Emotions, Behavior and Sociality: Then & Now
20 years of changes in science & society

Aging with Stroke
It may complicate the process

Rx for Caregivers
Personal reflections on the realities of daily caring

Life at the Curb
Isn’t It a Pity

The Initial Shock
A Caregiver Perspective
Guidance for caregivers at the beginning of a loved one’s recovery

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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.
Alternative therapies such as aerobic exercise, resistance or strength training, and isometric hand grip exercises may help reduce your blood pressure, according to the American Heart Association. In a new scientific statement published in its journal *Hypertension*, the association said alternative approaches could help people with blood pressure levels higher than 120/80 mm Hg and those who can’t tolerate – or don’t respond well to – standard medications.

However, alternative therapies shouldn’t replace proven methods to lower blood pressure – including physical activity, managing weight, not smoking or drinking excessive alcohol, eating a low-sodium, balanced diet and taking prescribed medications.

An expert panel assessed three alternative remedy categories: exercise regimens; behavioral therapies such as meditation; and non-invasive procedures or devices including acupuncture and device-guided slow breathing. The panel did not review dietary and herbal treatments.

“There aren’t many large, well-designed studies lasting longer than a few weeks looking at alternative therapies, yet patients have a lot of questions about their value,” said Robert D. Brook, M.D., chair of the panel and an associate professor of medicine at the University of Michigan in Ann Arbor. “A common request from patients is, ‘I don’t like to take medications, what can I do to lower my blood pressure?’ We wanted to provide some direction.’”

The panel found:

- All three types of exercise reduced blood pressure. Walking programs provided modest benefit while, somewhat surprisingly, four weeks of isometric hand-grip exercises resulted in some of the most impressive improvements – a 10-percent drop in systolic and diastolic blood pressure. However, isometric exercise should be avoided among people with severely uncontrolled high blood pressure (180/110 mm Hg or higher).

- Behavioral therapies such as biofeedback and transcendental meditation may help lower blood pressure by a small amount.

- Strong clinical evidence is lacking to recommend yoga and other relaxation techniques for reducing blood pressure.

- There isn’t enough evidence to recommend acupuncture for lowering blood pressure. However, device-guided slow breathing did prove effective in lowering blood pressure when performed for 15-minute sessions three to four times a week.

“Most alternative approaches reduce systolic blood pressure by only 2-10 mm Hg; whereas standard doses of a blood pressure-lowering drug reduce systolic blood pressure by about 10-15 mm Hg,” Brook said. “So, alternative approaches can be added to a treatment regimen after patients discuss their goals with their doctors.”
Chronic or persistent pain is a common — and under-recognized — complication of ischemic strokes according to new research in *Stroke*. In a large trial of treatments to prevent a second stroke, researchers found that 10.6 percent of more than 15,000 stroke survivors developed chronic pain.

“Chronic pain syndromes are common, even following strokes of mild to moderate severity,” said Martin J. O’Donnell, M.D., lead author and professor of translational medicine at the National University of Ireland and associate clinical professor at McMaster University in Canada. “It is associated with greater decline in physical and cognitive function, making it an important medical complication after stroke.”

Researchers examined data on 15,754 people who had survived mild to moderate strokes and were followed for an average 30 months in PRoFESS (Prevention Regimen for Effectively Avoiding Second Strokes), the largest study to determine the prevalence of chronic pain after ischemic stroke.

Of the 1,665 stroke survivors reporting chronic pain beginning after their stroke:

- 25.8 percent were classified as having central pain, which can present as touch, temperature or other sensations being perceived as pain.
- 14 percent had peripheral neuropathic pain, a tingling, burning or shooting pain due to damage to nerves outside the brain and spinal cord.
- 12.4 percent reported pain from spasticity.
- 8 percent experienced shoulder pain caused by stroke-related weakness or spasticity.
- 5 percent said they had more than one type of pain.
- 44.3 percent had unclassified pain syndromes.

Significant risk factors for post-stroke pain included increased severity of stroke; female gender; greater alcohol intake; recent symptoms of depression; diabetes and vascular disease of blood vessels supplying the lower limbs.

Patients who developed post-stroke chronic pain were more than twice as likely to become more dependent during the follow-up period compared with those whose recovery wasn’t complicated by pain. Patients with non-central causes of pain were more likely to experience cognitive decline.

Start this fall, millions of uninsured Americans, including more than seven million people with heart disease or stroke, will have new health insurance options. On Oct. 1, Health Insurance Marketplaces will open in every state plus the District of Columbia. These marketplaces will provide a single location where individuals and small businesses can shop for private health insurance that fits their budget. People with pre-existing medical conditions cannot be turned down or charged higher premiums because of their condition. Financial assistance will be available to most people who are currently uninsured to help make the premiums affordable.

Open enrollment for the new Health Insurance Marketplace is scheduled to end March 31, 2014. Depending on when you apply, your coverage will start as soon as January 1, 2014, or within six weeks.

If you or someone you know needs health insurance, contact the Health Insurance Marketplace to apply or to learn more:

- Online: Healthcare.gov
- By Phone: 1-800-318-2596
- In Person: There may be counselors in your area who can help you apply. Visit Healthcare.gov or call 1-800-318-2596 for more information.
- En Español: Llame a nuestro centro de ayuda gratis al 1-800-318-2596.
Anyone who knows me will tell you that I thrive on challenges, hard work and stress. These three items have served as the secret combination for personal satisfaction for most of my 33 years. The first few months of 2012 were no different. I was steering my business to its most successful quarter ever. I was writing extensively for a local magazine. I served on a nonprofit board, and I was an active member of my local Rotary Club. In my mind, happiness was largely tied to the successful completion of activities that furthered my career, increased my network and forged new professional opportunities.

Everything changed in the evening hours of April 20, 2012. I had just finished dinner when I felt a strange pain deep inside the back of my head. It was a sudden yet subtle pain, like a coil springing forth after being wound too tight. After a moment, I realized my ability to move my right side had been compromised. Suddenly, I remembered the commercials I had seen about the signs of stroke. The urgency of my situation sank in, and I rushed to the hospital.

Testing confirmed that a clot had settled in my brain. In the early hours of the following morning, I found myself in the same situation as so many others whose stories have appeared in these pages. I found myself recognizing for the first time that life is remarkably fleeting and inherently valuable. Up until that point, I had lived life haphazardly, as if there were an infinite number of days stretched out before me.

