Working Out Your Speech Muscles
Which methods are best for speech recovery?

Victim or Survivor?
An Important Distinction

Getting Behind the Wheel
Driving after stroke requires planning and preparation

Life at the Curb
I’ve Just Seen a Face-book

Stroke before 50
Younger survivors face unique challenges

Survivor and mother Larisa Diephuis, 40, with her son Ian
Cover Story

8 Stroke before 50
Younger survivors face different life challenges than many of their older peers — for example, the types of reactions from others, raising young children and losing careers.

Features

6 Working Out Your Speech Muscles
It seems logical that non-speech mouth exercises would benefit speech production, but the evidence suggests otherwise. The process of speaking is more than mouth calisthenics.

14 Victim or Survivor? An Important Distinction
At first, survivor Mike Little was angry that his therapist challenged him when he called himself a victim. Later he came to understand, and embrace, her point.

Departments

2 Stroke Notes
4 Readers Room
16 Everyday Survival
We talked to an expert about vehicle modification and driving after stroke.
18 Life at the Curb
John Kawie discovers that he is a Facebook addict.
Do sudden, unpredictable emotional outbursts disrupt your life?

You are not alone.
You may be one of more than a million Americans suffering from Pseudobulbar Affect (PBA).

Pseudobulbar Affect can happen when disease or injury damages the area of the brain that controls how you express your emotions. The result: sudden, unpredictable crying, laughing, or other emotional episodes that can be disruptive and embarrassing.

But you are not alone. More than a million people diagnosed with neurologic disease or injury also have PBA—impacting their lives, and the lives of those close to them.

If you or someone you care for experiences these episodes and has been diagnosed with a condition such as multiple sclerosis (MS), Lou Gehrig’s disease (ALS), Parkinson’s disease, Alzheimer’s disease, stroke, or traumatic brain injury, it may be due to “short circuits” in brain signaling. It may not be depression. Learn more about how you might begin to take control.

To learn more, please visit www.PBAinfo.org
To address the low awareness and under-diagnosis of upper limb spasticity, the maker of BOTOX® has joined forces with several patient advocacy organizations and Henry Winkler — best known as Fonzie from “Happy Days.”

The educational campaign called “Open Arms: Raising Awareness of Upper Limb Spasticity” aims to reach those who are impacted by upper limb spasticity and don’t know where to turn for help. At OpenArmsCampaign.com, those affected by upper limb spasticity will learn how to recognize the condition and find resources to help locate a neurologist or physiatrist trained to manage and treat the condition. Throughout the year, several educational seminars will be hosted across the country, as well as on the Internet.

Tightness or stiffness in upper limbs significantly hinders many survivors’ ability to perform everyday activities, like getting dressed, maintaining proper hygiene and eating. A person dealing with upper limb spasticity may have a clenched fist, an arm that is pinned tightly against the chest or a flexed elbow or wrist that cannot be straightened without discomfort and force.

Winkler is personally familiar with the impact of upper limb spasticity. His late mother struggled with the condition, without treatment, for 10 years after a stroke.

“My mother was a proud woman, a busy bee, always on the go,” Winkler said. “So, it was very difficult for me to watch her revert inward as she was less and less able to do things for herself. She became fully dependent on her family and live-in nurses to help her with simple, ordinary tasks. Much less was known about upper limb spasticity during her time, and now, not only do we know more about how to manage this condition, there are treatment options available.”

The FDA recently approved BOTOX®, which is made by Allergan Inc., as the first and only botulinum toxin for the treatment of upper limb spasticity. While not a cure for the condition, BOTOX® may allow people with upper limb spasticity to open the affected hand or arm.

For more information about upper limb spasticity, or to find a neurologist or physiatrist who treats the condition, visit OpenArmsCampaign.com or the official campaign page on Facebook (Facebook.com/openarmscampaign).
More than a quarter of ischemic stroke patients with documented symptom start time arrived at Get With The Guidelines® – Stroke hospitals within the first hour of stroke onset. This allows the opportunity for quicker treatment with clot-busting drugs that can reduce stroke damage, according to a study in *Stroke: Journal of the American Heart Association*.

The “golden hour” refers to the first 60 minutes after stroke onset, when there is the greatest chance to restore blood flow and save threatened tissue. People who arrive within the first hour are more likely to receive tissue plasminogen activator (tPA) than are those who arrive between one and three hours after onset. Researchers studied data on 106,924 acute ischemic stroke patients with a known stroke onset time presenting to 905 hospitals participating in the American Heart Association/American Stroke Association’s Get With The Guidelines – Stroke quality improvement program between April 2003 and December 2007.

Besides determining how often patients reached the hospital within the first hour, researchers identified features that distinguish golden-hour patients from patients who arrive later. They also examined the treatments those patients receive.

People arriving within the golden hour tended to have more severe stroke deficits and more frequently arrived by ambulances than those arriving later. Once they got to the hospital, these patients more frequently received tPA.

More than one in four patients arriving in that first hour were treated with tPA, compared with only one in eight patients arriving one to three hours after onset and virtually no patients arriving later.

However, hospitals did not treat early arriving patients as promptly as would be ideal, the researchers said. The national guideline goal is to treat patients with intravenous tPA within 60 minutes of their arriving at the emergency department. Only about one in five of the golden-hour patients were treated within that timeframe. 

