with the muscles in my left leg,” he said. “At one point, I was on the treadmill with Mike Klonowski, my physical therapist at RIC, next to me, and I realized that I had to use my hip to swing my leg forward. That was a breakthrough moment. That day I couldn’t walk enough.”

But that was only the beginning of an incredibly long, frustrating and exhausting process of learning to walk again. He spent hours on the treadmill, which he calls “that infernal machine.” But the effort paid off, and in November 2012, he challenged himself to climb 37 flights of stairs at the Willis Tower, the tallest building in Chicago, with the help of his physical therapists. That was good practice — two months later, on January 3, 2013, not quite a year after his stroke, he climbed the steps at the Capitol to the cheers of the other senators and vice president. “That was one of the best days of my life,” he said. “My colleagues who watched me climb those steps that day told me it was the first bipartisan
moment that had happened in a while — now that is something to cheer for, and I owe it to the hard work of my dedicated rehabilitation therapists.”

As with most stroke survivors, returning to work was an enormous accomplishment, but that was not the end of the story. “My left arm and leg are not what they used to be. My left leg bears weight so I can walk, but I often use a cane or wheelchair to get around,” he said. He continues to do as much therapy as he can fit into his schedule. “I try to go to Walter Reed Memorial Hospital once a week.”

On November 3, 2013 he returned to Willis Tower to participate again in the stair-climbing event, which is a fundraiser for RIC. The second time he climbed 41 floors by himself, admitting that it was a bit harder without the help of his therapists. He also used the occasion to draw attention to what he calls his “stroke agenda.”

“I am focused on how we can get people who have suffered stroke to return to work, and how we can give them a chance to recover their lives and come all the way back,” he said. Since returning to the Senate, he has introduced several pieces of legislation to do just that. He supports more research into rehabilitation science at the National Institutes of Health and has drafted language to secure funding for that. “I have introduced legislation that would redefine and modernize rehabilitation. Last year I introduced another bill that would evaluate a national need for rehabilitation innovation centers. In addition, I am working with the Centers for Medicare and Medicaid Services to ensure that stroke severity is included in hospital outcome measures.”

Beyond altering his legislative focus, the stroke changed him. “My stroke was the hardest thing I’ve ever had to overcome, and the biggest lesson in life I have ever learned by a country mile,” he said. “I am no longer the glass-half-empty guy. Every day is an opportunity, and I am grateful to be alive, grateful to be here.”

Sen. Kirk got some sound advice from Jason Cunningham, a 9-year-old stroke survivor. “He said, ‘Do not give up on yourself. All the hard work is worth it.’ His words encouraged me to work harder at my recovery.”

Early in his recovery, walking was challenging, but he used the prospect of returning to work in the Senate as his inspiration. He offered this advice to our readers: “Find what motivates you and build off of that. For me, it is making my life matter by doing work that matters to others. And caregivers, remember a stroke is not the end of the world — your loved one will come back.”

Sen. Kirk climbs the Capitol steps for the first time after his stroke with the assistance of Vice President Joe Biden, Sen. Joe Manchin, and Sen. Dick Durbin (L to R)
There are two carotid arteries in the front of the neck and two vertebral arteries in the back, and they transport all the blood that feeds the brain. The carotid and vertebral arteries have three layers: a thin inner lining; a middle layer which is the thickest and consists of smooth muscle; and the outer layer, made of connective tissue.

A dissection in these arteries occurs when the inner lining tears and detaches from the artery. It’s not a tear that goes all the way through the vessel and leaks blood. As with any cut, the body generates clotting factors to stop the tear from spreading. “It’s like a piece of loose wall or shelf paper that is sticky and allows a clump of dust to form underneath it,” Dr. Kasner said. “But when the tear happens in an artery, that clump is a clot (thrombus) that can block off the entire artery, or a piece of the clot can break off and travel up to the brain. Either of those can cause an ischemic stroke.”

Dissections result from a wide variety of causes, and are usually very different from the more typical buildup of plaque in the arteries (atherosclerosis). Dissections are sometimes the result of an injury, like whiplash from a car accident or blunt force trauma from sports injuries. Dissections have also been reported from holding the head in an odd position, like when someone holds a cell phone between the ear and shoulder, or turning the head while backing up a car, or...
even sneezing hard. Dissections have been reported in persons after chiropractic manipulation of the neck. In addition, certain medical conditions such as Marfan syndrome, a genetic disease of the connective tissue, and fibromuscular dysplasia (FMD), a blood vessel disease where the middle of the artery wall grows abnormally and deforms the artery, can also cause dissection. In these patients dissection is called ‘spontaneous,’ meaning that it occurs without trauma to the head or neck.