With sunlight just starting to seep through the closed blinds, I realized that the things of value in my life were not the result of all the aforementioned stress. It was not the board meetings, the client calls or the paychecks that occupied my mind in an effort to fuel my recovery. It was the fact that I had been given a gift afforded to far too few people with the same diagnosis. I had been given a second chance.

In addition to being fleeting and valuable, life is intentional in its revelations. As it seems, there are no accidents when it comes to much-needed epiphanies. I had a lot of down time over the next several days, and I spent every second of it building a silent determination that I would overcome this. “If I overcome this,” I promised, “I will change everything.”

Today, I have made good on that promise. I have let go of the misguided ideology that drove me before. Now I focus on what is truly valuable. You see, my partner and I have since welcomed a little girl into our lives, and I intend to spend every minute of my second chance showing her that love, family and personal joy are the greatest gifts given to us. We must be mindful of what is really valuable as we endeavor to be our “greatest self,” and we must recognize that every second of life is truly worth fighting for.

Victoria L. Kidd, Survivor
Winchester, Vir.
Still Skiing

I had my stroke (dissection of right carotid artery) 10 weeks before my 50th birthday – after I had made reservations to treat myself to a helicopter ski trip to Valdez, Alaska. I had been advanced-recreational skiing for several years in the U.S. and foreign countries. I was in very good physical shape, so the stroke was a total surprise. I had none of the risk factors like high blood pressure, cholesterol, overweight, diabetes or family history. I never smoked.

During rehab, my physical therapist told me that I would never ski again because of the balance needed. After the inpatient, outpatient and home rehab (and a lot of work), my balance did return. One year after my stroke, I was skiing again in the Wasatch Mountains in Utah. Alaska helicopter skiing was my 52nd birthday present. I have been skiing several times since the PT told me I would never ski again. I was an above-average skier before, but now I have had to relearn many things. With a positive attitude and hard work, many things can come back. My left side is still weaker on the tight slalom turns. Skiing might be all downhill but you have to go up first, either by helicopter or chair lift. Same for many things!

Unfortunately not everything comes back post-stroke. For me, it was fine motor skills of my left hand. I still can’t do shirt buttons or neck ties. Fortunately, you don’t need either of these on a ski slope.

Doug Penny, Survivor
Raleigh, N.C.
It’s safe to say that for most families, stroke is a life-changing event. Although some patients make a complete recovery, most survivors have some kind of lasting physical, cognitive, emotional or communication deficit. Not that many years ago, there were few treatment options for these losses. Yet in this final installment of our “Then & Now” series, we’re looking at the advances in emotional and behavioral treatments.

**Post-Stroke Depression**

An example of how things have changed is the approach toward depression. It wasn’t always recognized as a debilitating condition that derails recovery. It was often dismissed by families (and some professionals) as the “understandable” consequence of the losses the stroke caused. Now research studies indicate 30 to 50 percent of survivors develop depression after a stroke, prompting doctors and therapists to be more proactive in treating post-stroke depression.

“Research and clinical experience shows that there is a strong relationship between stroke and depression,” said neuropsychologist William Garmoe, PhD, ABPP-CN, of the National Rehabilitation Hospital in Washington, D.C. “This may be the direct effect of the neurologic and biochemical changes in the brain. It may also be the result of psychosocial changes, such as changes in physical and cognitive functioning, loss of one’s typical role in daily life, inability to work, or changes in relationships and sexual ability, among others. These may be experienced as losses that contribute to depression and demoralization.”

When a stroke survivor is diagnosed with depression, rehabilitation typically stops until the depression is treated — which is a big change over treatment in the past. The good news is that post-stroke depression is very treatable. “Post-stroke depression responds very well to standard therapies used for any depression, such as fluoxetine, citalopram, venlafaxine, amitryptilene and sertaline,” said physiatrist Brendan Conroy, M.D., also of the National Rehabilitation Hospital. “Psychological counseling, or ‘talk therapy,’ is considered to be a mainstay of the treatment of this and most forms of depression.”

**Pseudo-bulbar Affect**

While not as common as post-stroke depression, pseudo-bulbar affect (PBA) can significantly affect survivors. The hallmark of this deficit is crying or laughter that is out of proportion or inappropriate to the stimulus — such as laughing at funeral or crying at a joke. Also known as reflex crying...
or emotional liability, the condition makes social interaction unpredictable and difficult.

For years, there was little that doctors and therapists could do for this condition. With the advent of anti-depressants, PBA was sometimes treated with tricyclics or selective serotonin reuptake inhibitors like fluoxetine. These were only moderately effective. (See “A Social Disability,” January/February 2012.) “Additionally, there are behavioral strategies that a survivor can use to help shift what he or she is focusing on to a less emotional topic,” Dr. Garmoe said. “That may help quickly ‘turn-off’ the emotional expression.”

In 2007, when we addressed PBA (then called “involuntary emotional expression disorder”), we talked about a new drug then in development. (See “Living with Emotional Thunderstorms,” May/June 2007.) In January 2011, the FDA approved that drug, which is called Nuedexta™ (dextromethorphan quinidine), specifically for PBA. Analyzing data across studies, it appears to be faster acting than the anti-depressants, with few side effects.

Support Groups — Getting & Giving

In the past, survivors often received a kind of “cultural pass” from society. The prevailing belief seemed to be that survivors couldn’t produce results anymore. One way to combat this has long been through stroke support groups.

Over and over we hear from survivors and caregivers that recovery really began when they joined a stroke support group. That’s likely because survivors can be challenged in increments in that environment. It’s one reason we have advocated for stroke support groups since the beginning of Stroke Connection.

Scientific studies have validated the importance of social support in stroke recovery. Social interaction and simply feeling connected to others helps ease the depression and isolation so common after stroke. Stroke groups challenge survivors to get beyond their doctor-imposed, therapist-imposed, family-imposed and self-imposed limitations. They also give caregivers a venue to connect with other caregivers, to validate their feelings and get advice and strategies from others who have walked the path they are now on. “Sometimes you get the answer you need,” a survivor once told us. “Sometimes you have the answer someone else needs. Either way, it’s a blessing.”

It seems to be true that attitude plays a major role in emotional and physical healing. One of the greatest benefits of a stroke support group is the chance to be around people with great attitudes. Survivors often find the can-do attitude of an effective stroke group to be infectious.

