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Waiting to See How the Story Ends

Lessons on the road to recovery

Life at the Curb

Those were the days

When Loved Ones Lash Out

Understanding and dealing with abusive behavior

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Right Place at the Right Time



I read the article titled “Give Me 5” in the July/August 2008 issue with great interest. I can personally attest to the value of these steps, particularly *No. 5 — FEEL: Is their headache severe?* Fourteen years ago I woke up one morning with the worst headache I have ever experienced. It felt as if someone

was driving a railroad spike down through the top of my head. I was living alone at the time, and fortunately I decided to get up and go to the doctor. That is the last thing I remember for about four months. I have been told that I did make it to the doctor’s office and had been with the doctor for less than 10 minutes when an aneurysm in one of the arteries in my brain ruptured. If I had not been in a doctor’s office when this occurred, I would most likely have died. Instead, after about 18 months of rehabilitation, I was able to go back to work. Just recently I retired.

At the time this happened I had no particular knowledge of the warning signs of stroke. The only thing I knew was that the headache was so severe that I thought something had to be seriously wrong, but I had no idea just how seriously wrong it was. I have since learned that survivors of ruptured cerebral aneurysms are few and far between, and I am one of the very few lucky ones. I believe that the “Give Me 5” campaign is vitally important, and I commend you for publishing this article.

Henry J. Bennett, Survivor
Portland, Oregon

Editor’s Note: For more information on the Give Me 5 campaign, visit www.giveme5forstroke.org.

A John Kawie Fan



I just received my latest issue of *Stroke Connection* and I enjoyed all the articles, but what I love most are the articles by John Kawie. His humor and outlook are so refreshing and uplifting. I look forward to reading his column immediately. Please keep up the good work, and please keep John in all of your future issues.

Norma Abdallah, Survivor
Parma, Ohio

Attention Readers

Many of you received a letter from *Stroke Connection* in June as a reminder to renew your subscription with us. If you haven’t had an opportunity to respond, please send your \$12.00 annual payment to:

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Our goal is to provide *Stroke Connection* to as many stroke families as we can. If you would like to continue to receive *Stroke Connection* free of charge as a courtesy, or if you no longer wish to receive *Stroke Connection*, please let us know that as well. If we do not hear from you, your subscription could be cancelled without notice.

We appreciate each and every one of you. Thank you for your ongoing support.

Debi McGill, Editor-in-Chief
Stroke Connection

We’d like to hear from you!

E-MAIL US AT: StrokeConnection@heart.org. Or send letters to: **Editor-in-Chief, Stroke Connection, 7272 Greenville Avenue, Dallas TX 75231.** Letters may be edited for length and scientific integrity. The opinions presented are those of the individual and do not reflect those of the American Stroke Association.

After surviving a stroke, some of the toughest challenges are the ones you can't see.



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IMPORTANT INFORMATION: If you have a stomach ulcer or other condition that causes bleeding, you should not use PLAVIX. When taking PLAVIX alone or with some other medicines including aspirin, the risk of bleeding may increase, so tell your doctor before planning surgery. And, always talk to your doctor before taking aspirin or other medicines with PLAVIX, especially if you've had a stroke. If you develop fever, unexplained weakness or confusion, tell your doctor promptly as these may be signs of a rare but potentially life-threatening condition called TTP, which has been reported rarely, sometimes in less than 2 weeks after starting therapy. Other rare but serious side effects may occur.

Please see important product information for PLAVIX on the following page.



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- had a recent heart attack.
- had a recent stroke.
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- heart-related chest pain (unstable angina).
- heart attack.

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Clots can become dangerous when they form inside your arteries. These clots form when blood platelets stick together, forming a blockage within your arteries, restricting blood flow to your heart or brain, causing a heart attack or stroke.

WHO SHOULD NOT TAKE PLAVIX?

You should NOT take PLAVIX if you:

- are allergic to clopidogrel (the active ingredient in PLAVIX).
- have a stomach ulcer
- have another condition that causes bleeding.
- are pregnant or may become pregnant.
- are breast feeding.