A NEW STUDY found that continuing warfarin therapy during pacemaker or defibrillator implantation in patients with moderate to high-risk of producing clots is safe and cost-effective. According to research published in the *Heart Rhythm Journal*, cessation of warfarin with bridging anticoagulation resulted in a higher incidence of bleeding complications and a longer hospital stay. In addition, patients with temporarily interrupted anticoagulation suffered from a higher risk of transient ischemic attacks (TIAs) than those who continued warfarin therapy.

The retrospective study evaluated 459 patients on warfarin therapy who underwent antiarrhythmic device surgery from April 2004 to September 2008 in Minnesota. There were three patient groups: continued warfarin therapy (48 percent), cessation of warfarin with heparin (another anticoagulant) bridging therapy (26 percent) and temporarily interrupted anticoagulation without bridging therapy (24 percent).

The study found that patients who continued taking warfarin had a lower incidence of bleeding and a shorter hospital stay. Patients who continued treatment on warfarin experienced no TIAs.

Because of concerns about excessive bleeding and potential associated complications, many doctors temporarily stop warfarin therapy with or without bridging therapy with heparin in patients preparing to undergo device implantation. This study indicates that continuing warfarin is beneficial to these patients from a safety and cost standpoint.
I am a 55-year-old stroke survivor and I recently competed in the disabled rider division at a horseback riding competition in Athens, Texas. I came in second place, and I must admit, I was grinning from ear to ear!

The right side of my body, including my hand, leg and foot, are paralyzed. I wanted to find something I could do in spite of these limitations. I heard about therapeutic horseback riding and decided to look into it. I found Stable Strides Farm in Flower Mound, Texas. Fortunately, a stroke survivor was having a lesson the day I visited. She sat on the horse very straight, walked and even trotted the horse. I found out from her husband that she had been doing it for three years and loved it, and that when she was not on a horse she was in a wheelchair. That did it for me. I may be a slow walker, but I was going to be a horseback rider!

At Stable Strides Farm, Mandy Cleveland instructs for a program called Teaching Independence in Life through Independence in Riding. During my first lesson I was a little bit scared. What if the horse threw me? How do I get on the horse? Will there be enough volunteers to help me? Am I too old for this? Mandy said: “Stop worrying. I am not going to let anything happen to you.” The barn had a ramp, and two volunteers helped me get my right leg over the horse. Two other volunteers held me straight until everything was right. I was sitting on a horse and the feeling was unbelievable!

During my 30-minute lessons over the next weeks, I learned to walk the horse, trot, do circles and trail patterns. That’s when Mandy suggested I enter the competition in Athens and I nervously said OK. Mandy told me Athens did not have a ramp, so I would have to get on the horse from her pickup truck.

The day of the competition, I wondered what I had gotten myself into! I had only had eight lessons, but I was determined to go through with it. When the time finally came to compete, I sat on my horse with my heart pounding. I did all the patterns, but I couldn’t make my horse trot. Nevertheless, I felt so excited because I had finished my first competition. People from Stable Strides and people I had never met came up to me saying things like: “Congratulations, you did a great job! What a ride. You looked so good.” It was totally amazing.

That day I was entered in two classes, and I placed second in my second competition. I still may walk slow, but now I can ride a horse and compete as a disabled rider.

Tracy Virant, Survivor
Dallas, Texas
What a wild ride the past 13 years have been! Eight brain and spinal surgeries beginning when I was a newly married 26-year-old. It was July 1997 and I collapsed while working out at the gym. I was rushed to the hospital where it was determined I had bleeding on the brain from an aneurysm I didn’t know I had. Doctors had to stabilize me before they could clip the bleed. After that, they sent me to a rehab hospital. I was there a short time but wasn’t doing well because of fluid building on my brain. So it was back to the first hospital for a shunt.

After nine weeks in the hospital – including my 27th birthday – I got to go home on my husband’s birthday. What a gift to both of us! But that’s when the real work began. I was in speech, occupational and physical therapy three hours a day, three days a week for several months. Probably the hardest thing to deal with was the fact I had a paralyzed vocal cord, leaving me without a voice. I worked as a television news anchor and reporter, so speaking was my life. I had to wait nearly nine months before we could do anything about that.

I finished my therapies and scheduled a vocal cord implant to be done at Vanderbilt Voice Center. I had the implant and went back to work, and no one knew the difference. Going back to work was hard because I was basically starting over. I didn’t realize I had memory problems until then. But I stayed with it and was feeling pretty good.

Then one day I sneezed and felt as though my head were going to explode. My shunt stopped working, so it was off to the hospital again. That happened four more times in the next six months. Each time doctors would just move the shunt over, and it would start working so they’d stitch me up and send me home. After the sixth time, I wasn’t feeling all that great. MRIs revealed a golf ball-sized cyst pressing on the shunt, causing it to malfunction. Doctors used an endoscope to puncture the cyst and everything started working just fine.

After a few years I began having some numbness in my right hand. My general practitioner treated me for carpal tunnel syndrome, but the condition didn’t get better. When the headaches started I decided it was time to see my neurosurgeon. After extensive tests, he diagnosed me with “syromengelia due to chairi malformation.” In layman’s terms, my brain was sagging into my spinal canal and causing a cyst to form. More surgery was needed, and I had to see a specialist in north Florida.