Social interaction and simply feeling connected to others helps ease the depression and isolation so common after stroke.

Some of the benefit from attending support group gatherings is the simple act of getting people out of their homes. Stroke families get to see different faces and hear different voices, a perfect antidote to watching TV. Of course, for some survivors, getting out is a problem. Fortunately, Internet support groups, which have arisen in the past 20 years, offer many of the benefits of emotional support and information-swapping that regular groups offer. Find a stroke support group near you by visiting strokeassociation.org/strokegroups.

All in all, stroke is still a life-changing experience, but there are ways to deal with it in 2013 that weren’t there in 1993. Depression and PBA are treatable, and support groups offer a valuable resource for recovery in-person or on the Internet.

The past two decades have produced a wealth of benefits in stroke treatment, prevention, rehabilitation and recovery. With new developments in neuroplasticity, imaging, rehabilitation science and the Internet, the next 20 years hold the promise of more good things to come.

All we want for our birthday is another fabulous 20 years. Your $20 gift helps us be here for stroke families. Thank you for supporting Stroke Connection!
Addressing the Concerns of Long-Term Survivors

Stroke is occurring in younger people: In a recent 10-year period, the rate of strokes in people younger than 55 increased 84 percent among whites and 54 percent among African Americans. Now one in five strokes happens to those 20 to 55 years old. In the 1990s, that statistic was one in eight. Younger survivors mean that people are going to be living with the consequences of stroke for longer periods. We look at the challenges of long-term survival through the eyes of a survivor and a health professional.
At 40 years post-stroke, I’m one of three long-term survivors in my “young stroke support group.” The three of us have been lucky enough to survive so long we might appear to have wandered into the wrong meeting room.

Although our group members range in age from 23 to 65, we all had strokes in young adulthood or midlife. For some group members, their stroke experiences are just a few months back. For the three “elder youths,” our stories are long and winding.

Understandably, group members whose strokes are more recent sometimes ask us how our recovery has progressed over the decades, with questions like:

“Did most of your recovery happen in your first year after your stroke?

Did you see steady improvement over time, or did you sometimes plateau?

How often did you see sudden gains or losses? Did you ever figure out why those sudden shifts occurred?”

When I hear their questions, I flash back to the indescribable shock of being a young stroke survivor forced to learn how unpredictable life could be. I also wonder whether my four decades of wrestling with these issues could still be relevant for today’s young stroke survivors.

My stroke – in 1973 – was so long ago, there were no CAT scans, no stroke wings in hospitals, no survivor support groups, no public education campaigns about TIA or tPA. Post-hospital re-entry into your pre-stroke life was a mystery you resigned yourself to coping with on your own.

Driving home from our meetings, I sometimes wonder how I became so alienated from neurological care and why I waited until retirement to join a stroke support group like ours. Two scenes pop up:

- The day I was discharged from inpatient rehab on a single-point cane, confused because 10 days of testing had not identified the cause of my stroke but aware that my deficits were minor compared to those of other patients I was leaving behind.

- An office visit with one of my favorite neurologists when I was just 10 years post-stroke: When I asked him what my neurological future was likely to be, his honest answer was direct but chilling:

“I wish I could give you some likely scenarios for your recovery. But none of my stroke patients have survived as long as you have.”

Given that this was the best information I could get from a highly skilled and compassionate neurologist, I decided there was little neurology could do for me at that time. Once I got back to work, I would simply have to self-manage any additional recovery. I wandered off on what some might consider a “prodigal patient path.”

Socially and in the workplace, I focused on concealing my deficits whenever possible and finding creative ways to accommodate them when I couldn’t. Other than getting treatment for post-stroke depression, I sought medical advice (a neurologist or physical therapist) on just a few occasions over the decades, such as when I worried that sudden changes in my motor skills or severe headaches might mean another stroke or the onset of another neurological condition.

Left to my own hypotheses about a post-stroke healthy lifestyle, I played it very safe. No cigarettes, alcohol or drugs. A low-normal body-mass-index and regular exercise. A diet that shunned salt, fat and sugar. Yoga, Feldenkrais and balance classes. Prozac to prevent recurrences of the major depression that surfaced soon after the stroke. And stress-minimizing lifestyle choices when it came to decisions about driving, jobs and parenting.

Overall, this prodigal stroke patient has lucked out for four decades. There...
If I survive into my 70s, will it be difficult for my healthcare providers to distinguish between problems caused by my “old stroke” and normal aging issues?

have been no recurrences, just complications in my treatment options when I was diagnosed with breast cancer 10 years ago and learned tamoxifen was out of the question for a stroke survivor. And my current bout with “genu recurvatum,” a stiff-knee gait that causes mild knee and hip pain.

But now I’m turning 65 and preparing to see how my “aging trajectory” is going to get along with my “old stroke trajectory.” As I move into my 70s, I wonder how health issues typically associated with aging (such as balance problems, arthritis, memory problems) will affect my ongoing recovery from stroke and the quality of life I’ve struggled to maintain.

Should I continue to see a neurologist only when I’m concerned about what seems to be a new neurological problem or a worsening of my old stroke deficits? Other than the breast cancer treatment issue I’ve already navigated, are there other medical problems for which I should make sure my medical team includes a neurologist? If I survive into my 70s or beyond, will it be difficult for my healthcare providers to distinguish between problems caused by my “old stroke” and normal aging issues … and will it matter if they can’t tell the difference?

This prodigal patient would really like to know if medical science has advanced beyond my former neurologist’s vague prognosis in the early 1980s. Since that time, what have we learned about the experiences of long-term stroke survivors? And how many other long-term survivors are out there struggling to manage their own uncertainties about “aging with stroke?”

**Stroke Connection** suspects there are many, many of your who are struggling with your own uncertainties, with questions similar to Carol’s. There has been no research into the needs of long-term stroke survivors, so we talked with physiatrist Payal Fadia, M.D. about this situation. Dr. Fadia is medical director of post-acute services at Shepherd Center in Atlanta, Ga. Shepherd specializes in treatment, care and rehabilitation of brain and spinal cord injury.

**Stroke Connection:** Some spinal cord injury, multiple sclerosis and traumatic brain injury researchers suggest long-term survivors of these neurological conditions age “faster” than people who have never had those conditions. Is this true for stroke survivors?

