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Berlinda Love became the caregiver for two disabled parents after her mother’s stroke. Through them she has learned that disability affects the whole family. She has also learned the joy of small victories as well as the strength to overcome.
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.
African-Americans with heart disease who practiced Transcendental Meditation regularly were 48 percent less likely to have a heart attack or stroke, or to die from all causes, compared with African-Americans who attended a health education class over more than five years, according to new research published in the American Heart Association journal Circulation: Cardiovascular Quality and Outcomes.

“We hypothesized that reducing stress by managing the mind-body connection would help improve rates of this epidemic disease,” said Robert Schneider, M.D., lead researcher and director of the Institute for Natural Medicine and Prevention in Fairfield, Iowa.

For the study, researchers randomly assigned 201 people to participate in a Transcendental Meditation stress-reducing program or a health education class about lifestyle modification for diet and exercise.

- 42 percent of the participants were women, average age 59, and half reported earning less than $10,000 per year.
- Average body mass index was about 32, which is clinically obese.
- Nearly 60 percent in both treatment groups took cholesterol-lowering drugs.

Those in the meditation program sat with eyes closed for about 20 minutes twice a day practicing the technique, allowing their minds and bodies to rest deeply while remaining alert.

Participants in the health education group were advised, under the instruction of professional health educators, to spend at least 20 minutes a day at home practicing heart-healthy behaviors such as exercise, healthy meal preparation and nonspecific relaxation.

Researchers evaluated participants at the start of the study, at three months and every six months thereafter for body mass index, diet, program adherence, blood pressure and cardiovascular hospitalizations. They found:

- There were 52 primary end point events, which included death, heart attack or stroke. Of these, 20 events occurred in the meditation group and 32 in the health education group.
- Blood pressure was reduced by 5 mm Hg and anger decreased significantly among Transcendental Meditation participants compared to controls.
- Both groups showed beneficial changes in exercise and alcohol consumption, and the meditation group showed a trend toward reduced smoking. There were no significant differences between the groups in weight, exercise or diet.
- Regular meditation was correlated with reduced death, heart attack and stroke.

“Transcendental Meditation may reduce heart disease risks for both healthy people and those with diagnosed heart conditions,” said Schneider, who is also dean of Maharishi College of Perfect Health in Fairfield, Iowa.
Time Lost Is Brain Lost
Learn to act F.A.S.T. to save a life

Professional basketball player Juaquin “Hawk” Hawkins knows firsthand that a little stroke knowledge can go a long way — and possibly even save a life. Hawkins was 34 and in top physical condition with no history of health issues when he had a stroke in 2008. Even worse, he didn’t recognize the warning signs, nor did the people around him.

One in three Americans don’t know at least one of the signs of stroke. So the American Stroke Association’s Together to End Stroke initiative, with Covidien as its inaugural sponsor, is helping Americans recognize the stroke warning signs with the F.A.S.T. awareness campaign.

F.A.S.T. is:
• Face Drooping - Does one side of the face droop or is it numb? Ask the person to smile.
• Arm Weakness - Is one arm weak or numb? Ask the person to raise both arms. Does one arm drift downward?
• Speech Difficulty - Is speech slurred, are they unable to speak, or are they hard to understand? Ask the person to repeat a simple sentence, like “the sky is blue.” Is the sentence repeated correctly?

Time to call 9-1-1 - If the person shows any of these symptoms, even if the symptoms go away, call 9-1-1 and get them to the hospital immediately.

“Stroke can happen to anyone at any time and it is largely preventable, treatable and beatable,” Hawkins said. “When you learn to prevent stroke, you improve the outlook for your future and live a healthier lifestyle.”

Hawkins fought his way back and played professional basketball again 14 months after his diagnosis.

The American Stroke Association partners with hospitals and healthcare professionals to translate the latest stroke research into guidelines and ensure they’re being used to improve patient outcomes. The ASA also gives healthcare professionals resources to educate their patients about their risk or condition and help in their recovery from stroke.

To join Together to End Stroke or learn more about using F.A.S.T. to recognize a stroke and to learn all of the warning signs, visit strokeassociation.org/warningsigns.

TIAs Are Serious

TIA (transient ischemic accident or “mini stroke”) can lead to serious disability, but is frequently deemed by doctors too mild to treat, according to a study in the American Heart Association journal Stroke.

“Our study shows that TIA and minor-stroke patients are at significant risk of disability and need early assessment and treatment,” said Shelagh Coutts, M.D., lead author of the study at Foothills Hospital in Calgary, Alberta, Canada. “We should be imaging patients earlier and be more aggressive in treating patients with thrombolysis if we can see a blockage no matter how minor the symptoms are.”

Thrombolysis is a treatment used to dissolve dangerous clots and restore healthy blood flow to the brain. TIA and minor-stroke patients don’t typically receive this treatment because the condition is frequently not deemed serious enough to warrant it, researchers said.

Among the 499 patients studied, 15 percent had at least minor disability 90 days after their original “mini stroke.” Computed tomography (CT) scans showed some patients had narrowed blood vessels in the brain and others reported ongoing or worsening symptoms. Those patients were more than twice as likely to have disability at 90 days.

Patients with type 2 diabetes had a similarly high risk of disability. Also, women were nearly twice as likely as men to be disabled 90 days after TIA.

“For every second after a mini stroke, the patient’s brain may be losing oxygen — possibly leading to a major event,” Coutts said. “If a scan finds that you have a narrowing of a blood vessel in or outside of the brain, you are at a high risk of being disabled.”

Recurrent strokes posed the greatest threat to patients. Of those who had recurrent strokes, 53 percent were disabled, compared to 12 percent of patients without a recurrent stroke.

“The symptoms of a TIA may pass quickly,” Coutts said. “But, if you experience them, you should immediately go to the hospital, where proper scans can be done. If ignored, these symptoms can lead to death. This is not a benign disease.”
I worked for a large manufacturing facility for 14 years. During that time, I did many jobs. In 2002, I was a facilitator, trustee, member of the executive board and candidate for financial treasurer of my union. I was also a wife, mother of three and a college student. At one point, I was working overtime, attending union meetings and going to night classes. My husband, Frederick, was very supportive and did most of the cooking. At the time, I did not realize that I was overdoing it.