We road tripped to Shands Hospital at the University of Florida in Gainesville where I had decompression surgery. I was in the hospital for about five days, and that was by far the most painful and difficult surgery to recover from. I could hardly move afterward and was discharged using a walker. I spent at least six months in physical therapy just so I could walk unassisted again. That surgery was in November 2004, and since then I have been back to physical therapy three times because I was having trouble. I still have trouble, but I won’t let it keep me down! All is good now.

As I said at the beginning, it’s been a wild ride. But it’s one I’ve survived, I’m proud to say. I’m very lucky to be able to live normally; I have a good job. It hasn’t been easy by any means, but it’s important to know you can survive.

Amy Ofenbeck, Survivor
Fort Myers, Florida
any people experience speech problems after a stroke. This can be devastating, because communication is an important human behavior. These speech problems can be treated in a variety of ways. One therapy method that has received increasing attention in recent years is non-speech oral motor therapy. When we use the word “motor,” we basically mean “movement.” In non-speech oral motor therapy, the person is asked to perform various non-speaking activities with different parts of the mouth. These activities may include blowing horns, blowing bubbles and isometric strength training. An example of this training would be the survivor pressing his or her tongue or lips against some type of resistance, such as a tongue depressor held by the clinician. The activities may also involve stimulating parts of the mouth with ice or heat.

Because these non-speech activities involve the mouth, it seems logical to assume that improved ability to perform these tasks would lead to improved speech. However, despite the fact that these techniques have been around for years, there is still no good evidence to show that working on non-speech oral motor skills improves speech. This is true for adults with acquired speech problems from stroke, traumatic brain injury or neurological diseases. It’s also true for children who are having problems learning to speak. In fact, there is good evidence from studies of normal motor learning and of motor recovery after stroke and traumatic brain injury to show that speech and non-speech motor skills are very different. Here are some reasons why:

1. **Motor learning/recovery is task specific.**
   The brain is not a static organ. It changes constantly as we experience life. The ability of the brain to change is referred to as “neuroplasticity.” The brain actually changes to learn a new skill or recover an old one. The research on recovery of motor functions after stroke has shown that several important factors drive neuroplasticity. One of these is specificity. The greatest gains are made when the practice is specific to a skill someone wants to learn or regain. So, if you want to learn to hit a baseball, you have to practice hitting a baseball. Similarly, to try to regain speech skills, you must practice speaking.

2. **Speech is a complex process that involves a sequence of coordinated movements.**
   Normal speech involves a variety of moving body parts, including the lungs, the larynx (voice box), the roof of the mouth, the tongue and the lips. Movement of these structures during speech is very rapid, and precise timing of each movement is important. This is true even when you say a single word. Some of the non-speech oral motor techniques work on just one body part, such as isometric exercises for the tongue. Also, even when more than one part is involved, such as during horn blowing, these body parts are being held in a relatively constant position — unlike the rapid movements that occur during speech. Another important factor that has been shown to drive neuroplasticity in the motor system is complexity. Non-speech oral motor therapy tasks are simply not as complicated as speech.

3. **Successful speech is rewarding.**
   Another important factor driving neuroplasticity is salience, or how important an activity is to someone. Although this area
needs to be studied further in relation to motor control, I would argue that the successful speech is more important for adults than blowing a horn or doing “tongue push-ups.”

4. Different areas of the brain are used for speech and non-speech oral movements.

There are several ways to study how the brain works. These include functional magnetic resonance imaging (fMRI) and positron emission tomography (PET). Studies using fMRI and PET have shown that different areas of the brain are active during speech as compared to non-speech oral movements. In general, during speech, there is more activation on the left side of the brain, while during non-speech oral movements, the activity is similar on both sides of the brain.

Although the use of non-speech oral motor therapy has become increasingly popular, there is little evidence to support its use. In fact, there is much evidence to show why these techniques are unlikely to help survivors regain their speech. It’s unlikely that practicing these techniques would hurt someone, but they do take time. And one of the most precious things we possess is time. Therefore, it is important that therapy make the best use of a survivor’s time. Moreover, some third-party payers, such as Medicare, limit funding for speech therapy. And it’s critical that these limited dollars be used in the best possible way. If you have speech problems after a stroke or head injury, here are some things you can do:

Work with a speech-language pathologist on ways to improve your speech.
Practice saying sounds, words and sentences whenever you can.
If your speech-language pathologist or other therapist suggests non-speech oral motor treatments, ask what you should expect to gain and if there are other treatment options.

Additional Resources

The Academy of Neurologic Communication Disorders and Sciences has developed evidence-based practice guidelines for dysarthria and apraxia of speech, the two likely speech problems after a stroke. The guidelines were developed by reviewing the research literature to search for evidence to support the use of various therapy techniques. The link to the academy’s website is provided below.
The American Speech-Language-Hearing Association sponsored an evidence-based review of non-speech oral motor exercises. The link to that document is also provided below.
ancds.org/practice.shtml
http://ajslp.asha.org/cgi/content/abstract/18/4/343?etoc

To find an ASHA-certified speech-language pathologist near you, go to asha.org and click on “Find a Professional” or call (800) 638-8255.