**Dr. Fadia:** Stroke itself is not progressive (in other words, once the stroke happens and the injury has occurred, the brain injury usually does not progress, unless someone has another stroke); however, it is often disabling, and can lead to long-term impairments of physical, cognitive and emotional function. Whether survivors have an accelerated rate of aging, may go back to the underlying cause of the stroke, how that is managed, and how they can maintain an active lifestyle afterwards. Most strokes are caused by vascular problems, so someone with circulation or blood pressure problems can have ongoing underlying disease processes that might affect their long-term disability and aging.

**SC:** Will long-term survivors have special medical needs as they age? In other words, are people with a stroke history facing “double jeopardy” as they navigate a stroke and an aging trajectory?

**PF:** There is overlap as far as the medical issues we face with aging and the long-term medical complications for survivors. For survivors, the emphasis needs to be on identifying their stroke risk factors and reducing them to minimize their chances of having another stroke. Normal aging issues can contribute to the existing disability that survivors are already facing.

**SC:** Will they face long-term health problems due to their “old strokes”? Are there symptoms they should watch for? Are there any preventive steps they can take?

**PF:** Stroke survivors are roughly four to five times more likely to have a second stroke than those who haven’t experienced a stroke. Therefore it’s important that risk factors be controlled. Preventive measures may include taking aspirin or other blood thinners, cholesterol-lowering medications, managing high blood pressure and diabetes, smoking cessation, eating a healthy diet and getting regular physical activity. Other long-term complications can include seizures, swallowing...
problems that can lead to aspiration and pneumonia, and bladder incontinence. Musculoskeletal complications may include shoulder pain, spasticity and contractures. It’s important to maintain range of motion of the affected joints and having a sustained stretching program to prevent frozen shoulder and permanent joint stiffness that can affect long-term mobility and functional use. The use of splints and bracing can also help.

Psychosocial issues including depression as well as family coping can be ongoing for years after the acute stroke as patients and their loved ones continue to face the challenges of their loss of function and identity regarding possibly returning to employment and driving. Symptoms of depression to look for can include a lack of appetite, insomnia, and an unexplained decline of functioning.

**SC:** Are long-term survivors at increased risk of other health issues associated with aging (e.g., depression, dementia, osteoarthritis, osteoporosis, falls)?

**PF:** Yes, they may face health concerns associated with aging sooner as the problems they have from their stroke can impact the same issues. Stroke can lead to paralysis and when a survivor is unable to stand or walk and put weight through their joints, they are at risk for osteoporosis sooner than most of the aging population. Combined with decreased balance, that can lead to a higher incidence of falls with subsequent fractures, and often the fractures are what eventually lead to the lack of independence, not the stroke itself.

Loss of function and independence can lead to a decline in mood, adjustment disorder and depression. Cognitive deficits are also linked to vascular disease and stroke and can also appear earlier than typical age-related problems.

**SC:** Are survivors’ earlier gains in recovery going to be harder to maintain as they get into their 60s, 70s and beyond?

**PF:** As survivors age, staying as active as they may have been in the early years of their recovery may be challenging, and therefore may lead to a decrease in the size of muscles or atrophy that can contribute to weakness and a general decline in function. The American Heart Association recommends at least 30 minutes of moderate-intensity aerobic activity at least five days per week for a total of 150 minutes with moderate to high intensity muscle-strengthening activity at least two or more days per week for additional health benefits. That level of activity may be unrealistic for survivors to maintain, especially as they get into older decades. What may be more realistic is developing a customized maintenance program working on stretching, strengthening, weight-bearing exercises and endurance based on a survivor’s individual impairments to prevent or minimize loss of earlier gains, and potentially even continue to make more gains.

**SC:** What kind of long-term neurological follow-up care is recommended for a survivor who is a decade or more post-stroke?

**PF:** As stroke survivors age, they should be seeing their primary care physician on a routine basis to follow up on risk factor reduction and secondary stroke prevention. This should include management of blood pressure, diabetes, high cholesterol, as well as monitoring the potential long-term complications discussed above.

Based on the type of stroke one has or its subsequent complications, there may be a need for more specialized medical care involving a neurologist. For example, certain stroke survivors may have developed seizures or a movement disorder that requires more specialized neurological management. If the stroke was caused by high blood pressure, atrial fibrillation or other types of heart disease, seeing a cardiologist is also recommended.

**SC:** How long should survivors continue to see rehabilitation specialists?

**PF:** As a rehabilitation specialist, I feel it’s important for stroke patients to follow up with someone who can identify their deficits, as well as monitor their progress and recovery over time. They can also recommend further therapeutic interventions that may be beneficial, and be aware of potential long-term complications of stroke that can arise, such as spasticity. The goal is to improve their quality of life, while decreasing caregiver assistance. The brain is always trying to reorganize itself and heal. Even though we see the greatest rate of recovery in the first 12-18 months, there is ongoing recovery at a slower pace that should be monitored. If there are no new changes or complications affecting their functional status, then I would recommend routine annual follow-up.

**SC:** Will a long-term survivor’s treatment options for other health problems be limited by his or her history of stroke?

**PF:** It primarily depends on what treatments we’re talking about. Certain medications can have side effects that are more devastating in stroke survivors. There are medications that survivors take such as blood thinners that may interfere with the ability to undergo surgical procedures. The take-home point is that survivors should disclose their complete medical history, including current medications and medical problems to the treating physician so they don’t run into complications.

Clearly research into the long-term impact of aging with stroke would be extremely useful for the growing numbers of younger survivors in our country. Until then, Dr. Fadia’s advice to maintain regular follow-ups with your rehab specialist and other members of your healthcare team is sound and may help curtail some of the potential challenges or setbacks that may occur with aging.
I try to find practical solutions: a spill-proof urinal, vinyl bed pads, a shower chair, a gel cushion to avoid skin ulcers, toilet rails in addition to the grab bars we already have, a seat belt for his wheelchair.

Transferring from a wheelchair to an automobile is a lengthy, arduous process, not to mention getting to the car itself. That involves either eight steps or a steep gravel path, which might as well be a mountain. Consequently, all of it requires assistance from someone stronger than me. Since it’s so hard for him to get out, I got a bigger television so he could watch films at home.

One morning when I was cleaning up the mess he’d made on the floor at 3 a.m., I said, “I can’t do this.” So I began researching home-care agencies and interviewing potential caregivers. This was complicated by the fact Ted didn’t want any strangers in the house.