**Symptoms**

Stroke is not usually the first sign of a dissection. More often, symptoms develop over a few hours or even days, even in those people who have traumatic injuries. Those initial symptoms include headache or neck pain, often radiating behind the eye because the carotid arteries run behind the eyes. Another symptom is pulsatile tinnitus, a pulsating, whooshing sound in the head, which is actually the blood flowing through the vessels. “Occasionally, people will have a drooping eyelid and a smaller pupil on that side,” Dr. Kasner said. (This is called Horner’s syndrome.) Other symptoms include trouble swallowing or a decrease in the sense of taste.

**Diagnosis**

Carotid dissection is typically diagnosed using an MRA (magnetic resonance angiography) or CTA (computed tomography angiography) scan. “Carotid ultrasound is less sensitive. An invasive catheter angiogram is arguably the best test but is not usually necessary because most of the time you can see it by MRA or CTA,” Dr. Kasner said.

Dr. Kasner indicated that some unexplained strokes may, in fact, be carotid dissections. Patients who have stroke symptoms may get a carotid ultrasound and an electrocardiogram (EKG), neither of which can detect a dissection, so they may be told no cause was found. “Occasionally I see patients who tell me, ‘I had a really bad cold. I was sneezing my brains out, and then I had this pain in my neck and eye. My eyelid was drooping. And two days later, I had a stroke, and they didn’t figure out the cause. They told me everything looked normal. Now it’s two months later, time enough for the tear to heal, and my guess is that that was probably carotid dissection, but because the right test wasn’t done at the right time, it was missed. So dissections probably are misdiagnosed in some patients.”

**Genes, Environment or Other Causes?**

In addition to Marfan syndrome and FMD, there is some evidence that people with an inherited collagen abnormality called Ehlers-Danlos syndrome may be prone to dissection. “There probably is a familial genetic component, but in big part dissection is environmental, typically related to some trauma,” Dr. Krasner said. “However, we all hold our cell phones in a funny way, or turn our heads when we back up our cars, and most of us don’t get dissections. So there may be some underlying weakness of the arterial wall that we don’t know about.”

“That said, the most common ‘cause’ of dissection is ‘spontaneous,’ meaning without major trauma, but often with a predisposing factor like sudden neck turn or heavy lifting,” Dr. Kasner said. “That list includes weird stuff like sneezing, coughing, rocking a baby, holding a cell phone with the shoulder, riding a roller coaster, etc.”

**Treatment and Recurrence**

Survivors of a carotid dissection are usually treated with clot-prevention therapy, such as aspirin or anticoagulants. However, there is a very low risk of recurrent stroke once the tear has healed. If patients have recurrent strokes despite medical therapy, then they might be treated with stents. “The highest risk (of recurrent stroke) is actually in the first couple of days after the stroke, and then it declines substantially,” Dr. Kasner said.

Of all the uncommon causes of ischemic stroke, Dr. Kasner estimated that dissection is the most common. “If all of the uncommon causes together are about five percent of all strokes, dissection is probably a quarter of those,” he said.

**ARTERIOVENOUS MALFORMATION (AVM)**

An AVM is a tangle of blood vessels in the brain or on its surface that diverts blood directly from the arteries to the veins, bypassing normal brain tissue. Because the arterial blood is under high pressure, and the walls of veins are not made to withstand arterial blood pressure, there is a danger that the veins will rupture or leak and cause a hemorrhagic stroke. About half of AVM patients have an intracerebral hemorrhage. “However, when AVMs rupture they may bleed both into the brain itself as well as into the subarachnoid space around the brain,” Dr. Kasner said. “So those patients have intracerebral hemorrhages as well as subarachnoid hemorrhages.”

**Symptoms**

Typically AVMs cause no symptoms before they rupture or leak, although some people have seizures before or instead of having hemorrhages. Increased blood flow around the AVM may also cause headaches. However, unless they have a stroke, people with AVMs may never know they have one. It’s estimated that about one in 200–500 people may have an AVM, and they are more common in men. The age range for a problem to arise is typically 15 to 40.
About 10 to 15 percent of AVM bleeds result in death. The chance of permanent brain injury is 20 to 30 percent. Unless they are removed or closed off, there is always a risk that they will bleed, and each time blood leaks into the brain, normal brain tissue is damaged. This results in loss of normal function, which may be temporary or permanent.

Diagnosis

AVMs are diagnosed through some form of angiography (blood vessel imaging), though large ones are visible with MRI or CT scans. “In general, they are hard to diagnose in any kind of preemptive fashion just because they don’t have symptoms,” Dr. Kasner said. In other words, it’s unlikely that a person would go to the doctor and ask to be checked for AVM.