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Stroke before 50
As we have talked with younger stroke survivors about their experiences dealing with the effects of stroke, we have noticed four major issues that seem to consistently bubble up: raising children after stroke, reactions from other people, loss of friends and loss of a career.

In addition to talking with survivors and caregivers, we also discussed these issues with Dr. Sara Palmer, a rehabilitation psychologist and assistant professor in the Department of Physical Medicine and Rehabilitation at Johns Hopkins School of Medicine. Dr. Palmer and her husband Jeffrey B. Palmer, M.D., are authors of the book *When Your Spouse Has a Stroke: Caring for Your Partner, Yourself and Your Relationship*, to be published by Johns Hopkins University Press next spring.

Following are just a few young survivors’ thoughts about the major issues they face, as well as Dr. Sara Palmer’s insights on dealing with those problems.

**Raising children after stroke**

Stroke recovery and raising children does not seem to be a match made in heaven. Survivors face anxiety and stress as they realize the physical, emotional and cognitive limitations that affect their ability to raise their children. Children require a lot of energy, and sometimes survivors just don’t have it to give. For the children, there may be great frustration and confusion as they try to navigate a relationship that may have changed dramatically.

Survivor Beth Harrell, who was 45 when she had her stroke, had to give up taking care of her 9-year-old son Jacob, who went to live with his dad in another state. “I was a stay-at-home mom, and Jacob and I were inseparable,” Harrell said. “It was so hard to leave him; I miss him every day.” Harrell now lives with an adult daughter. “My children were affected most by the emotional changes I experienced: the frustration of daily things, the confusion, my impatience with myself and having to learn to depend on others. I would cry over anything and sometimes nothing. They could not understand that although I wasn’t in physical pain, emotionally, I was a wreck. The fact that my life had been turned upside down was so hard for me.”

Sarah Teague of Churubusco, Ind., had a stroke two years ago, when she was 29. Married 10 years, she has 6-year-old twin sons, Ben and Nick. She continues to manage vision problems, left-side numbness and central pain as a result of her stroke. “My children are still small, so it affects them because I am unable to do the things I used to do, like riding a bike, playing catch, or just running in general,” Teague said. “My dizziness and vision problems make it impossible to do those things without falling or hurting myself. My nerve pain also takes its toll on me daily, especially when it interrupts my sleep. It is hard on the twins that mommy is always tired or can’t do something I used to do. Once one asked me, ‘Mommy, when will your stroke be over?’ I think now they have accepted that this is how Mommy is now.”

In some ways the physical limitations affecting parenting are easier to handle because couples can divide chores so that the spouse provides the physical care their children need. This allows the survivor to be involved with the children in other ways. “Even with physical limitations, survivors can be active parents,” Dr. Palmer said. “They can still pass on values, make rules, discipline, provide emotional
support and closeness to their children, talk and play with them, and do many enjoyable activities. Survivors who have some cognitive limitations can use their strengths in parenting. For example, even with memory problems, a parent may be able to read to his children, and a survivor with aphasia may be able to cook or drive carpools. Parenting is not an all-or-nothing activity."  

Larisa Diephuis of New Orleans survived a stroke in November 2009, then had brain surgery to remove an arteriovenous malformation 4½ months later. She was 39 at the time and the mother of 4-year-old Ian. “After both the stroke and surgery, my balance was way off, and I constantly felt seasick and could not walk or read,” she recalled. “I told Ian that I had a boo-boo in my head and needed to rest to get better and could not play with him like I used to. For a long time, my husband had to put him to bed because I often went to sleep before he did. Recently I started putting him to bed again, and the first night I fell asleep in his bed and he clung to me. He was so happy that I was better.”

Dr. Palmer points out that any explanation of stroke symptoms needs to be age-appropriate. “In addition, children need to be reassured that they are not the cause of the problem,” she explained. She also recommends explaining to children that often survivors get better over time and that things may change as their mom or dad continues to recover.

Diephuis is concerned about what will happen when her short-term disability ends and she returns to work. “I will have to rest more and may not be able to do as much with Ian,” she said. “I’m not sure if I will be able to ‘do it all’ again like I used to.”

Limited energy is among the most common effects of stroke, especially early in recovery. Because of this, Dr. Palmer suggests that survivors prioritize the responsibilities and activities that are most important to them and their families. “One of the most common accommodations at work is a change of work hours or schedule. This can make it possible for the survivor to get adequate rest and save some energy for quality time with family,” she said. “Getting more help with household chores can also free up time for playing with children, helping them with homework or attending their after-school events.”

Teague’s lack of energy has caused her to question how to be involved with her children and when to accept help. “It is hard to watch someone else share activities that I’m not able to do,” Sarah said. “But then I ask myself, ‘Do I want my children to miss out because I can’t do something?’ For me, the answer is a definite no because they have already had to adjust to so much. I want them to do whatever other children do, even if I’m not doing it with them.”

Diephuis had a helpful insight about children and disability. “Kids handle disability more naturally than adults,” she said. “When I came home from surgery, my nieces, nephews and son barely noticed my head was shaved and that I needed a walker. They were just happy I was home. They thought the walker was cool and were happy to bring it to me. Kids really want to help as much as they can.”