On June 18, 2002, I was working the midnight shift and had a bad headache. I had recently lost the election for financial treasurer. Later I learned that I had actually won but the incumbent had tampered with the ballots. While writing a letter to thank the membership, I noticed that my handwriting looked funny. I talked to a co-worker about it, and she said, “Your motor skills can be altered from a stroke. You should go to your doctor.”

At my doctor’s office, my speech was slurred, and he asked if I had been drinking. He was joking, but I told him about the headache and my handwriting. He ran some tests and told me that I had to go to the emergency room because I might have had a stroke. I was terrified! The ER doctor ran more tests before telling me I had had a stroke and admitted me to the hospital. I couldn’t believe it – I was only 38 years old. I thought about the election, the stress and the injustice done to me.

I was diagnosed with mild aphasia and dyspraxia. Over the next few months my speech got worse and I lost the ability to read and write. Frustrated, I cried for many days. My neurologist referred me to a neurology clinic where they finally determined that I had the stroke because my arteries were small and I got blood clots.

My neurologist prescribed Plavix, aspirin and vitamin B-12. She was concerned that I might bleed on the blood thinners, so I was on medical leave for eight months. During that time, I had speech therapy. I eventually returned to work with restrictions. It was a challenge because my supervisor frequently questioned me and I felt like I was discriminated against due to my deficits. I took a buyout in 2008.

In 2011, I went back for speech therapy because I felt my skills were declining. I learned to compensate for my deficits and cope better, and I regained my confidence. I learned to listen closely before responding and began to record my school lectures so I could replay them to improve my comprehension. I am two semesters away from graduation. I learned strategies to retrieve words such as picturing the word, using a similar word or describing the word. To pronounce words better, I learned to tap my hand or foot to get the syllables out. Finally, I learned to type on the computer. It was hard, but I was determined.

I am determined to live life to the fullest. However, I learned that I did too much too fast. You must have balance in your life. It is important to take care of yourself, eat right, exercise and go to your doctor regularly. The important thing is never to give up hope.

Trina Harris, Survivor
Detroit
Learning Who I Am

It has been three years since my stroke. When I reflect on what has changed and what has remained the same, this is what I see.

Perhaps the biggest change has been my willingness to accept my circumstance. It wasn’t always that way. For the first six months, I tried desperately to be the person I was before.

I realized that I would never to able to change other people’s perceptions, but I could change how I allowed them to influence and impact me. I made the decision not to be defined by others’ misconceptions; by allowing myself this, I have felt a huge relief and freedom. It allows me to choose how I respond to them. Admittedly, this is not always easy, as it is natural to want to feel accepted.

I hesitate to say I have lowered my expectations. Rather, I like to think I have changed the yardstick and made my goals more realistic. Where before I expected to swim 20 lengths of the gym pool, I have learned to be proud of managing five. For a long period, I felt myself clouded in darkness, ashamed of what had happened, while struggling to accept it at the same time.

But slowly I learned to accept this new version of myself and began to open the door and invite new people into my life. These people did not know the person I used to be, but were willing to be friends with the person before them. This has allowed me to open myself up to other avenues that previously I would never have ventured into. Along with it, I have gained new and valued friendships.

I am forever indebted to my family. It is never lost on me the huge toll the stroke has had on them. While I am still touch sensitive, we have learned to find our own rhythm. I still long for a warm embrace from my family and to have the superpower-like strength so as not to feel exhausted after attempting to communicate. I know that our bond as a unit has grown stronger. While my stroke had the potential to divide us, we have not allowed it to define us. Instead, it has strengthened us.

I have had to face some harsh truths: My speech will never return. My body will never look like those in glossy magazine covers, but I can work to make it as strong as possible and be proud of the image I see reflecting back at me.

Strokes affect people differently, and each survivor feels the effects uniquely.

I am reminded of this as I page through online support groups and comment on remarks. There is always someone in a worse situation than my own. I was once where they are now and I am never truly alone. Should I falter I have refuge.

While the stroke took many things away, it has allowed me to be grateful, too. In the beginning, I was still waiting to find my voice. Now, three years later, I am learning to listen. My stroke has given me this gift. Before I was uncertain who I was; now I stand firm in my beliefs and know who I am.

Lesley Potgeiter, Survivor
South Africa
We continue to celebrate Stroke Connection’s 20th anniversary with the second of our four-part series on changes in stroke treatment and therapy since 1993. This time we focus on the significant developments in speech/language therapy.

Before 1993, the thinking was that once stroke damage was done, it was essentially permanent. Advances in neuroscience have enabled doctors and therapists to see that the brain has the potential to regenerate neuronal connections, so when something is lost, it is not necessarily lost forever.

Dr. Neila Donovan, assistant professor in the Department of Communication Sciences and Disorders at Louisiana State University, has worked in this field for 27 years and seen tremendous developments.

“Research shows that behavioral interventions really do have an effect,” she said. “We now know, for instance, through meta-analysis, that the minimum amount of therapy a survivor should have is two hours a week. We also know that more treatment leads to better outcomes.”

Unfortunately, those studies were done when up to 30 weeks of speech therapy were paid for; now Medicare only pays for about 10 sessions. Thus one of the biggest changes in speech therapy since the 1990s is a severe reduction in availability of an adequate amount of therapy for Medicare recipients.

Speech pathologist Dr. Martha Sarno, research professor in the Department of Rehabilitation Medicine at New York University Langone Medical Center, notes: “The extent of reimbursement for speech-language pathology services for survivors with communication disorders has been severely reduced. Survivors cannot rely on receiving these services unless they are well-insured. Often therapy is accessible while hospitalized during the acute period but may not be available later.”