His long-term care insurance requires a lot of paperwork. First, I had to find an agency that the insurance would accept. Then we had to find caregivers that we would accept — preferably someone who had experience with older men and who would be strong enough to assist his faltering, weakened body.

Although the physical therapist had given him exercises, the aides nervously backed off when his legs trembled, his blood pressure tumbled and he said softly, “I can’t.”

After several trips to the emergency room, with hours of waiting in a tiny windowless cubicle, it became evident that the husband that I knew, who vigorously walked two miles a day, was not coming back.

Ever.
I had found a new job, that of caregiver. Much to my dismay, I was short-tempered and irritable as I wiped up spilled food and urine from the floor and his clothes.

Worst of all was the loss of my companion and friend for nearly half a century.

The humiliation he suffers is real and watching this deterioration is agonizing for both of us.

Being something of a Pollyanna, I initially kept saying, “Think about what you can do, not what you can’t.” But as the first list decreases, the second list grows.

If you are struggling with a similar situation, here are a few things I have learned. Remember, you can’t help if you are exhausted so take the following to heart:

• Get enough sleep. If your spouse thrashes all night or has vocal nightmares or messes the bed, consider separate beds or even separate rooms. It doesn’t mean you care less. You need rest to have the energy to face the next day’s onslaught of problems.

• Join a caregiver support group that fits your specific needs.

• If your spouse is in the hospital or a skilled nursing facility, figure out how many visiting hours you can tolerate. Some people keep bedside vigils. Others find they can only tolerate two hours a day without becoming depressed or overtaxed. Do what you can.

• Try not to be impatient. Count to 10, preferably in a foreign language, before you let that sharp retort fly.

• Don’t expect to be thanked. Or be hurt because you weren’t.

• Take time to exercise every day, breathe fresh air and look at nature — walk, swim, garden ... do something.

• Try to keep everything under control at your home. Having the carpets or air vents cleaned can wait.

• Be super careful when driving. Think only about the road and where you are going. Accidents can happen when you are upset, so be extra vigilant.

• If friends offer help, say, “Yes.” Have a list prepared of what small jobs someone else could do for you: deliver a meal, visit with your spouse, research a necessary but unfamiliar item you need to buy, etc.

• Find a few people with whom you can talk honestly. This will keep you from blurtling out your sorrow to the startled bank clerk, who simply asked, “How are you today?”

• When people offer unsolicited advice, smile and respond, “Thanks, I’ll consider it.”

• Ask the attending physician for some kind of appraisal and prognosis: “What’s happening? What’s ahead? What do you recommend?”

• Eat sensibly. You may crave sweets and comfort food, but have them in moderation. You know the drill: lean protein, lots of vegetables and fruit. Not so much sugar, salt and fat. Happily, a square of dark chocolate is good for you!

• Meditation helps many people. Perhaps it will be useful for you, too. There are videos and classes galore.

• Make a budget that allows you to hire help so you can have some time away. While costs can be astronomical, it may be better to invest in assistance than revamping your living quarters. Since Ted can only stand for a few seconds, long enough to transfer from wheelchair to car seat with help, I have decided to forego the outside chair lift and elaborate ramp to buy more hours from an agency.

• Look ahead and research housing options for respite and possibly the future. (See “Long-Term Care Options,” November/December 2011.)

I keep this message from World War II taped to my computer: “Keep Calm and Carry On.”

It helps. As does the quote, “This too shall pass.”

Editor’s Note: Ted passed away after this article was submitted for publication. We thank Joanna for allowing us to publish it, as we hope it will be helpful for many family caregivers.
Over the two decades of Stroke Connection, many stroke families have shared stories like this: In the beginning, there was fear, and the fear was overwhelming. After the fear came courage. Then we learned about stroke, rehabilitation and recovery, which is individual and unique. And then, finally, came perseverance.


People who haven’t had any experience with stroke don’t really know what it is, and when it’s happening they are inevitably confused. Those who recognize stroke is happening understand it is life threatening, and that causes a lot of fear. “People often respond to fear with denial or minimization: ‘You’re fine. That tingling will go away soon,’” Dr. Jacobs said. “Some people are in denial and won’t take action to get their spouse medical help.”

Knowledge conquers fear, Dr. Jacobs said, but when we are overwhelmed with fear we’re not good listeners or critical thinkers. At the moment of shock, the spouse can’t take in much. As the shock dissipates, spouses are able to understand more of what’s happened and where the road ahead goes. “When spouses can have that path laid out for them, their feelings of being overwhelmed go away,” Dr. Jacobs said. “They know that there is a prescribed path and there are people who are knowledgeable to guide them. That provides a lot of reassurance.”

Stabilizing the survivor reduces fear and begins recovery. At first, there is often a lot of hope because recovery is variable, and one can always hope for complete recovery. “Since there are a minority of stroke survivors who do recover fully, that hope is not unwarranted,” Dr. Jacobs said. However, there is also no exact science to know how fully someone will recover, and that uncertainty is stressful. So in order to maximize recovery, survivors need to take full advantage of the medical resources and rehabilitation possibilities as early as possible. “There is a window of opportunity that we want to take full advantage of,” Dr. Jacobs said. “To maximize that opportunity, the caregiver has to be supportive. They’ve got to gain some skills, especially in regard to rehab.” One way that the spouse can deal with the uncertainty is by becoming part of the treatment team and taking on a role that is really essential in improving the survivor’s recovery.

Negotiating the cul-de-sac

It is common for caregivers to feel anger and guilt. If the survivor didn’t handle his or her health risk factors, the spouse may be angry about that. But it’s also important to realize that it is not always possible to know the reasons for a stroke. “Whatever the cause, anger is not actually going to facilitate the recovery process,” Dr. Jacobs said. “The pertinent question is, “How do I engage my loved one in rehab so they can maximize their recovery?’ If caregivers direct their anger at their loved ones, they might impede their survivor’s ability to engage in rehab. I do think caregivers are justified in feeling anger at times, but that anger needs to be addressed elsewhere. Lambasting the survivor can actually be detrimental.”

Caregivers may also feel guilt that they did not do enough to prevent the stroke. “Guilt is a cul-de-sac,” Dr. Jacobs said. “It doesn’t lead anywhere. It doesn’t lead people to become better problem-solvers, it doesn’t lead them to take effective action.”