The reactions of other people

Because most people think stroke only happens to elderly people, they often express disbelief when they run into a young survivor. One response that is particularly hurtful is the implication that the survivor did something that caused the stroke, like using illegal drugs.

Caregiver Monica Foster recalled how her husband, Bryan, experienced this response from the medical staff at the hospital where he went for treatment after his stroke in 2000 at age 31. “He was accused two different times of being a cocaine addict, even though his blood and fluid screens were clear,” she said. “Two different doctors started off the exam with, ‘So, Mr. Foster, how long have we been doing drugs?’ He was livid and so was I.” As
it turned out, his ischemic stroke was caused by a clot that formed in his leg and passed through a congenital hole in his heart that no one knew was there. The hole has since been repaired.

Dealing with the reaction of others to any kind of disability can challenge even the most adept communicators. Dr. Palmer suggested this situation is an opportunity to educate people about stroke and its causes. There are congenital heart and blood vessel problems, as well as risk factors like diabetes, hypertension and a family history of stroke that can affect younger people as well as older people.

Teague knows well the skepticism of the general public. “It’s hard to see the shock on people’s faces when you tell them,” she said. “I hate that look of ‘what did you do to have that happen?’ Like it was my fault. I had an artery dissection, and yes, I was only 29, but it happens. Please don’t judge me.” Teague has also been frustrated at comments from relatives who think she should be over the stroke because it happened more than a year ago.

Sometimes family members are judgmental out of ignorance. “This is another opportunity for education,” Dr. Palmer said. “Survivors and caregivers can explain that recovery from stroke often takes a long time and that progress is gradual. It’s a good opportunity to tell people about some resources where they can find out more.”

Diephuis is often surprised at the response from friends who tell her she’s lucky. “A hemorrhagic stroke before I was 40, several MRIs, two angiograms, an AVM, brain surgery, brain swelling, my head being drilled into to relieve the swelling, 10 days in ICU, bruising up and down my arms from the IVs, PICC lines, and A lines, shots in my stomach to avoid clots, steroids, salt tablets, etc.” she said. “I certainly do not feel lucky. I think that people feel the need to say something positive. I know they mean I am lucky to be alive, but to me lucky means something good happened, and this definitely isn’t something good.”

Of course, it is natural for friends to go straight for the positives, in part because it makes them feel better and more hopeful. “What survivors need is empathy for what they have gone through rather than for someone to assume they know what the survivor is feeling,” Dr. Palmer said. “Just being there and listening to the survivor is helpful. A good place to find that sort of understanding is in a stroke support group.”

Harrell has experienced another painful response. “I have had people say, ‘You’ve got it made. You don’t have to go to work, your bills are paid. Things like that. I finally told a relative, ‘That is true, but I lost my house, my job, my car and my son. So tell me again how lucky I am.’”

People make comments about disability insurance because they see it as a “free ride,” and may assume that the survivor would rather not work. “But disability payments are deserved, and they are a necessity that makes life possible for survivors who can’t work after a stroke. What’s more, most survivors want to make a contribution to society, and many miss their work very much,” Dr. Palmer said.

Firefighter Bill Adams of Katy, Texas had a stroke at 38 while at work. He thinks the way people respond to survivors is more because of ignorance than insensitivity. “As a first responder, I have dealt with many stroke patients,” he said, “but I never fully understood what was actually happening to them.
Classes, books, science and talking to people can only get you so far in understanding what is going on in the changed mind of a stroke survivor. I am by no means saying we survivors should have to explain ourselves to everyone we meet. I am simply saying think of how much you knew pre-stroke about brain injury. Compare that to the vast amount of knowledge you have today about the same subject.”

As stroke families well know, the general public is not knowledgeable, and it can be tiresome to always be educating people. “Survivors shouldn’t feel obligated to be the ‘spokesperson’ for stroke all the time,” Dr. Palmer said, “but educating others can make survivors feel more empowered, as well as helping people be more aware of what a stroke can do.”

Loss of friends

For caregiver Wylene Jones, 45, of Cleveland, Tenn., life changed dramatically after her husband David’s stroke in 2009. Never very outgoing, he has turned more inward, which has affected Wylene and their two children. And after a while, friends just weren’t around anymore. “When he was in the hospital, many people volunteered to come and stay with David so I could run errands or get out of the house. But when I called on them, they always had an excuse...”

“I have made several friends (on Facebook) who are expanding my horizons. Without them I might just sit in my room and be critical of what I can’t do.”

Michael Proffitt: survivor
Age at time of stroke: 49

like I am stuck on an island – just me and my family.”

Depression is common after stroke, in both survivors and caregivers, and makes it harder to get back into life. “It is important to talk about mood changes with your doctor, and to get assessed for depression,” Dr. Palmer said.

“I have made several friends (on Facebook) who are expanding my horizons. Without them I might just sit in my room and be critical of what I can’t do.”

Michael Proffitt: survivor
Age at time of stroke: 49

“And if it’s there, it needs to be treated, with psychotherapy, medication or both. If it’s not treated, survivors are less likely to participate in social events, and others will be less comfortable around them — and the family ends up getting more and more isolated. I always encourage families to find some sort of respite care, either with other family members or paying someone to come in. It is not healthy to be on that island alone. Respite care is good for caregivers, but it is also good for the survivor, who is often concerned about having to lean so heavily on their spouse or children.”