Genes, Environment or Other Causes?

Although they are present at birth, AVMs don’t seem to be inherited. “There’s some developmental component, which may in part be environmental,” Dr. Kasner said.

Treatment and Recurrence

There are several treatment options depending on the AVM’s size and location. AVMs do need to be removed or neutralized. As long as they remain there is danger they will hemorrhage.

• **Surgery.** If an AVM has bled or is in an area that can be easily operated on, surgical removal is a good option. When the AVM is completely taken out, the possibility of any further bleeding should be eliminated. Depending on the complexity of the tangle of blood vessels, the surgery may be very intricate. “This is a cluster of abnormal blood vessels, and unless you get a 100 percent of it, people can essentially recruit new blood vessels to connect to it,” Dr. Kasner said. “That means the AVM can come back if not completely eliminated, so patients need to be monitored closely even after treatment.”

• **Stereotactic radiosurgery.** An AVM in an area that’s difficult to reach by regular surgery may be treated with stereotactic radiosurgery, which is a form of radiation therapy that focuses high-power energy on the cluster of blood vessels to damage them. Despite its name, it is a treatment, not a surgical procedure, so no incisions are made. The goal is to make a scar that will cause the AVM to “clot off” so blood no longer flows through it.

• **Interventional neuroradiology/endovascular neurosurgery.** Another option is to treat part or all of the AVM by inserting a catheter inside the arteries that supply blood to it. Then the abnormal vessels are blocked off with various materials such as special glues, micro coils and other materials used to stop blood flowing to the AVM.

“If they’re successfully treated, the risk of recurrence should be fairly low, but it’s sometimes hard to treat them completely,” Dr. Kasner said.

If untreated, the chance of an AVM bleeding is 1 to 3 percent per year, which means over 15 years, the total chance of an AVM bleeding into the brain is 25 percent. Because of this increasing risk, it is unwise to leave an AVM alone once it has bled.

CAVERNOUS ANGIOMA (CA)

A cavernous angioma is a cluster of small, abnormally formed blood vessels in the brain that are enlarged and irregular in structure. These blood vessels have very thin walls and lack the elastic fibers present in larger vessels. As a result, these blood vessels are prone to leakage, which can cause hemorrhagic strokes. “They can present in a similar fashion to AVMs with headache and hemorrhagic stroke, but they tend to be smaller and more localized and are generally much less dangerous than AVMs,” Dr. Kasner said.

CA may occur in the brain, brain stem or spinal cord.

Symptoms

Typically they don’t bleed into the space between the brain and skull. Bleeding may cause any stroke symptom, including weakness, numbness or double vision. Other symptoms may include headaches, seizures, and hearing or vision loss. They rarely cause a large, life-threatening hemorrhage. About a quarter of people with CA never have any symptoms related to them.

Diagnosis

They are diagnosed by MRI, where the collection of vessels, which are described as looking like a mulberry or a piece of popcorn, is typically surrounded by a dark ring of old blood from previous leaks. CA lesions are not visible on typical angiograms. The location and number of mulberry-looking lesions determine the severity of this disorder. The malformations can change in size and number over time.

Genes, Environment or Other Causes?

There are two forms of CA — familial and sporadic. The familial form is passed from parent to child, and people with this form typically have multiple lesions. Those with the sporadic form have no family history of the disorder and usually have only one malformation. In the familial form, an
affected person inherits the mutation from one affected parent. Most people with CA have the sporadic form.

**Treatment and Recurrence**

Surgery to remove the lesion is the preferred treatment for CAs that are leaking and accessible. Surgical removal eliminates the risk of future bleeding. Because CAs are not visible on an angiogram, any type of surgery using catheters is not possible. At this time, it is not known whether stereotactic radiosurgery (described above as a treatment for AVM) may be helpful in treating some deep or inaccessible lesions.

For more information about cavernous angiomas, contact the Angioma Alliance, angiomaalliance.org or 866-432-5226.