Started in 1987, the National Aphasia Association has provided several avenues to help survivors with aphasia. Designed specifically as a resource for people with aphasia, NAA has developed a national network of more than 350 aphasia community groups. These range from informal support groups to groups in speech rehab settings; survivors attend them after they’ve finished their speech therapy. The groups are usually free or low cost, not reimbursed, and are usually run by clinic supervisors and students. In some university settings, these groups may be used to provide clinical training for speech-language pathology graduate students under faculty supervision.

“These serve a need in the aphasia community that never ends,” Dr. Sarno said. “Engaging in social conversation is important for persons with aphasia who need speaking opportunities to help restore their identities. The NAA aphasia community group network is an important contribution to meeting the needs of survivors with aphasia.”

For years, NAA has sponsored regional conferences to help survivors with aphasia. These conferences feature lectures on important topics for living successfully with aphasia.

“In addition, the major benefits of these conferences are that survivors have the chance to share experiences...
with others in similar circumstances, as well as hear about recent research activity,” Dr. Sarno said.

Several aphasia centers have been established over the last 20 years. These places provide a program of services designed for people with aphasia and their caregivers, in addition to being a place they can meet and interact with each other. These centers are generally open three to five days a week. They’re usually founded and funded by a family or organization in a local area, such as the Adler Center at Kessler Rehabilitation Institute in New Jersey and the Houston Aphasia Recovery Center.

“This is a movement to help families with aphasia that is a response to the reduction in funding,” Dr. Sarno said.

Scanning technology has been a boon to speech therapy because it enables therapists to look at brain function.

“Now we can do functional MRIs and see how therapy changes brain activation,” Dr. Donovan said. For instance, there have been studies done on survivors with aphasia that demonstrate that the right side of the brain takes over some of the language functions, compensating for damage to the left hemisphere, but with treatment, language function is restored to the left side.

Both professors said that computers and language software have had an impact. However, they warn that neither is a cure-all.

“For the most part, computer-based therapies really don’t generalize to spontaneous speech in any way that makes me want to use them for treatment,” Dr. Donovan said.

Some could be useful for practice, but there is not currently good evidence for them as therapies in and of themselves.

“We need better programs or to rethink what we want them to do,” she said. “The danger is thinking that a program provides ‘more’ therapy when patients may be learning incorrect behaviors instead of correct ones.”

Dr. Sarno mentioned the need for a specialist “who can match the software with the problem.”

“In the hands of the patient alone, it may not work at all, but with good direction, it can be helpful,” she said. “Persons with aphasia should also be guided by a speech-language pathologist in the selection of alternative/augmentative communication devices.” (See Everyday Survival on p. 18 for more on new communication technologies.)

An emphasis on evidence-based practice has made a difference in the way aphasia is treated.

“We’re now ethically bound to provide our clients with treatments that have evidence behind them,” Dr. Donovan said. “That’s a big step forward, and it puts us on an equal basis with doctors and others doing evidence-based practice.”

Dr. Sarno said contemporary research addressing the effects of neuroplasticity gives hope for long-term change that will affect practices in aphasia rehabilitation.

“Increasing knowledge of neuroplasticity has the potential for extending the current span of treatment time provided for persons with aphasia,” Dr. Sarno said.

What’s on the horizon?

“The medical community needs to change its approach,” said Dr. Donovan. “Aphasia needs to be evaluated outside the medical model and seen not just as an impairment that affects the body, but one that affects a person’s identity and ability to fulfill life roles. These are issues for which there are no accurate measures.

“As long as we keep aphasia in a biomedical model, we’re not going to get far because it ends up being a chronic condition,” Dr. Donovan continued. “We really have these issues of participation and quality of life, and for aphasia it affects everything – access to healthcare, participation in managing your health, the ability to stay alone.”

After 20 years of progress, it’s still quite a challenge to understand aphasia. 

“‘Aphasia needs to be evaluated outside the medical model and seen not just as an impairment that affects the body, but one that affects a person’s identity...’”

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! Help stroke families today.
Returning to Work

For many younger survivors, going back to work is often the measure for recovery. They sometimes rush through rehab so they can jump back into their jobs. However, they may find that they are no longer capable of doing what they did before, despite having completed rehab with flying colors. Even with possible accommodations provided by their employers, working life moves faster and requires more stamina than they have post-stroke.

By Jon Caswell
We interviewed three survivors about their experiences returning to work after stroke. One of those survivors, Steve Park, is a vocational counselor who works with disabled people, and we also got his input as an expert in this area. We also spoke with Paul Wehman, chairman of the physical medicine and rehabilitation department at Virginia Commonwealth University School of Medicine, and physiatrist Richard Kunz, an assistant clinical professor in the same department. Both saw returning to work as a benefit to recovery: “Work is very therapeutic,” Dr. Wehman said.

That said, Dr. Kunz advised not to rush it. “Take time to get better,” he said. “The most important thing is to heal. Going back to work and financial pressure have to take a backseat to that. Take the time and make it a rational return to work.”

There is no simple answer about when someone is ready to return. Decisions should be made on an individual basis. “I have patients who have relatively severe functional impairment who go back to work, while other patients with less impairment do not,” Dr. Kunz said. “It depends on the person’s perception of themselves. Actual functional ability is rarely the thing that it boils down to.”

One variable Dr. Wehman mentioned is how much a survivor’s self-image is connected to their work ethic. “Some individuals see themselves as workers, and the concept that they will never work again is foreign to them,” he said. “It is important for survivors to accept that things have changed. Even when a person appears to have made a full physical recovery, there are changes – stamina, language, sequencing, attention, noise tolerance and memory – that may not be obvious in the rehab environment.

Steve Park remembers that when he first returned to work, he refused to accept that his skill level had changed. “The denial can go on for years, especially with a big change in vocation. It did for me,” he said. “Rehabilitation is a process, with individuals having to learn for themselves what their limits are.”