Adams and his wife had plenty of support while he was in the hospital, but that went away once he returned home. “In my case, I think people tended to stay away for fear of seeing a strong, young person be bedridden, unable to move and function independently,” he said. As lieutenant of a fire squadron, he worked closely with a crew of five men, none of whom visited him in the hospital or in recovery. “That hurt, and I have never confronted them or inquired why they did not come to see me,” Adams said. “I attribute it to the fact that they saw their boss in such a difficult situation, and they were afraid that if this could happen to me it could happen to them.”

Michael Proffitt of Olympia, Wash., had a stroke at age 49. After weeks in a coma, he characterizes his recovery as slow. He has found Facebook to be a good way to reach out to people. “I have re-connected with a woman I went to high school with, and she has been very supportive. We walk together several times a week. I have made several friends there who are expanding my horizons. Without them I might just sit in my room and be critical of what I can’t do.”

Dr. Palmer pointed out that Facebook is a good way to supplement friendships but shouldn’t become the survivor’s whole world. “Survivors are better off when they interact with people face to face,” she said. “Getting
out into the community, whether it’s taking classes, worshipping, going to a restaurant, or attending a baseball game, expands opportunities to develop meaningful relationships. Getting ‘out and about’ also increases physical activity, which helps recovery.” In particular, peer support groups are a great way to begin meeting people and getting comfortable with socializing.

Although she has not lost many friends, Diephuis feels that they cannot understand what she has been through. She, too, has found supportive relationships online. “I have created great new friendships through an AVM survivors group online. The neat thing about that is you sometimes become friends with people you might not otherwise. I feel like I couldn’t have survived this without other survivors to reach out to.”

**Loss of a career**

One of the biggest adjustments younger survivors face is the loss of meaningful employment. As one survivor put it, “The hardest thing for me was getting used to the possibility of 30 or 40 years of idle time.”

Giving up work was hard for Harrell. “I felt and still feel somewhat useless,” she said. “I was a very hyperactive person and truly do miss working. I can certainly relate to having too much time on my hands. I no longer have the satisfaction I got from a hard day’s work. I feel less pride in my accomplishments.”

Teague has similar feelings. “It is hard to admit to myself and the world that I am disabled to the point where working is impossible,” she said. “I had planned on going to work when my children entered school, but that is not possible. I feel very low about the fact that I don’t contribute financially to my family.”

Although this is a big challenge for young survivors, it is also an area where a lot of professional help is available. “Every state has a vocational rehabilitation program where survivors can have their skills re-evaluated,” Dr. Palmer said. “Even if you can’t work, you may be able to volunteer or take on another role in the family that gives you a sense of being valuable and useful.”

Jones suffered a devastating loss of income when she had to stop working to take care of her husband. “I had always worked two or three jobs since 1983,” she said. “The unpaid work that I am doing as my husband’s fulltime caregiver is much harder than any job I have ever had. It is harder physically, mentally and emotionally. I really miss working.”

It is common for survivors to feel anxiety when returning to work. Skills assessment can relieve some of that anxiety. Neuropsychologists can evaluate cognitive abilities and make recommendations to employers about work accommodations, such as having a quieter work area, taking more frequent breaks or using memory aids. “Physical therapists and occupational therapists can evaluate physical abilities related to specific work tasks; they can connect survivors with assistive devices and technologies that will help them get the job done, and make recommendations to an employer about what will maximize the survivor’s efficiency,” Dr. Palmer said. “It’s good to get both a physical and cognitive evaluation so survivors and family members can know exactly what is possible in the vocational realm, and what type of help is necessary to make it work.”

Vocational counselors can be helpful in this process, too, and can also help a survivor find a new career path if their old job is no longer doable.

Profitt was a chef with his own restaurant before his stroke. Although no doctors told him he couldn’t cook again, it was clear that his lack of mobility and short-term memory would prevent him from working in a kitchen. “I was depressed for six months because I couldn’t cook anymore. I’m sad because I like to cook for people. I don’t get the positive reinforcement that I used to. I cooked for six friends last week, and it was great, but then I slept for two days. I can cook some now, but I couldn’t run a kitchen. But two years ago I couldn’t even cook. I have limitations, but I am slowly making small holes in them.”

Younger survivors face different challenges than older survivors. Having many years post-stroke changes the equation somewhat, but it also means there is more time for recovery. Also more time to find a way to make a contribution to your family and your community. For many that starts with participation in a support group. To find out if there is a stroke support group near you, visit strokeassociation.org/strokegroup.
In 2004, while reading a book in bed, I had a cerebral hemorrhage. Following emergency brain surgery to remove the blood clot that had formed inside my skull, I was sent to the VA Medical Center in Minneapolis because I am a combat veteran of the Vietnam War. It was at the Medical Center where I did my rehab. This large VA hospital is a teaching facility. Following my admission, I was assigned to the Traumatic Brain Injury ward. Many of my fellow patients were soldiers wounded in Iraq or Afghanistan.

Now that it’s been a few years and I’ve gained some perspective on the experience, I feel it is important that I share lessons I learned. I hope my experience can save some people some grief and help with their recovery.