Considering that our brains contain 100,000 miles of blood vessels, which carry 20-25 percent of the blood in our bodies, it is not too surprising that there are multiple ways people can have strokes. Perhaps the best any of us can do is make prevention a habit, whether or not we have the genes, gender or race that increases risk. Here are tips for lowering your risk of stroke:

- Control your blood pressure because there are no good outcomes from high blood pressure.
- If you smoke, stop — it doesn’t do one good thing for you … and many bad things.
- If you have diabetes, treat it. If you don’t know whether you have it, find out because diabetes increases your risk of stroke and heart disease.
- Find out if you have a heart rhythm disorder — it is a leading cause of stroke.
- Every human body has some level of atherosclerosis (even babies!) so have your cholesterol checked and control it if needed.
- Reduce your stress. Every day do something you enjoy.
- Commit to eating better — less sodium, less added sugar, less fat, fewer calories, more fruits and vegetables.
- Get active — 150 minutes of moderate intensity aerobic activity per week is recommended, but whatever your body allows you to do, do it — some physical activity is always better than none.
- Maintain a healthy weight.

**ISCHEMIC STROKE**

accounts for about 80 percent of all strokes. The most common causes of ischemic stroke are heart problems such as atrial fibrillation and hardening of the arteries (atherosclerosis), where clots form in the heart or arteries and then block blood flow to the brain. “A third important cause is small vessel disease, which occurs when the microscopic blood vessels of the brain narrow and close off, typically because of high blood pressure,” Dr. Kasner said. “Those three account for the majority of the known causes of ischemic stroke.”

The primary cause of bleeding strokes is chronic damage to blood vessels from high blood pressure that causes them to rupture. In older patients, typically over 70, another major cause is cerebral amyloid angiopathy. “In this condition the blood vessels walls have deposits of an amyloid protein that makes them brittle and prone to bleeding, even without high blood pressure,” Dr. Kasner said.

High blood pressure increases the risk of stroke — 77 percent of Americans treated for a first stroke have blood pressure over 140/90.

Those causes account for approximately three-quarters of all strokes. Of the remainder, most are categorized as “cryptogenic strokes.” This means the patient had a stroke, but the cause was never determined. Sometimes this is the result of the patient receiving a limited evaluation, possibly because the hospital lacked the proper equipment. Other times, a thorough examination doesn’t give doctors enough information to determine the cause.

“Five percent of all strokes are due to the ‘other determined causes,’” Dr. Kasner said. “In younger stroke patients, the ‘other determined causes’ account for about 25 percent of all strokes.”

**e-ZINE BONUS:** Click for a more comprehensive list of uncommon causes of stroke and an update on fibromuscular dysplasia.
Over the years, we have published many stories about survivors who have had strokes caused by dissections, AVMs and cavernous angiomas. Here are updates to a few of those stories. For even more stories, visit StrokeAssociation.org/uncommonsurvivors.

**Sarah Teague**

Sarah Teague of Churubusco, Indiana was 29 when she had an arterial dissection in 2008 as the result of a chiropractic adjustment. Married 10 years, she was the mother of then 6-year-old twin sons. Her stroke left her with vision problems, left-side numbness and central pain. The dizziness and vision problems made it impossible for her to play with her sons, and the nerve pain took a daily toll.

When we talked with her recently, she was still dealing with those issues, taking a daily aspirin and checking in with her neurologist once a year. Although she takes pain medication, she says the best solution to the pain is to stay busy and distracted. “Being young (she is 35) and looking fine on the outside, people tend to forget what you’ve been through and what you’re going through,” she said. “But we’ve all adjusted. This is the new normal.”

**Elizabeth Ludwick**

Elizabeth Ludwick of Valencia, Cal. was a 36-year-old wife and new mother when she started having dizzy spells and vision problems. At first she thought they were related to having a new baby and not getting enough sleep. “But the dizzy spells and vision problems persisted after I got enough sleep,” she said. She went to several doctors, who all pronounced her healthy. “One doctor told me it was all in my head, and he was right, sort of,” she wrote in our January/February 2012 issue.

An MRI six months after giving birth revealed a 2 centimeter cavernous angioma deep in the right side of her brain. “They said I better never need surgery because the CA was very difficult to reach,” she wrote. “They also said watching and waiting was the only thing we could do, since surgery was the only treatment for CA.” She watched and waited for 18 months, during which the CA doubled in size. She decided watching and waiting was a bad gamble and opted for surgery. During surgery, she had a stroke and was paralyzed on her left side. “My family was devastated, but I...
felt it was only temporary, and it was for the most part,” she wrote. She met and exceeded her therapy goals and started a blog (thankfulforeveryday.blogspot.com) to help others dealing with this situation.

When we contacted her for an update, she had big news: “I was medically cleared for another pregnancy and am due to have our second baby any day, almost exactly three years from my surgery/stroke. Although I am not 100 percent recovered, I am thankful for how much I have improved. Surgery still is the only treatment for CA, although there are plans to begin clinical trials for possible medications that could prevent bleeds.”