**Tips for Returning to Work**

Steve Park survived a stroke at age 31. Unable to return to his career as a refrigeration technician, he went to school, earned a master’s degree and has worked as a vocational rehab counselor ever since. We told that part of Steve’s story in “Tough Work” in our July/August 2004 issue. He currently works in the Supported Employment Division for LifePath Systems, a nonprofit agency located in a Dallas suburb. He outlined these tips for survivors wanting to go back to work.

- Contact the Vocational Rehabilitation agency for your state as soon as possible during or after rehabilitation for a stroke that affects your ability to work, even if you are not sure about eligibility.
- If you are receiving Social Security benefits, find out about the Ticket to Work program.
- If you are not sure about returning to work, try a volunteer job. By volunteering, you will increase your endurance, discover personal strengths/interests, help the community and it looks great on a resume.
- Enroll in a junior, community or a county college and study an area of interest for you. Science, writing, literature, math, history, physics, philosophy, electronics, welding, pottery, drama and a host of other learning opportunities are open at any age. School can be inexpensive rehabilitation.
- Expect to be treated just like people who don’t have disabilities.

**“Rehabilitation is a process, with individuals having to learn for themselves what their limits are.”**

Steve Park, Survivor
Although employment can be good therapy, the healthcare system is not really focused on getting survivors back to work.

psychologist to help patients develop that insight,” Dr. Kunz said. Without insight, survivors often set themselves up to make mistakes that they don’t recognize but employers do.

“As long as patients understand what their limitations are, they can learn to work around them and develop compensatory strategies,” he said. “We find that employers are open and willing to work with patients as long as they know what they’re getting into.”

While physical deficits are challenging, Drs. Wehman and Kunz said those challenges are easier to overcome than cognitive deficits.

“One of the issues with cognitive impairment is that it impacts everything,” Dr. Kunz said. “If you have dense hemiparesis but are cognitively intact, you can still figure out your toileting, your hygiene, your mobility, taking your medications – all things that go on after stroke. But if you are significantly cognitively impaired, all your other problems become exacerbated.”

Important issues to consider: Can you learn to use a cane or walker? Are you able to develop hygiene habits and don’t require assistance? Can you maintain your health going forward?

“Cognitive issues make it harder to progress across the board,” Dr. Kunz said.

**SSDI & SSI**

Social Security Disability Insurance (SSDI) is a program of the Social Security Administration that pays benefits to disabled people and certain family members if the disabled person is “insured,” meaning that he or she has worked long enough and paid Social Security taxes. (For more information, visit ssa.gov/disability)

Supplemental Security Income (SSI) is a federal income supplement program funded by general tax revenues (not Social Security taxes). It is designed to help aged, blind and disabled people who have little or no income. It provides cash to meet basic needs for food, clothing and shelter. (For more information, visit ssa.gov/ssi)

Although employment can be good therapy, the healthcare system is not really focused on getting survivors back to work. There are many challenges a patient and his or her support system will have to deal with themselves. This includes issues like how to disclose a disability?

What accommodations are necessary? Will I be eligible for benefits if I start working and it doesn’t work out?

“These are all reasonable questions that our service delivery system does not answer in a nice, seamless way,” Dr. Wehman said. “That is not an excuse, it’s just what happens.” (See “Ticket to Work & Work Incentives,” p. 12.)

Dr. Wehman stresses the importance of the employee realizing it is up to him or her to make things work. That includes asking for help whenever necessary.

Both professors pointed out that there’s a lot of attention paid to survivors during the acute treatment and rehab and recovery phases of stroke. “Medically, we’re pretty strong in knowing how to help people there,” Dr. Wehman said. “And from a vocational rehab standpoint, we are pretty strong, but we need the patient to advocate for themselves, to ask for specialized supportive employment or support services as soon as they feel they are ready, because if they don’t, nobody is going to go knocking on their door.”

Every state has a vocational rehab program that can help with this phase of recovery. In addition, the Employment Network providers in the Ticket to Work program will collaborate with survivors on developing plans and strategies for returning to employment.

Dr. Wehman also noted that some survivors worry about jeopardizing their disability payments by going back to work. Part of the fear is what happens if they can’t remain employed. However with Social Security Disability Income (SSDI) and Supplemental Security Income (SSI), there is a trial work period. (See “Ticket to Work & Work Incentives,” p. 12.)

“The Social Security Administration has a giant work incentive program to encourage people to work and keep their benefits to a certain level of substantial gainful activity,” Dr. Wehman said. “Anybody who has questions about losing
Larisa Diephuis loved her job as a program manager for a national nonprofit organization. Managing two programs, in New Orleans and Baton Rouge, La., she had a full-time staff of six and oversaw up to 30 part-time staffers.

One day in November 2009, she had “a killer headache.” She went to the hospital, where they discovered a hemorrhage in her cerebellum. “It was due to an arteriovenous malformation, but it was so small they couldn’t find it right away,” Larisa said.

She went out on disability for three months, at full salary, and her job was held open for her. During those three months, doctors located the AVM. She returned to work, within six weeks, then went to Boston for surgery to remove the tangle of blood vessels. She planned to be out for a month at the most, but there were complications. One month turned into three. And when she returned to work, she was no longer the 50-hour-a-week multi-tasker she had been.

“I wanted to go back to work exactly how I was before, but I wasn’t the same,” Larisa said.

Typing was a struggle, as was reading documents. “Things had changed while I was gone, and a lot of reading was required for me to catch up and my processing speed was so much slower,” she said. “My information processing and attention were both affected.”

She also lacked the stamina to work 10-hour days. Though many of her co-workers were sympathetic, a few— including her supervisor— seemed to view her time away as time off and couldn’t understand why she wasn’t rested and ready to go. She had changed, but the only place she could really assess how she had changed was at work.

“For instance, it’s hard for me to fully participate in meetings because there’s so much going on,” she said. “Multi-tasking is a huge issue for me. And noise. I deal best with people one on one, so I can’t lead meetings anymore. I really wanted to go back to work, but it took a while to figure out what I could do. My job had to change. People were frustrated that they had held my job for me. It was just difficult all around.”