One day following occupational therapy, a few of my fellow patients and I were discussing our injuries. As I was speaking to the group, I referred to myself as a victim because I didn’t know what else to call myself. I wasn’t feeling sorry for myself, but I didn’t know what else I could be if not a victim.

A young nursing student was standing nearby and heard me refer to myself as a victim. She spoke up and said: “A bunch of us in class were talking about this, and we decided that you shouldn’t think of yourself as a victim because I didn’t know what else to call myself. I wasn’t feeling sorry for myself, but I didn’t know what else I could be if not a victim.”

I disregarded what she said. Later, when I got back to my room and had time to think about her comment, I wondered, “Who does she think she is?” It angered me because she hadn’t experienced serious brain injury and couldn’t possibly know anything about it. Why should I care what a few clueless students think about the mindset of people who’ve been brain damaged? They couldn’t know about the chaos of my ruined, fun-house vision or the way people’s speech sounded garbled like they were speaking underwater. My reality was so alien and foreign to what I had known the normal world to be, I couldn’t believe people who hadn’t experienced it could possibly understand the overwhelming effects of brain injury.

My mistrust of her opinion was a common attitude among stroke and brain injury patients in my ward. Much of what my therapists told me I doubted because I knew they had no personal experience. I thought they were doing nothing but parroting what they read in a book. Consequently, much of our therapist’s efforts were met with suspicion, disbelief and doubt. I don’t know why most patients felt this way, but as far as I could tell nearly everyone did.

Now that several years have passed since my stroke and that terrifying medical thrill ride is over, I’ve had time to digest the nursing student’s advice. What I didn’t understand at the time was this – if we think of ourselves as victims, we have psychologically surrendered and given up. We find solace in feeling sorry for ourselves: “Life is so unfair. See what happened to me? Don’t you feel sorry for me? Please say yes.” This impedes our recovery!

Conversely, if we think of ourselves as survivors, we have the mindset of a fighter, determined to keep moving forward.
until we win: “I refuse to be beaten down. I will not give up on myself or on my recovery.” The difference in a victim’s mindset and a survivor’s is night and day.

During my traumatic brain injury and recovery, I had no one to talk to who had been through it. As I’ve explained, therapists, doctors and nurses didn’t count because none of them had been through the experience, so all they could do was repeat what they had read in a textbook.

My experience was horrifying and I’d have given anything to speak with someone who had been through a similar experience and survived, but there was no one around I could speak with who had the bona fides. Consequently, when I was discharged from the VA after two months of rehabilitation, I was determined to volunteer at my community hospital to guide other stroke and brain injury survivors. I wanted to do for others what I wished someone had done for me.

Once I got home, I went to my community hospital and pitched my counseling idea to them. They were very receptive, although no one had done this before.

For two years I spoke one-on-one with newly injured stroke and brain injury patients. Because I had been through the experience myself, I had the bona fides, and the patients nearly always listened closely to what I had to say.

Much of my talk with patients was encouraging them to consider themselves survivors and not giving up or think of themselves as victims. My talks were aimed at getting people their fastest possible recovery with the least pain and anguish possible.

In addition to speaking with hospital patients, I also carried my message to different stroke support and caregiver groups.

My volunteer work was rewarding emotionally because I was able to see people grow and move forward as they fought for maximum possible recovery. It was a wonderful experience because people came up to me and said things like: “I heard you speak a few months ago and it changed my life. Thank you for your help.”

This isn’t why I began my volunteer efforts. When I began, I didn’t expect thanks. I didn’t expect anything, but it was nice just knowing I’d helped people through a dark and scary time the way people like the nursing student helped me through a rough patch. My volunteer work was my way of saying thank you to her and others at the VA medical center who helped me when I needed it most.

By the way, my recovery was nearly 100 percent successful. Looking at me or speaking with me today, you wouldn’t know I’d survived a devastating stroke. I have a few lingering effects and my life was turned upside down, but I get by.

An experience that at one time loomed so large in my life is today just a tiny footnote. It has slipped into unimportance. Most days I don’t even think about it.

THE WARNING SIGNS OF STROKE:

- Sudden numbness or weakness of the face, arm or leg, especially on one side of the body
- Sudden confusion, trouble speaking or understanding
- Sudden trouble seeing in one or both eyes
- Sudden trouble walking, dizziness, loss of balance or coordination
- Sudden, severe headache with no known cause

If you experience some or all of these warning signs, don’t wait. Call 9-1-1 right away.
for most Americans, driving is a sacred right, so losing it feels like a serious penalty. Many survivors measure recovery by whether and when they can pilot a car again. In reality, their deficits are sometimes too great for that to be possible, but in other cases vehicles can be modified to accommodate those deficits. We talked to Elin Schold Davis, coordinator of the Older Driver Initiative at the American Occupational Therapy Association, about vehicle modification.

Schold Davis emphasized that before stroke families consider modifying a vehicle, they should first get an evaluation of the survivor’s ability to drive safely. “Reflex speed, scanning and strength all need to be at a certain level before someone can drive,” Schold Davis said. The evaluation should be conducted by a credentialed driving evaluator, ideally an occupational therapy driving rehabilitation specialist, Schold Davis said. “This will have a cost associated with it, but it is well worth the money,” she said. “The evaluation helps the family see all the issues and provides a menu of options to choose from.”