Gary Drach of San Carlos, Cal. knew from age 13 that he had an AVM but didn’t tell even his closest friends for fear of how they might respond. “My logic was that I was living on borrowed time,” he said in a May/June 2010 article. “After all, I was only 13. I planned to live into my 30s.”

Then in 2000, at age 47, he woke up with a terrible headache. “I knew I was in trouble when my speech slurred and my right arm went numb.” At the ER, he heard his wife Peggy, a nurse, tell the staff that he was having a stroke. That night the doctors told her to prepare for the worst. Over the next few months, he had two surgeries to cauterize the AVM and a third to remove it, followed by two months in the hospital and five years of rehab. “I had a three-word vocabulary — yes, no and ’peekles.’” Over 18 months, he learned to walk again with an AFO, regained his driver’s license and got some speech back. In August 2009, he got a service dog named Donald, and his self-confidence improved to the point that he began volunteering in the rehab unit at the hospital where he had once been a patient.

When we contacted him in December for an update, he and Peggy had recently spent three weeks in Paris: “A flat city, my walking paradise, and the people are very courteous, or do you think the cane had something to do with it? I left Donald at home, but I will take him when I return. We’ve made several road trips and flew with Donald to Seattle — he’s a natural! Unfortunately, the rehab hospital where I volunteered has closed. In the past 13 years I have learned to cook. Peggy is thrilled to come home from work and find the wash is handled, the dogs are brushed and walked, grocery shopping is done, and dinner is ready.”

**GARY DRACH**

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My Unforgettable Day

By Kara Kellerman
Family Member | Pinckneyville, Ill.

In July 1993 I was ten years old and my mom, Cora, was 51. I’m her only child, and we are very close. Back then, we were each other’s world. It was a hot summer, and the TV news covered the flooding going on just west of us. We lived out of town and I spent most days outside riding my motor scooter, climbing trees or swimming in our small pool. I was quite the tomboy, only coming inside to eat meals and then rushing back outside.

My friend Abby lived down the road, and we spent most summers back and forth at each other’s houses. This day was no different. Abby was over, and we were outside soaking up the sun. Mom said she was going to pick berries. There was a small patch along one of the fields by our house, and she would make pie or other tasty desserts with them. She donned her straw hat and out the door she went in her summer shirt with a cold cloth draped around her neck.

She came back about an hour later sweating and pale. She said, “Girls I’m not feeling real well. I’m going to get a drink and lay down to take a nap. Abby’s mom will need to come pick her up later.” “OK,” we said and were out again. My elderly grandmother also lived with us and kept an eye on us as we continued to play. Abby’s mom came to get her several hours later, and my mom still slept. This was strange, but I was ten and didn’t think about it for long.
It was early evening when Mom finally got up, but something was different. She said her arm felt funny, like it was tingling. She said her head hurt but she thought she had just overdone it outside in the sun. We were off to bed early that night, but when we awoke the next morning, something was definitely wrong. The whole right side of my mom’s face drooped and she could barely talk. Her right arm wasn’t just tingling, it was numb! She couldn’t even use it. I got on the phone and called my Aunt Judy who lived close by. She came to the house, helped Mom to the car and away they went to the hospital.

A feeling of fear settled in my stomach. The fear of the unknown is the worst fear of all. Was my mother okay? When would she be home? It seemed like days went by, but in a few hours my aunt called from the hospital to let us know that my mom was headed to St. Louis in an ambulance. She had had a stroke and needed special care at a bigger hospital.

Stroke? What did that mean? I was with my grandmother and told my aunt I was okay, but inside, I was shaken. St. Louis seemed so far away. My father had taken me there a couple times, and I knew it was big. All I wanted was to be with my mom in St. Louis, but my grandmother did not drive anymore.

Mom was completely paralyzed on her right side. She was unable to communicate her basic needs to medical personnel or let them know if she had pain. When she arrived at the hospital in St. Louis, she was by herself, doctors and nurses talking to her rapidly, and Mom unable to say “yes” or “no.” She was at a teaching hospital with the best equipment and newest advances in technology related to stroke. Crowds of interns stood around staring at her. She said later that was the most uncomfortable feeling she had ever experienced.

Her body was now foreign to her. It was like a broken piece of machinery that she had no clue how to operate. In addition to her health issues, she was also worrying about her young child at home.

The next day, I woke up and tried to call my aunt, but the phone was out. Panic stricken, I cried. Pulling myself together, I hashed out a plan: I would ride my motor scooter to someone’s house and use their phone. I had never ridden on the road before. In fact, I remembered my father telling me that it was not licensed and the police would arrest me if I did. What choice did I have? I had to get to a phone, so off I went. No luck at the first two or three houses. My cousin Vivian lived down the road several miles. It didn’t seem far away in a car, so how bad could it be?