Fortunately, several people, including the head of human resources, wanted to find Larisa another role because she had been successful with the company for over seven years. They didn’t so much find a role as create one: Today she does initial phone interviews of potential new hires all over the country. She works 30 hours a week from home.

“With most employers there is not a problem when the accommodation is inexpensive — say, a piece of software, a change in desk height or work schedule,” Dr. Wehman said. “But the employer needs to know upfront what they are dealing with. They don’t like surprises.”

Vocational retraining or additional education may be necessary, as it was with Steve.

Since we published Steve’s story in 2004, there is a new opportunity in education called Massively Open Online Courses (MOOC). Many MOOC’s are offered by large and prestigious universities; they are exactly the same courses paying students take, but the MOOC versions are typically free, though no credit is awarded.

“I think distance education and online training and virtual education can be a valuable source of learning because it allows people to learn at their own pace,” Dr. Wehman said. “However, I honestly believe that having specialized help, accommodation and at least temporary support relearning the job at the job site is more valuable in most cases.”

Steve said he believes most employers are aware about rules preventing discrimination based on disabilities. However, the ADA does not require that someone be hired.

“There are myths about employing people with disabilities,” Steve said, “like the employer’s insurance rates will increase, or they will be absent more or accommodation will be prohibitively expensive. But I am noticing the employment world is getting better for people with disabilities as the disabilities in the workplace are brought out in the open, but sadly, discrimination still exists. The stroke survivor has to be willing to be a self-advocate.”

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Profile: Survivor Thomas Scott

Thomas Scott of Allen, Texas, had a stroke in 1997 at age 43. Although it left him with aphasia and right-side weakness, he returned to his job in building maintenance for a large property company about a month after his stroke. No longer able to climb ladders, he was switched from light technician to general plumber and told that whatever accommodation he needed would be made.

“One accommodation my managers made was allowing me to rest when I needed it,” he said. In addition, his co-workers helped with his duties. Occasionally he would forget things, like where he left his tools. “And sometimes I would not complete the assignment,” he said. Rather than being reprimanded, “I was told to slow down and pay attention to what I was doing.”

Over the next 15 years, he worked for two supervising engineers.

“The first was more tolerant of my disability than the second,” he said. “But I worked for him for eight years, so I guess he didn’t have that much of a problem with how I worked.”

In March 2012, due to a downturn in the economy, Thomas was laid off and is now on disability while looking for another job.

Ticket to Work & Work Incentives

Social Security’s Ticket to Work program supports career development for people with disabilities who want to work. SSDI beneficiaries ages 18 through 64 qualify. The Ticket program can connect you with a variety of free employment support services.

The Ticket program and Work Incentives allow you to keep your benefits while you explore employment, receive vocational rehabilitation or gain work experience. Cash benefits often continue throughout your transition to work and are eliminated only when you maintain a level of earnings, known as “Substantial Gainful Activity.”

How It Works

Everyone who receives SSDI or SSI is eligible to participate in the Ticket to Work program. To participate, contact an Employment Networks (EN) provider in your area to see if the services they offer are right for you. These providers offer career counseling, vocational rehabilitation as well as job placement and training. You may also receive services from your state vocational rehabilitation agency and then receive ongoing services from an EN.

The Work Incentives program makes it possible for you to explore work while still receiving healthcare and cash benefits. This program allows you to keep your Medicaid/Medicare benefits during your transition period.

There are other Work Incentives programs available. SSDI recipients can enroll in the Trial Work Period (TWP) program. The TWP allows you to test your ability to work for at least nine months. During that time, you receive full SSDI benefits no matter how much you earn as long as your work activity is reported and your disability continues.

A program called Expedited Reinstatement (EXR) is available to both SSDI and SSI recipients. If your benefits stopped because of your earnings level but you had to stop working because of your stroke, you can request to have your benefits reinstated without having to complete a new application. While Social Security determines your benefits reinstatement, you are eligible to receive temporary benefits for up to six months.

Another program, Protection from Medical Continuing Disability Reviews, prevents you from having to undergo a medical continuing disability review while you are participating in the Ticket to Work program.

Ticket To Work & Work Incentives

ssa.gov/work
Help Line 866-968-7842
866-833-2967 (TTY/TDD)
Resources

Job Accommodation Network
The Job Accommodation Network (JAN) is the leading source of free, expert and confidential guidance on workplace accommodations and disability employment issues. JAN’s consultants offer one-on-one guidance on workplace accommodations, the Americans with Disabilities Act (ADA) and related legislation, as well as self-employment and entrepreneurship options for people with disabilities. Assistance is available both over the phone and online.
askjan.org
800-526-7234 (Voice) | 877-781-9403 (TTY)

U.S. Department of Labor’s Office of Disability Employment Policy
For a contact list of state vocational rehabilitation agencies, visit askjan.org/cgi-win/typequery.exe?902

Rehabilitation Services Administration
The Rehabilitation Services Administration oversees grant programs that help individuals with physical or mental disabilities obtain employment and live more independently through the provision of counseling, medical and psychological services, job training and other individualized services.
www2.ed.gov/about/offices/list/osers/rsa/index.html

National Disability Rights Network
A resource explaining common terms and concepts used in the public vocational rehabilitation system.
202-408-9514 (voice) | 220-408-9521 (TTY)

The ADA: Your Employment Rights as an Individual With a Disability
This booklet explains the part of the ADA that prohibits job discrimination. This part of the law is enforced by the U.S. Equal Employment Opportunity Commission and state and local civil rights enforcement agencies that work with the Commission.
eeoc.gov/facts/ada18.html
800-669-4000 (voice) | 800-669-6820 (TDD)

ADA National Network
The ADA National Network provides information, guidance and training on the Americans with Disabilities Act (ADA), tailored to meet the needs of business, government and individuals at local, regional and national levels.
adata.org
800-949-4232 (Voice/TTY)
Last year, I faced a special challenge: How to celebrate the 40th anniversary of my stroke? January 20, 2013, was just around the corner, marking 40 years since a stroke destroyed half of the left hemisphere of my cerebellum. Within that one afternoon, I went from being a 24-year old doctoral candidate teaching a dance class at my university to an inpatient at a teaching hospital relearning the use of my left side.