Next, survivors and caregivers need to understand exactly what steps must be taken to resume driving so survivors can work toward accomplishing those things.

**Vehicle modification**

Most states require any vehicle modification to be performed by a certified installer. Regardless of the law in your state, Schold Davis suggests using a certified installer because devices installed improperly put the driver and others at risk and could pose liability issues. The driving specialist should be able to help you find a qualified installer. You can also visit the National Mobility Equipment Dealers Association website to locate someone in your area (nmeda.org).

Most vehicles are modifiable, but some are less expensive to adapt. “Sometimes it’s cheaper to buy a different vehicle,” Schold Davis said. “Some accept wheelchair or scooter lifts better than others. Couples where the caregiver has health limitations may want to modify the passenger side to accommodate him or her. It may be expensive, but it can also help the family maintain their desired level of independence in a way handicap transit services may not.”
Cost

Modifications can be expensive for a stroke family. Many insurance plans, including Medicare, do not cover vehicle modification, even when prescribed by a doctor. However, there is sometimes wiggle room with private insurance. “Vocational rehab agencies are a possibility if the survivor is returning to work,” Schold Davis said. “Some veterans have this assistance, and some health systems have money available on a sliding scale. In any case, getting this money will require some champion in the family to do a bit of research.”

All vehicle manufacturers have mobility divisions, and they will know which vehicles best support particular modifications. Most also offer incentives such as $1,000 off medically required modifications. Some manufacturers offer other incentives, such as extended OnStar, a satellite-based, in-vehicle safety, navigation and communication system.

Training should be included as part of the modification package. This is not required in all states, but survivors need to know how to use this equipment.

Bottom line: Stroke families should not do anything until the survivor has been evaluated. Then enlist the help of an occupational therapist to help correct the problems so that driving is safe for the survivor, the family, other drivers and pedestrians. Only then should you think about modifying your vehicle.

Resources

nhtsa.gov/cars/rules/adaptive/brochure/brochure.html for information on vehicle modification

aota.org/olderdriver for help finding a driving specialist in your area

safedrivingforalifetime.com for safety tips on driving with a disability as well as other helpful information

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I've Just Seen a Face-book

“Really, John! It’s 2010. Get yourself on Facebook!”
the basso voice on the phone implored.

It was Peter Homans, my old prep school buddy and rock band mate. Back in ’65 he taught me the opening organ riff to “I’m a Believer,” which in turn got me noticed by an extremely hot, 15-year-old Amy Klempner. She offered to share, among other things, her last Marlboro behind the gym after the dance.

Anyway, Peter pressed his case by emphasizing that Facebook was free, easy, would connect me with other stroke survivors, and get the word out about my new DVD. As a final argument (did I mention his father was a trial lawyer?) he informed me that even Lassie had a FB page. Well, that did it. Come on, a dog? I wasn’t going to be shown up by a canine star of a canceled TV show.

So I perched in front of my Mac and proceeded to pay homage to that Internet deity we know as Facebook. With a few clicks of the mouse I was staring slack jawed at the labyrinth of questions under the “Create Your Own Page” section. Sex? Check. Birthday? Check. Marital status… hometown…current town? Check. Check. Check. I was movin’ at a pretty good clip until I had to upload my headshot. If you don’t do this you wind up with one of those creepy, generic silhouettes where you look like you’re in the Witness Protection Program. For some reason I kept uploading a picture of Travis, my brother-in-law’s new puppy. We have more pictures of him on our desktop than People magazine has of Kim Kardashian. Click. Travis. Click. Travis. Click. Travis. “#@:*!” I exclaimed. At that point I hopped onto the windowsill of our 12th floor apartment and my wife, Marilyn, had to talk me down. Hey, this could be a great alternative to the electric chair. Tell the guy on death row to get a Facebook page and be sure to upload his mug shot. It’s a do it yourself execution with guaranteed lower utility bills.

Minutes turned into hours when my IT person (Marilyn) breezed by, hit a key and voila! I was finally staring at yours truly. I had arrived. I had a Facebook page. And I immediately proceeded to do what all new users do: look up every girl I ever dated — starting with Amy. I felt like a stalker. (Restraining Order app anyone?) Suddenly, people’s faces started popping up in front of me like ghosts. I thought I was hallucinating from exhaustion but I discovered it was a “Poke.” That’s Facebook-speak for “Hi, we know what you’re up to.”

Days turned into nights. By the time I got to “Lucy Zimmerman” I resembled Steve McQueen in the movie “Papillon.” I knew it was too late. I was hooked. I began accumulating friends wherever I could get them. Charles Manson? Friend. Bernie Madoff? Friend. Lassie? Oh, okay… friend. I had gone from the Pokee to the Poker. I needed rehabilitation, but my insurance company wouldn’t cover it. If they did, you’d be reading this article in a magazine called “FC” (Facebook Connection) and my column would be called “OTW” (Off The Wall).

Eventually, Marilyn threw cold water on my face and demanded I get some air. As I trudged down 9th Street my penal colony look was a dead giveaway. People didn’t seem to notice I had a stroke. Instead, they nodded knowingly as I passed and whispered, “Facebook.”

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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.


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