Bottom line, anger and guilt need to be ventilated elsewhere. In the beginning the main effort needs to be put into engaging the survivor in rehabilitation and making a big effort there. That push is one that will make a difference in the future.
A stroke is bound to throw a relationship off its stride. The spouses may never get back to how things were, but a new normal can be created.

Marilyn Manno and her husband, stroke survivor/comedian John Kawie.
A whole new job

Caregivers have months of uncertainty ahead of them. Dr. Jacobs counsels them to recognize this, and to adopt the mindset that they have started down a path that has no immediate end in sight. “They have to put themselves in a frame of mind that they have embarked on a new journey and this journey is going last for a while,” he said. The hardest part is at the beginning, when the person they love is in their worst functioning state. The survivor is more than likely going to recover to some degree. The caregiver is empowered when they acknowledge they have a new and important role: “They have to play cheerleader; they have to play rehab assistant; they have to apply the things they learn from therapists,” Dr. Jacobs said. “They are taking on a whole new job.”

Regaining control

A stroke is bound to throw a relationship off its stride. The spouses may never get back to how things were, but a new normal can be created. For the caregiver spouse, that means increasing his or her knowledge and embracing the new role. They should work with the healthcare team as closely as possible, but they must also remain firmly on the side of the survivor, always advocating for more rehab.

Caregivers also need to talk to others who understand, such as other stroke caregivers, if possible. They need social support in general. They need to talk to whoever they talked with and vented to in the past. “New caregivers feel like they have plunged into an alien world and they need to give themselves time to acclimate,” Dr. Jacobs said. “They have to be patient with themselves and others.”

Survivors may be physically different, but they are also emotionally different; their personalities have changed. “The crucial question for most caregivers is, ‘How do I find a way to have a relationship with this person?’” Dr. Jacobs said. “There is a lot of grief in that process, really grieving, not just who the person was but grieving what the relationship was. It’s pretty certain that the relationship will change – the caregiver is going to be doing more of the hands-on tasks, maybe doing the family finances, making decisions they’ve never had to make before. That’s very stressful, but it is also very sad because one of the partners is no longer able to take their part of the marital responsibilities.”

Dr. Jacobs suggested that caregivers get counseling to help them adjust. “Whether the spouse gets professional or pastoral counseling, these are people who can offer support and guidance and can commiserate that life has changed permanently,” Dr. Jacobs said. “That new life entails a change of perspective and making more sacrifices than the caregiver has ever had to make. Those kinds of adjustments are facilitated by having a guide working with you.”

The immediate aftermath of a stroke is one of the most difficult times anyone will ever go through. In talking with caregivers, it’s clear that it is a period that they don’t recall very well later. They remember where the loved one was when the stroke occurred but recollections of what happened afterward are blurry because the caregiver was so emotionally overwhelmed. “My advice to spouses is just hang in there and be patient with yourself and accept that this process will unfold slowly,” Dr. Jacobs said.

Initially, I was annoyed with John’s behavior. We were at breakfast with friends, and he was drooling food and not keeping up with the conversation. When I realized it was more than bad manners, my annoyance quickly turned to fear, especially when I saw the frightened look in his eyes.

At that point, all I cared about was getting John to a hospital so they could fix whatever was happening. It was there that we first heard the word “stroke.” I was naive and clueless about what a stroke entailed. Stroke was something my old relatives had – not the 47-year-old man I married just a week before.

I wasn’t really scared, at first, because I didn’t grasp the gravity of the situation. But every day John was in the hospital and his left side wasn’t functioning the way it used to, I became more alarmed. This wasn’t going to be like a heart attack where they fix you up, give you some pills and you walk out unaided.

When the enormity of the situation settled in, I wondered what the future would hold. Would there even be a future? It was then I first realized that life as we knew it was gone.

There’s no planning for this kind of thing. You’re thrust into this new universe of terminology that you didn’t know existed and were never prepared to enter. You have to be a quick study; I was not. Overnight I went from newlywed to “caregiver,” a term I had never heard before. Then came the foreign world of rehab filled with wheelchairs, canes and braces, a world where you’re not only a caregiver but also a patient advocate, trying to get the best healthcare possible.

When John didn’t recover the use of his left arm and leg during that first week, I remember thinking, “He might never recover.” I had no idea of what to expect. He kept repeating the same phrases. His timing — something he valued as a comedian — was...
off. When I realized that John was affected both physically and cognitively, I knew we had a long haul ahead of us. I had to prepare myself before every hospital visit to make sure I didn’t show John how upset I was at this new person he’d become. I tried to be the positive energy in the room so that he would work harder at his therapy.

I was surprised at how insensitive doctors could be. After one examination, a well-known neurologist blurted out to John that he would never regain the use of his arm. John was so upset that he broke down in his office. I called the doctor the next day and reamed him out for his bedside manner. He apologized, but told me he was just being honest. I told him that he took away the one thing that John clung to – hope – and that no one knew for sure how the brain could rewire itself. By then I was becoming more knowledgeable about stroke and more of an advocate for John.

John was a stand-up comedian with no health insurance. The week we were married I signed him up for my company’s plan; the coverage kicked in three days before the stroke, which turned out to be a godsend. When John was first admitted to the ICU, my company’s health department assigned me a “case manager” – yet another term that was foreign to me. Salley turned out to be John’s guardian angel and I don’t know what I would have done without her. She helped us navigate the complex and overwhelming world of healthcare, fought for more therapy than most received, explained endlessly and patiently what I was ignorant about, to the point that we became a team fighting for John.

John was released from the hospital after two months. After that, I remember not wanting to be home much. Work was a safe haven. I would arrive early and just chill, enjoying my coffee and alone time, and in the evening I’d find things to delay my return home, just to have a few extra minutes of peace and normalcy. Work was structured, orderly – a total contrast to what our apartment had become. My work space became a home away from home with friends stopping by to gossip and share news. John was not handling conversation well and I was feeling lonely. I also felt extremely guilty. If I found myself having a good time at work I would suddenly tear up realizing it had been months since I was able to experience some sense of fun and laughter with my new husband. I had given John so much of my energy the first few months that I wanted some me-time. I now realize caregivers need this, but at the time I felt very selfish about it.