Four decades later, realizing how fortunate I was to have accumulated so many “post-stroke” years with significant deficits but no recurrences, I wondered whether I had discovered any experiences worth sharing with other survivors. The idea of developing an expressive writing group composed of stroke survivors soon emerged.

In my own recovery, I had relied on deep reflective writing practices like journaling and legacy letters to help me make sense of how stroke had changed my life. I had found the simple process of finding words to convey my fears and resentments softened my fierce need to make sense of the experience. When I sat down to write, the blank page welcomed nagging questions about why I had suffered a stroke at such a young age and how it would affect my future. The more I wrote, the more I discovered inner resources that my pre-stroke self had never been forced to call on.

So I decided my 40th anniversary celebration would focus on finding ways to share expressive writing techniques with other survivors. I decided to develop a writing workshop that would support them through the process of harvesting their individual experiences of recovering from stroke. By sharing their writing with each other during the workshop, they would find a greater appreciation of their own coping skills and more confidence in their capacity to rebuild their lives.

Internet searches did not turn up any ongoing stroke survivor writing groups, but there was a growing body of studies on the health benefits of expressive writing about traumatic events including several studies of stroke-related writing. One meta-analysis of expressive writing by stroke survivors found five recurring themes:

- Feelings of sudden and overwhelming catastrophe
- Loss of control, as taken-for-granted abilities and ways of relating to others are disrupted
- Uncertainty, loss of confidence in the body, and a long-lasting fear of recurrence
- Social isolation, as the stroke limits their ability to engage in social and physical activities they used to enjoy
- Adaptation and reconciliation, as survivor-writers come to focus on positive aspects of life they believe they can control

A few years ago, I had taken a course in a life-writing technique called “guided autobiography.” My next step was to reconnect with my teacher, Dr. Cheryl Svensson, a professor at the University of Southern California, to discuss whether the guided autobiography workshop method could be tailored...
When I sat down to write, the blank page welcomed nagging questions about why I had suffered a stroke.

to address the unique concerns of stroke survivors. Thanks to Cheryl, within the month I had prepared the “Life After Stroke” workshop for a test run. And thanks to my local stroke association, I soon found an opportunity to pilot the workshop with local survivors.

In March 2012, the Montgomery County Stroke Association sponsored this new pro bono writing workshop for survivors who wanted to explore how stroke had changed their lives. As in the guided autobiography model, the “Life After Stroke” workshop involved a series of meetings where individuals wrote and shared brief essays in response to questions like:

• What was a typical day like for you in the months just prior to your stroke? What were your most important plans and goals in your life?
• In the early days of your recovery, did your medical team expect too much or too little of you? What about your friends and family?
• Did your close relationships survive the stroke? Who got closer? Who got more distant?
• What have been the most difficult losses to accept? How long did it take you to realize your recovery was likely to be a long-term process?
• What are the most important differences between the person you were the day before your stroke and the survivor you are today?

Following a series of four sessions, participants in the pilot workshop offered encouraging assessments. Some said the workshop had helped them understand how stroke had reordered their priorities and expanded their attention to the little pleasures in life. For others, the workshop offered an opportunity to appreciate how stroke had deepened their compassion for themselves and others.

“The workshop greatly aided my insights into how writing about my affliction(s) could benefit others who either are experiencing similar situations or could experience these situations. This medium is particularly effective if one has difficulty in articulating one’s feelings. No one wants to be or feel alone — survivor or caregiver.”

Bill Perrick, workshop participant

As part of our ongoing 20th anniversary celebration, Stroke Connection is planning a FREE writing workshop online with Carol Keegan. For more details or to sign up, visit strokeassociation.org/strokeconnection.

• Suppose someone you care about had a stroke. What is the most helpful piece of advice you could offer them?
It was Saturday, June 5, 2010, when I accompanied my mother, Parrie Bernice Love, to a ladies meeting at the local library. At the conclusion of the meeting, she had a stroke. I knew then that it would be a long, hard journey for all of us, particularly my mother. But I also knew that she would somehow overcome it, and that our close bond as a family would give her the desire and encouragement to get well.

My mother was 75 years old when the stroke occurred, and had multiple medical problems, including congestive heart disease, diabetes and hypertension. She had also had a heart attack. However, she never smoked, drank alcohol or consumed illegal drugs.

Her husband and children talked to her every day, although we did not know if she could hear us. We sang to her and played uplifting songs on her CD player; we massaged her arms, legs and feet to stimulate her nervous system. She would often rock her left leg back and forth to the music, confirming to us that she did hear and appreciate it.

Through this experience, I have learned that there is hope for the stroke survivor who receives family encouragement and physical therapy. I know survivors can regain their speech and use of their limbs. My mother was sent to a rehabilitation center where she received intensive therapy three or more hours a day. The more therapy she could tolerate, the more she received. The stroke affected her right side and paralyzed her arm, hand and leg. She also experienced right-side neglect, which caused her to lean to the left. The doctor told us to sit on her right side, which would cause her to use that side more and it would soon return to normal, which proved true. We watched her overcome one hurdle after another over the next two years.

It was important that she see my father regularly, and vice versa. He wanted to go with us every day, so we took him in his wheelchair. Although this was tiresome, the healing effect it had on my mother was worth the effort. We found that the way we spoke to her was critical. Our words were always encouraging and positive. She had become somewhat afraid and depressed, often crying, but when she saw us come in, her whole demeanor improved.
She retained her independence, always wanting to feed herself and do as much of her personal care as possible. This was a great sign. It proved that she was ready to get better and was not going to let anything stand in her way. We dressed her just as she had dressed prior to the stroke. At any given time there were enough clothes for the week in her closet, and her own toiletries. She told us what clothes she wanted to wear each day. She went to the in-house hairdresser; it gave her a sense of pride to have her hair done. Her nails were clipped and she wore her favorite makeup. All of these things gave her the feeling that she would one day live the life she had before.