When I arrived, she was shocked and wondered where my mom was. I didn’t understand the problem. I explained what was going on, and we made several calls — to get the phone fixed, notify my dad who was out of town working and to check on my mom. I know why my family cringes at this now, but at the time it was what I felt I had to do.

My dad came home the next day, and we went to see Mom in St. Louis. Her speech returned in a few days. However, her coordination and ability to walk did not return as easily. My mother insisted to her doctors and nurses that she wanted to get back across the river to the Illinois side when they started her therapy. She would say, “Those bridges make me nervous and the flood waters are rising. I want to be on the same side of the Mississippi River as my little girl.”
For the next two months, I spent countless hours travelling with my dad or aunts to the hospital where she had physical, occupational and speech therapy. I was by her side every step of the way. I watched everything and soaked it in. Our lives had changed but we were all adjusting to the new roles. My mom was no longer taking care of me — I was taking care of her.

When she came home, a home health agency followed her, and I continued to observe her recovery. She had more meds to take, including a shot for her diabetes instead of the pill she took before. A short year later, I would learn from those nurses how to fill my mother’s insulin syringes and keep her medicine list up to date.

My life was different than other kids, but I feel I still got to be a kid. I just had more responsibilities. I disliked what had happened to my mom, but it made us stronger people. It makes you realize what is important in life. It is also where I got my first taste of the medical profession. A friend once told me that I was nursing long before I became a professional nurse.

After graduating high school, I attended a class to become a certified nurse’s assistant and started working at the local hospital. I also enrolled in a local junior college to attend nursing school. Of course, my mom was there with me, supporting me every step of the way. She was also there at my pinning when I graduated with my associate’s degree in nursing.

Twenty years have passed since that fateful day. I have been a nurse for 11 years, ten as a Registered Nurse. I have two children of my own and know how important staying healthy is so that I may be in their lives for a long time.

In 2009, my mother had another stroke. This one was much larger, with more debilitating consequences. This time when she went to St. Louis, I went with her. I was with her every step of the way, directing her care and making sure she received the best of the best.

She was unable to regain her independence after the second stroke and is now in a nursing home. She is content there, and they continue exercises to maintain her strength. My children and I visit every week. Most importantly, my children still have their grandmother, and the smile on her face is more than worth the drive to visit.

That single day in July forever changed the course of my mom’s life and my own. It shaped my life by introducing me to what my career would be. Not everyone finds their calling at ten years old.

Stroke can have destructive effects, and as a family, we still struggle sometimes with the dark side, questioning why it happened to us. But we are resilient and keep pushing forward, staying strong. The dark side turns to light for those who continue to strive for the goodness in life! Just like the bright sun on a hot July day.

Editor’s Note: Just as we are going to press, we’ve learned that Cora has passed away. We thank Kara for her willingness to share her story and send our condolences to her family.
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That is what Rosanna Radding’s neurologist told her three months after a stroke left her unable to use her left side.

“We were devastated. My partner Carol and I both cried. Until then, we had never thought about me not being able to do more. We never even let it enter our heads,” Rosanna remembered.

At that point, Rosanna was not walking well and felt unstable in her gait. She couldn’t do anything with her left hand and couldn’t raise her left arm. She was dealing with severe left neglect, a common post-stroke condition for those with right-brain injury in which the use and awareness of the left side of the body is limited or absent.

New Year’s Eve 1994, at age 43, Rosanna experienced a TIA. Out of the blue, the entire left side of her body felt very heavy, and her speech became slurred. Her symptoms resolved before paramedics arrived, but she was taken to the ER anyway and sent home shortly after. A few hours later, two minutes after midnight on January 1, 1995, she suffered a full-blown stroke that left her unable to move her left side.

Though she had made some progress three months later, Rosanna couldn’t accept the neurologist’s statement that she would never progress beyond where she was then. “Being the eternal optimist, I always kept the thought in my head that I would regain everything I had lost,” she said. “But I was scared and struggled with not being able to do the things I had always been able to do before the stroke, even the simplest of things like tying my shoes, buttoning a blouse or zipping up my jeans.”

So Rosanna started adapting and inventing things right away.

As an artist, Rosanna had always been innovative. When artists want to create something, they figure out ways to make their visions come to life, and Rosanna’s artistic training carried over into her new life.