One thing I learned is that rehabilitation is the key to recovery. I can’t emphasize that enough. PT, OT, cognitive, speech – they all help the survivor to heal. We were lucky that our case manager fought to get us more than most. Try to get as much from your insurance company as possible. When the insurance runs out, try to get involved in studies where therapy is included. In addition to the obvious benefits, therapy allowed John to socialize and rebuild his self-confidence. It sure beat staying at home all day, which can be an invitation for depression to sneak in.

A second thing I learned is that you have to be your healthcare advocate. Translation: Be pushy. When the stroke happened, I didn’t know what to ask the doctors, and I accepted most of what they said. Eventually, I learned to speak up. As the weeks went by, I became John’s voice. I asked questions and if I wasn’t satisfied with the answers I’d probe until I was. I found the younger doctors were more willing to share information, whereas the older doctors weren’t used to being questioned.

My advice to new caregivers is to hang in there. The person you love is still there, just a little lost and frightened. You might both get angry and frustrated along the road to recovery, but that’s natural and will hopefully bring you to a better place. Also, try to get a support system to give you some relief. You don’t realize how much energy you put into your spouse’s recovery, and if you get sick then you’re no good to anyone.

Approach recovery as a journey. It may not be the path you had planned, but once you’ve gone through it, you might discover strengths you never knew you had. I know we did. We’ve also become closer. I made up signs of support for John’s hospital room to help him get through the day. One said, “We’re in this together,” and 16 years later we still are; we make a great team.

Never give up hope. Neither of you. Nothing is impossible.

**Spouse as Cheerleader**

Dr. Jacobs recommends not dwelling on the future early on. Caregivers should instead focus on helping their survivor get mobilized and nurturing a sense of hope. “It’s the spouse’s job to come in and say, ‘Let’s go, we’re going to do this. I’m going to work with you to overcome this.’”

Spousal encouragement and cheer leading play a crucial role in getting survivors motivated. Survivors who feel demoralized and depressed are not the ones working hard in physical therapy and strengthening themselves. They are not getting the most neurological recovery because they are not using their brains as intensively as someone who is fully engaged. “The spouse who is helping as a coach and cheerleader is likely to develop an even stronger bond with his or her survivor because the two of them are bonding against the common enemy of stroke,” Dr. Jacobs said.
When my husband, Thomas, had his stroke in 1997, I was numb at first, in shock. I felt helpless. I was afraid that he would not make it, and if he did, what kind of quality of life would he have? I was concerned that I would not be able to assist him. It scared me when the doctor told me that Thomas would probably not be able to communicate, walk or work. I was told that there was little hope he would have any type of normal life. The doctor said that he might have to go into a nursing home.

My family was very supportive. We had been through this with my mother when she had a stroke. Thomas did not make a complete recovery, but he has proved the initial prognosis wrong. He is able to walk and communicate. And he has worked full-time for years. He has aphasia, which affects the way the brain processes information, so it can be challenging to communicate with him at times. But I have learned how to communicate with him, so that neither of us gets frustrated.

I have been a caregiver for 16 years and have had the opportunity to interact with caregivers on the American Stroke Association’s Stroke Family Warmline since 2012. Here’s what I can tell you from my experience:

- Take it a day at a time.
- Be patient. Notice and celebrate any improvement.
- Stay encouraging and hopeful.
- Take time to take care of yourself. If you don’t, you will not be of service to the survivor. You will feel overwhelmed and frustrated.
- Get involved with a stroke support group. You will gain a lot of useful information, and you will also discover you are not alone.
- Remember that your loved one does not want pity, just encouragement.
- You may lose friends and family members, because they feel uncomfortable and aren’t sure how to respond. They fear they may say something wrong, so they just stop coming around. They may have a hard time understanding the survivor, due to aphasia. (For more on coping with other’s reactions, see Expanding Comfort Zones, Fall 2012.)
- Prayer has helped me through the rough times.
- Realize that the survivor may not be the same person they were before the stroke. Some survivors’ personalities change as well as their behavior. The survivor often does not realize these changes.
- If you are able to access the Internet, go to stokeassociation.org. There is a lot of valuable information to help you understand the effects of stroke and what treatments are available.
- Accept the changes and move forward. Don’t look back; it will only hinder you in accepting and coping with the changes.
It never fails. As soon as I start feeling good about myself disability-wise, Mrs. H shows up and treats me like I'm one of those abused, helpless pets in that heart-wrenching Sarah McLachlan commercial. All I need is the song “Angel” playing in the background and I'd be buying Prozac by the pallet at Costco.

Mrs. H is a friend's mom who seems to flip the condescending switch the minute she sees me. It's as if NAPA — the North American Pity Association, whose motto is “If it's not perfect, we feel sorry for it” — had been on high alert and unleashed her into the world to make some stroke survivor (me) miserable.

My latest encounter was at a cocktail party. Marilyn and I were sipping martinis, laughing and carrying on all Scott and Zelda Fitzgerald-like when suddenly I heard that syrupy, patronizing voice. “Oh Johnny, keep doing what you’re doing dear. I think it’s just won-der-ful.” I popped a canapé into my mouth, turned around and found myself face to face with NAPA’s charter member.

When I was in kindergarten, my teacher Miss Bergman said the exact same thing to me. I was attempting to sculpt a hunk of clay into the image of a rabbit. The other kids were molding their material like they were Brancusi creating “Bird in Flight.” Meanwhile, my hare was looking more like Frankenstein with a Salvador Dali melted clock feel to it. With her sweater over her shoulders and arms folded, Miss Bergman stood over me and asked, “Johnny what is it?” I took off my Davy Crockett coonskin cap, stood up and proudly announced, “It’s the Easter Bunny!” That’s when she gently patted me on the head and said, “Oh Johnny, keep doing what you’re...”

The phrase was identical, but with a subtle difference. One was being kind to a little boy, while the other was treating me like a little boy. Kindness versus pity. When I was honing my comedy act at 2 a.m. to a sparsely filled club and the audience didn’t walk out, that was probably both kindness and pity. And let’s not forget the emotion that has its own section in the Hallmark card aisle: sympathy. To me, sympathy has an, “I feel your pain” implication. Whereas pity is more, “Man, I’m glad I’m not you.”

Maybe because I was an only child I’m not used to any of these feelings. My parents’ attitude was simple: “We only have one of these, so let’s not mess up by coddling it.” Very loving people, but if I were hooked up to life support they’d still make me do my homework.