She attended activities in the rehabilitation hospital, things like sing-alongs, church services and birthday parties. Going to these functions got her out of bed and moving around, and it also served to exercise her mind.

She wanted to improve and somehow garnered the power to do so. Her voice has started to return from aphasia and apraxia. At first she could form no words, but now she is speaking words more audibly and even a few short sentences. Fortunately, she never lost her knowledge and understanding, so she recognized everyone and everything around her.

After coming home, we found it best to get her out of bed daily and for her to sit for a while in a straight chair, as opposed to a soft recliner. This builds her muscle strength, which she needs to walk again. Standing beside the bed or using her hemi-walker allow for weight bearing, which is also necessary in order to regain nerve stimulation so she can walk. Much of that required a physical therapist, but the family also helped her to pivot and stand periodically, and she does appear to be stronger. The more exercise the better, and the stronger she becomes, the easier it will be for us to care for her.

We must be patient with stroke survivors. Remember, any small thing they accomplish is a great thing. At the rehabilitation center, Mother could walk six feet with the help of three people, which was a major accomplishment. The doctor’s goal for her was to walk much more. However, everyone improves at their own pace. She had to learn how to walk again in stages, beginning with standing from a sitting position, balancing her weight, bearing her weight and taking steps. It was like seeing a child walk for the first time — there was a glow in our eyes when she could walk without holding onto something and had acquired the freedom to move about.

Now we understand what being disabled means. The entire family is affected, particularly the daily caregivers. It is a big sacrifice for me to take care of my parents, both with serious illnesses. My entire life has been transformed into being their caregiver, and I have relinquished many of my aspirations as well as my social life. I make this sacrifice with love. The only time that I have for myself is in the early morning, when I get on my computer and write. I recently published a book, "Coping with My Mother’s Stroke, A Daughter’s Story" (Xlibris, 2011), the story of how our family managed to survive this devastating situation. I wrote it for caregivers and others who are caring for the aging and ailing of society.

Survivors can overcome many of the effects of a stroke, however, it demands that they (and their families) be committed to therapy, and that they (and their families) remain patient, allowing nature to heal their bodies in the proper timeframe. Survivors: Believe in yourselves and you, too, may experience a miracle in your life!
Technology Today

Technology is constantly changing our world. It happens quickly, and it can be confusing if you don’t keep up. If this article – which is about hardware and software technologies – uses terminology you’re unfamiliar with, visit Techterms.com for easy-to-understand definitions.

How Technology Helps

New technologies, such as smartphones and tablet computers, can help people with aphasia better integrate into society by assisting with conversational communication.

At the University of Michigan Aphasia Program (UMAP), we use the iPhone, iPod touch and iPad with great success. Their usefulness is enhanced with different applications (apps) and computer programs. Many devices and applications offer exciting and effective options for people with aphasia.

Helpful Hardware Devices

A significant advance in hardware technology is the touchscreen. A touchscreen allows you to work with your device just by touching it with your fingers; there’s no need for a mouse or trackpad. For some, this makes the process of navigating around their device much more intuitive and simple.

Touchscreen Devices

Smartphones combine phone, music, camera, email, Internet browsing, calendar, books and GPS in a compact, multi-purpose device. Because they use touch screens, these devices are most effective for survivors who have good visual and fine-motor skills, intact comprehension skills and strong cognition.

Web-enabled Media players such as the iPod touch allow users to store music, Google maps, birthdates, names, as well as job descriptions and titles that can be retrieved for social conversations. It also has a camera and allows texting. Basically, it is a smartphone without a phone. The benefit is there’s no monthly charge.

Tablet devices

Examples such as the iPad, Samsung Galaxy and Kindle Fire can perform many of the same non-telephone functions as smartphones or the iPod touch with the advantage of a larger display. This can be especially helpful if you use the device to read e-books or look up words in an online dictionary.

Helpful Apps

There are many different types of apps that have been developed specifically to help support people with various types of communication challenges.

**TEXT-TO-SPEECH:** Beneficial for nonverbal survivors or those who need models of words, phrases or sentences. You type in a message and the applications will say them.

**Examples:** Verbally, Speak to Me, Voice Reader Text, Speak for Me
TALKING PICTURE DICTIONARY: Beneficial for nonverbal survivors, those with difficulty initiating words or those who have trouble reading. These can be customized to include your vocabulary and they eliminate having to read.

Examples: Proloquo2go, VocaBeans, TalkTablet

PHONEMIC CUES: Phonemic cues are helpful when you know a word but need that first sound to say the target word.

Examples: Small Talk Phonemes, Sounds: The Pronunciation App

SPEECH-TO-TEXT: Beneficial when you know what you want to say but can’t spell the words. You speak the words into your device and the text can then be transferred into a text message, email, Facebook status, word processor and more.

Examples: Dragon Dictation, Dragon Naturally Speaking

Note: Many devices have built-in speech-to-text capability that can be used for short messages.

VIDEO CALL: This is beneficial if you have difficulty speaking or retrieving words and use gestures. The person on the other end can see your gestures and better understand what you’re trying to say. You may also see them, their gestures and facial movements, which make it easier to understand than a regular phone call.

Examples: Skype, Face Time, Google Hangouts

Helpful Tools

E-BOOKS: e-books come in a variety of digital formats and can be read from a smartphones, tablet, e-reader (such as a Kindle or Nook) or your computer. Depending on the format and the device you read with, you can have features such as pressing on an unfamiliar word and the definition will pop up, highlighting a particular passage or having the book read aloud to you by an app such as Blio. More books become available as e-books every day.

TALKING DICTIONARY: dictionary.com or Merriam Webster: These apps assist in determining meaning and pronunciation of words. They help you learn new vocabulary.

HOBBY/INTEREST APPS: Many apps have been developed for specific areas of interest and hobbies. They are a great way to help you get comfortable using your device(s). You can find apps for sports, cooking, gardening, bird-watching — you name it. Sometimes these apps are designed to let you connect with others who share the same interest.