It was Rosanna’s occupational therapist who first noticed her inventive approach to recovery. Thinking that Rosanna’s innovations could assist others, she told her about the Rehabilitation Engineering and Technology (RET) Certificate Program through San Francisco State University, which trains graduate students to design tools that help people with disabilities gain more independence, get jobs and enjoy recreational activities. Going back to school was a daunting prospect for Rosanna. “I didn’t even know if my brain worked well enough for it,” she recalled. “But I was willing to test it.”

Luckily her brain did work. Rosanna went on to earn her RET Certificate and develop the One Hand CanDo Cutting...
Board, a patent-pending chopping board designed specifically for one-handed use (onehandcan.com/cando-cutting-board). The CanDo Board cleverly uses a combination of prongs and bands to assist the one-handed chef in chopping, dicing and grating. Rosanna regularly conducts one-handed cooking demonstrations, teaching participants how to chop onions, grate cheese and prep garlic, along with other adaptations. She calls herself a motivational cook.

Her inventions don’t stop in the kitchen though. She also sculpts stone and creates custom jewelry. She has adapted her art tools, like her chisel, for one-handed use and has created a system for casting intricate wax jewelry models for gold and silver with only one hand.

Today, Rosanna walks well with a supportive foot brace. She still has trouble with her left arm, but she can raise it to shoulder height and use it for gross motor activities like carrying laundry or securing vegetables on her chopping board. She can hold things with her left thumb — all a far cry from what she was told she would ever be able to do.

Already a sought-after speaker, inventor and designer, Rosanna also maintains a website and video series called “One Hand Can” where she talks about post-stroke issues and offers solutions to one-handed people trying to “re-able” their lives in a two-handed world. Beginning this issue, readers can also find Rosanna’s inventive advice in Stroke Connection, as she pens a regular tips column about one-handed living.

She recognizes that many survivors feel daunted by the idea of adapting their lives, especially if they aren’t inherently creative. “It’s really not about creativity,” she said. “I believe anybody can do whatever they want as long as they are willing to engage their self-love, ingenuity, patience and perseverance. Creativity is secondary.” She also encourages survivors to utilize their network and ask for ideas from other people, including her, if they can’t figure out how to get something done.

Even with the growing popularity of her chopping board and cooking demonstrations, Rosanna doesn’t want to be known only for innovative cooking tips. Still, she maintains that cooking is the single most important form of rehab for a survivor because it helps regain independence, builds confidence and teaches skills that translate to other areas of life. It also strengthens the ability to think through steps, especially if, like Rosanna, one’s deductive reasoning was affected.

Rosanna gets excited as she describes a survivor who contacted her after buying her CanDo board. “He emailed saying that he didn’t think he could do anything. But now he’s having a blast. He can cook meals for his wife and son.”

She says that her inventions change her life because they’re changing other people’s lives.

And that’s something she can get used to.
Post-stroke 101, welcome to my world.

That is exactly how I felt on January 20, 1995, the day I was released from the rehab hospital after suffering a life-altering stroke. I had suddenly, and without perceptible warning, become a stranger in the strange land that my body had become in an instant three weeks before. Friday I had gone to work. Sunday, two minutes after the New Year, I was on my way to the hospital with an obvious diagnosis — stroke.

That first day home, I became immediately — and frustratingly — aware that there were many things that no one had told me about living life one-handed in a two-handed world. Granted, if you haven’t lived it, it’s nearly impossible to fully comprehend the challenges one faces on a daily basis. So, providing a survivor who has the use of only one hand workable solutions for all the challenges we are likely to encounter, before the fact, is nearly impossible. Then, of course, there are the more personal issues one may not be comfortable asking about. I’m a bit on the shy side and had difficulty asking and then discussing with my occupational therapist how to put a bra on. Okay, that turned out to be a fairly easy one — put it on over your head.

What I’m leading up to here as my first one-handed tip is at once simple and complicated, the sort of question one may not think or wish to put to an OT. Here was my challenge: when bathing, how to wash under my “good” arm considering I cannot use my affected arm and hand?

This is how I solved the problem, and I hope it allows one less embarrassing question to be asked by some shy survivor.

TWO SOLUTIONS

My first solution is to get a small, clean spray bottle. They are easy to find in the cosmetics, hair or travel accessory sections at drugstores and grocery stores. Rinse the bottle and fill it with anti-bacterial liquid soap. The soap needs to be less “creamy” and more the consistency of water. I use Hibiclens®, but there are others. When I’m in the shower, I hold the bottle in my good hand, reaching over the top of the bottle, so my thumb is in position to operate the trigger; I raise my arm slightly, aim the nozzle under my arm and spray. I let the liquid remain a couple of minutes and then rinse thoroughly.