Anyway, back to the cocktail party. My mouth was full, but that didn’t stop me from carrying on a conversation. “Mithith H, good to thee you. Thith cheeth ith fantathtic.” Just then she leaned in, massaged my hand and whispered, “I’m here dear. Be brave!” I think she figured I was having another stroke because the look on her face was priceless.

That’s when it occurred to me the woman was afraid. She had been all along. I’d moved forward with who I am now, but she couldn’t accept that. She never really saw me; all Mrs. H saw was the stroke.

Feelings of self-reliance and confidence instantly washed over me. I pulled my hand away, pointed to my mouth and said, “Awthum Brie. You thould try thum.” Then I politely walked away.

For every Brain Freeze video sold from 8/1/10 through 7/13/15, and after the recovery of startup costs, Parma Recordings will donate 17% of the retail sales price to the American Stroke Association. Brain Freeze contains adult language and situations that may not be suitable for all audiences. For booking information, contact John at jkawie@aol.com.

EZINE BONUS: Click to see a video clip from Brain Freeze!
Tips & Gadgets for Managing Daily Activities

By Carol Siebert | Occupational Therapist

After a stroke, routine activities can be a challenge. Tasks you’ve done routinely — getting dressed, fixing a sandwich, making the bed — demand time, attention and sometimes assistance that was not necessary before the stroke. As an occupational therapist, I redesign activities so that the demands — for time, attention and effort — are a better fit for a person’s abilities. Redesigning activities means altering the method of the activity, altering the tools used to do the activity, or both.

Redesigning is more than just matching methods or tools to tasks. We are all creatures of habit, and we each handle change differently, so how much redesign of an activity is acceptable is different for each person. Activities have meaning related to memories, roles, culture — so redesign has to respect the meaning of the activity.

Here are some redesign methods (tips) and tools (gadgets) that many people who have had strokes have found useful.

TIPS

Save Energy

Don’t let activities consume more energy than they deserve. The easiest way to do this is to sit rather than stand for any task that can be done sitting down: brushing your teeth, putting on a shirt, making a sandwich, even vacuuming the rug (try it!). Standing when it isn’t necessary is not “exercise.” Sitting when you can is a way to save energy for tasks that have to be done standing, or tasks that demand more physical energy.

Plan and Pace

Energy isn’t all physical. Learning new ways of doing things or having to pay close attention takes mental energy. Brains get tired, too. Pushing yourself when your body or your brain is tired leads to fatigue-related mistakes, difficulty controlling muscles and, sometimes, falls and injuries.

Before you start your day, think ahead. Plan to take breaks or rest. Break up more difficult or energy-consuming tasks into shorter, simpler tasks. Pacing yourself is essential to allow your brain and body to do their best.

Simplify

Simplifying activities is a great way to save energy and pace yourself. Simplifying reduces effort or gets more results out of a single effort. Some examples:

• Dressing and undressing is easier when clothing has fewer fasteners or has hook-and-loop fasteners instead of buttons or zippers.

• Making the bed takes much less time and effort if blankets and top sheets are replaced with a single comforter and duvet (comforter cover).

• Using a medication organizer that’s filled once a week means not having to deal with multiple pill vials every day — or multiple times each day.
Delegate

Delegation means assigning the right tasks to the right worker. As you save energy, pace and simplify, you may decide that some tasks or parts of tasks should be delegated — they take too much energy or effort in comparison to how important or meaningful they are to you.

Rather than giving up the activity, you may want to delegate the part you can’t do to a family member or helper, at least temporarily. Delegation is a management strategy to keep you in charge of your activities.

GADGETS

Reachers

Reachers have a trigger at one end and a claw or pinch mechanism at the other. When you squeeze the trigger, the claw or pincher closes. There are many different kinds of reachers. Some have a rubberized pinch and a magnet on the end to pick up small or metallic items. Others have a claw wide enough to grab your pants out of a bottom drawer or your cereal off the cupboard shelf. They may be called reachers, grabbers or pick-up tools. Some models fold so they can be carried in a tote, a walker basket or a wheelchair pack. Reachers are available in home improvement stores, medical supply stores and Internet vendors. You may find it convenient to have one in each room of your home — especially your bedroom, bathroom and kitchen.

Stabilizers

Stabilizers can make it possible to do tasks with one hand. My favorite stabilizers are rubber jar grippers and rubberized shelf liner. They can come in handy for a number of things:

- Putting a jar gripper under a jar helps hold the jar in place so one hand can twist it open.
- Putting a piece of shelf liner on the floor stops the shoes from sliding away while slipping feet into shoes. (Pick it up before walking.)
- Cutting shelf liner to the size of a placemat and putting it under the plate or bowl stops the plate from moving when you are cutting or scooping.
- Putting a jar gripper under a medicine bottle and using the heel of your hand to press down and twist makes it possible to open child-proof containers with one hand.
- Wrapping a stabilizer around the handle of a toothbrush, hairbrush, fork or even a pen makes the tool easier to hold while brushing, eating or writing.

Go high-tech

Delegate tasks to your smartphone, tablet or computer. There are apps available for phones and tablets that can help you schedule activities, remind you of appointments, extend your abilities or keep track of your health. Many of these apps are free (visit strokeassociation.org/strokeconnection for more details about helpful apps).

Monitor your home. If you have a home wireless network, you can install cameras inside or outside to monitor areas of your home from your computer, tablet or smartphone. If you have delegated tasks to others, this can allow you to supervise or monitor a helper who is in another room or see who is at the door without getting up from your chair.

Home automation systems allow you to control lights, start the coffee pot, adjust the thermostat or call for help. Simple systems are available for under $100 and allow you to control lights or appliances with remote control. More complex systems integrate wireless networks with your home’s electrical circuits or alarm systems. These can be programmed or can be controlled from smartphones or tablets even when you are away from home.

Whether a tip or gadget is right for you depends on your habits, your preferences and your needs. There is no one-size-fits-all cookbook for activity redesign. Give yourself time to try a new method or tool to decide if it works for you. It takes time to get used to, but it also takes time for it to become habit — to be automatic. If you need more advice or assistance identifying methods or tools specific to your needs, consult an occupational therapist in your area.

About the author...

Carol Siebert, MS, OTR/L, FAOTA, is an occupational therapist and the owner of The Home Remedy, a practice she established in 1997 to provide consultation and services to assist individuals to be independent in their homes. She lives in Chapel Hill, N.C.
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.