How Survivors Are Putting Technology to Use

Many survivors find helpful uses for even the most basic functions included on most devices.

William, who is unable to speak clearly and has difficulty understanding information, practiced family names and sentences with voice memos.

Dave uses the calendar to remember appointments, which allows him independence in his daily routine.

Violet uses the camera to record daily and weekend activities that enhance her conversations. This allows her to be more confident and independent in social interactions and less fearful of not being able to come up with specific words.

Henry uses the dictionary during reading activities, which helps build his vocabulary.

Tim uses his iPad and gestures to discuss golf with others. It is important that survivors use these tools independently so they learn from errors. It is also important to schedule daily practice using these tools. In the beginning, survivors should practice for 15 minutes twice a day. As they become more proficient and familiar with the technology, they will learn its versatility and be able to use it in many situations. The goal is for survivors to use the tools automatically, but this takes practice, persistence and support from others.

Thanks to these tools, most of our therapy clients are able to share their stories more easily and effectively. They are also able to communicate and interact in groups more successfully. By using these tools, survivors have another means to communicate.
In our articles about aphasia, we often write about augmentative and alternative communication (AAC) techniques. Well, now there are apps for that! And some of them are free!

One of the free apps is Verbally, an assisted speech solution for the iPad. It is designed to minimize keystrokes and maximize ease and speed by offering easy-to-see grids of core words and core phrases. Its versatile features enable creative communication and self-expression. And, because it’s easy to use, it allows survivors with aphasia to carry on conversations.

Verbally is the brainchild of Ajay Godhwani. It also was a labor of love.

“I created it for one person: Nirmala Godhwani, my aunt,” Ajay said.

Nirmala was diagnosed with ALS (Lou Gehrig’s disease). Within a few months, she completely lost her voice, and with it, the ability to connect with loved ones.

When Ajay saw the impact this had on his aunt, he began to research the available products. What he found were expensive options with lengthy wait times for delivery.

“Because ALS is a degenerative disease, the delay was even more frustrating than the cost,” he said. “Our aggravation grew as we started to use one of the products with Auntie and found it hard to learn, cumbersome and unreliable.”

Frustrated, Ajay quit his job, founded Intuary, and began working full-time on Verbally. Unfortunately, Nirmala died a month before Verbally was launched.

“As a result, we are committed to ensuring that others never have to suffer the same loss of connection,” Ajay said. “We are committed to always offering a free version of Verbally. This aligns with Intuary’s mission: to empower users through intuitively designed apps that are affordable and widely accessible.”

For more information, visit verballyapp.com.
Please Mr. Postman

Acme Healthcare Claims Department
TO WHOM IT MAY CONCERN:

My name is John Kawie, I’m a stroke survivor and my policy number is Z-I-P-P-O-4-U. I am submitting a claim for a physical therapy session that took place at the Intrepid Sea, Air & Space Museum in Manhattan. (Admission ticket enclosed.) This may not sound like a traditional rehab facility because it’s not. It’s worse. The brochure said our experience would be leisurely and educational. But I’m here to tell you I got the workout of my life. Let me explain.

My cousin Ray, a Navy vet, made a pilgrimage to NYC specifically to visit the Intrepid, the retired aircraft carrier that served in the Pacific during WWII and Vietnam, then later plucked astronauts from the Atlantic. It’s spending its golden years as a museum docked in the Hudson River, which has become a kind of retirement community for floating relics.

On a wind-blown fall morning we began our tour up on the flight deck, which seemed as tall as the Empire State Building. The elevator was under repair so we were forced to use the external stairs located on the side of the ship (portside!). I don’t know if you’ve ever tried to get to the roof of a skyscraper by clambering up a fire escape, but even a mountain goat would have slipped a nitroglycerin tablet under his tongue after reaching the top.

Once there I discovered we were essentially standing on a parking lot full of planes. It was the size of a shopping mall. “Hey there’s the Batmobile!” I exclaimed. “That’s the Stealth Bomber, idiot,” Ray replied. I saluted with an, “Aye captain, lack of oxygen.”

When I stopped hyperventilating we followed the signs down (yup, more stairs) to the MD (Navy speak for mid deck). We arrived in the middle of “The Day of Darkness,” a re-enactment of a Kamikaze attack complete with concussive explosions and thick white smoke pouring in from every direction like the movie “Backdraft.” Temporarily blinded, I slammed into the business end of a surprisingly solid fighter jet. (This claim will be submitted separately.)

Once our coughing subsided we tried the interactive exhibits, like the vomit-inducing G-Force Simulator (dry cleaning bill attached) and the thrill of re-entry in a Mercury space capsule as it crashes into the Atlantic at supersonic speed. How Alan Shepard refrained from screaming is beyond me. Apparently my scream was blood curdling because all the kids were crying as I emerged through the hatch. By the third deck, I was ready to visit Davy Jones’ locker.

One could argue that the $20 admission fee is a bargain for a PT session. Looking forward to hearing from you.

Sincerely,
John Kawie

DEAR MR. KAWIE,

Claims manager William Robinson forwarded your letter to me because frankly he didn’t know what to do with it. I must say yours is one of the most unusual claims Acme has ever received. However, we do want to respond as positively as possible.

While we can’t reimburse for dry cleaning, if you can verify there was a qualified physical therapist on staff we will process the rest of your claim.

Sincerely,
Ms. Genevieve Clark, VP, Acme Healthcare

DEAR MS. CLARK,

Thank you for your prompt response. There was a tour guide, Mindy, who said she works part time as a masseuse down in Chinatown. I hope this qualifies. Meanwhile I’m staying clear of any military themed museums.

Sincerely,
John Kawie

LOVING LIFE AT THE CURB?

Now you can have John Kawie in your very own home and support Stroke Connection! DVDs of John’s award-winning one-man show, Brain Freeze, are now available. Visit BrainFreezeDVD.com for more details!

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!
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.