Here is an alternate approach: Take a washcloth into the shower with you. Get it all wet and soapy. Hold it in with your functional hand. Raise your arm slightly and, while keeping a firm grip on the end of the washcloth, fling the loose end under your arm and capture it there by quickly lowering your arm. This may take some practice, but once captured, gently pull the washcloth out from under your arm. Repeat several times and rinse thoroughly.

There you have it. A bit personal and, I hope, helpful.

Practical and Innovative Tips for Post-Stroke Living

By Survivor Rosanna Radding

Grass Valley, Cal.

onehandcan.com

To wash under her unaffected arm, Rosanna uses a spray bottle filled with liquid soap, holding it on top and using her thumb to operate the trigger.

e-ZINE BONUS: Click for more tips on bathing, or visit our Tips for Daily Living Library at StrokeAssociation.org/tips and check out survivor Tia Thompson’s video tips for getting in and out of the shower. You can submit your own video, audio or text file to the tips library while you’re there!
When my cousin’s wedding invitation arrived I thought, “Fantastic! A chance to finally wear one of my Ermenegildo Zegna suits hanging lonely in the closet.” Sure, they were pricey, but definitely worth the splurge.

Why? Well, for sheer panache the Italians have it covered. Their unrivaled workmanship and style create a kind of understated 60’s cool. (Think Marcello Mastroianni fawning over Anita Ekberg in “La Dolce Vita.”) Any tailor worth his weight in pincushions will tell you this is the orchid of the haberdasher forest. The fit must be “perfetto!” If not, you might as well be wearing one of those tuxedo T-shirts and cargo pants. Take the trousers — there should always be a slight break at the top of the shoe. Too short and you’re Goober at the Mayberry church social. Too long and you’re saggin’ like a homie.

The last time I embraced my Marcello-ness was back during the “Balloon Boy” hoax of ’09. While I’m sure my waistline is still a svelte 31”, my wife (Miss Positive) reminds me of those bourbon balls I wolfed down during the holidays. Marilyn’s convinced my threads are going to fit me like an Italian sausage casing. One wrong move and the whole thing explodes like I’m a human party favor blowing worsted wool confetti all over the place. She starts quoting Burgess Meredith’s character from the first “Rocky.” “You don’t wanna be a tomato, do ya? So you better start breathin’ lightnin’ buddy, and doin’ some sit-ups.”

These suits are a lot more convoluted than my stroke-friendly wardrobe of crew-necks, polos and jeans. So Marilyn has to help me get dressed, which is more Mommy-putting-on-my-snow-pants than Marcello-chic. Back in Kindergarten I pretended I was a knight with my squire suiting me up in my armor preparing for a joust, but at 63 a fantasy like that can land you in the rubber room.

Fortunately, this is a wedding and not a funeral, so there’s time for our own dress rehearsal where we can split up the duties and go over the playbook. Right off the bat, I pick out a suit. Navy. Boom! Decision made. Shirt and tie? Not so easy. As soon as I zero in on one combo I end up liking another. Apparently the CVA has left me with major DD (decision disorder). It’s as if I’m my 13-year-old self trying to choose between Brigitte Bardot and Sophia Loren (a conundrum that still stumps me). Finally, I reach a solution. I turn to Marilyn and say, “You choose.” And she does.

Slipping into the shirt, I immediately have a problem dealing with those Tic Tac size buttons, which make me feel like I’m performing one-handed laparoscopic surgery on a gnat. Next Marilyn hoists up the pants and holds them waist high like it’s a hula hoop. This way I can tuck my shirt in. Then I suck it up, she hooks, buttons and I’m in.

Lastly, the accessory that can make or break the whole look, as well as our marriage: the necktie. There’s nothing more exasperating than trying to teach someone else to tie a tie around your own neck backwards when you can’t remember how to do it yourself. It begins with kind, cooing, patient/caregiver speak: “OK honey, atta girl, through the loop and…Ooopsie! Just a teensy bit too long.” Soon we’re slinging blood-curdling rants at each other a la George and Martha in “Who’s Afraid of Virginia Wolfe.” PG excerpt: “NO, NO! HOLD it. THEN loop it… That’s NOT what you said!... DON’T TIGHTEN IT NOW!... YOU TOLD me to!...”

Somehow out of this bubbling cauldron a knot magically appears. I slide into the jacket, look in the mirror and there it is. That 60’s cool. Satisfied, we break open a bottle of Valpolicella, and as we toast to our success, the stroke slips away. Well worth the effort.

LA FINE

Choosing a shirt and tie is like choosing between Brigitte Bardot and Sophia Loren.

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e-ZINE BONUS: Click to see a video clip from Brain Freeze.
Could you have symptoms of spasticity?

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