WHAT SHOULD I TELL MY DOCTOR BEFORE TAKING PLAVIX?

Before taking PLAVIX, tell your doctor if you're pregnant or are breast feeding or have any of the following:

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- liver problems
- kidney problems
- a history of bleeding conditions

WHAT IMPORTANT INFORMATION SHOULD I KNOW ABOUT PLAVIX?

TTP: A very serious blood condition called TTP (Thrombotic Thrombocytopenic Purpura) has been rarely reported in people taking PLAVIX. TTP is a potentially life-threatening condition that involves low blood platelet and red blood cell levels, and requires urgent referral to a specialist for prompt treatment once a diagnosis is suspected. Warning signs of TTP may include fever, unexplained confusion or weakness (due to a low blood count, what doctors call anemia). To make an accurate diagnosis, your doctor will need to order blood tests. TTP has been reported rarely, sometimes in less than 2 weeks after starting therapy.

Gastrointestinal Bleeding: There is a potential risk of gastrointestinal (stomach and intestine) bleeding when taking PLAVIX. PLAVIX should be used with caution in patients who have lesions that may bleed (such as ulcers), along with patients who take drugs that cause such lesions.

Bleeding: You may bleed more easily and it may take you longer than usual to stop bleeding when you take PLAVIX alone or in combination with aspirin. Report any unusual bleeding to your doctor.

Geriatrics: When taking aspirin with PLAVIX the risk of serious bleeding increases with age in patients 65 and over.

Stroke Patients: If you have had a recent TIA (also known as a mini-stroke) or stroke taking aspirin with PLAVIX has not been shown to be more effective than taking PLAVIX alone, but taking aspirin with PLAVIX has been shown to increase the risk of bleeding compared to taking PLAVIX alone.

Surgery: Inform doctors and dentists well in advance of any surgery that you are taking PLAVIX so they can help you decide whether or not to discontinue your PLAVIX treatment prior to surgery.

WHAT SHOULD I KNOW ABOUT TAKING OTHER MEDICINES WITH PLAVIX?

You should only take aspirin with PLAVIX when directed to do so by your doctor. Certain other medicines should not be taken with PLAVIX. Be sure to tell your doctor about all of your current medications, especially if you are taking the following:

- aspirin
- nonsteroidal anti-inflammatory drugs (NSAIDs)
- warfarin
- heparin

Be sure to tell your doctor if you are taking PLAVIX before starting any new medication.

WHAT ARE THE COMMON SIDE EFFECTS OF PLAVIX?

The most common side effects of PLAVIX include gastrointestinal events (bleeding, abdominal pain, indigestion, diarrhea, and nausea) and rash. This is not a complete list of side effects associated with PLAVIX. Ask your doctor or pharmacist for a complete list.

HOW SHOULD I TAKE PLAVIX?

Only take PLAVIX exactly as prescribed by your doctor. Do not change your dose or stop taking PLAVIX without talking to your doctor first.

PLAVIX should be taken around the same time every day, and it can be taken with or without food. If you miss a day, do not double up on your medication. Just continue your usual dose. If you have any questions about taking your medications, please consult your doctor.

OVERDOSAGE

As with any prescription medicine, it is possible to overdose on PLAVIX. If you think you may have overdosed, immediately call your doctor or Poison Control Center, or go to the nearest emergency room.

FOR MORE INFORMATION

For more information on PLAVIX, call 1-800-633-1610 or visit www.PLAVIX.com. Neither of these resources, nor the information contained here, can take the place of talking to your doctor. Only your doctor knows the specifics of your condition and how PLAVIX fits into your overall therapy. It is therefore important to maintain an ongoing dialogue with your doctor concerning your condition and your treatment.

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PLA-OCT07-B-Aa

New Shoulder Pain Study

Are you one of the many adults who have suffered from a stroke?

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- If you live in or near West Virginia, please contact **Diana Bowne** at **304-347-6193**.
- All others please contact **Charina Icamen-Curry** at **877-362-5664**.

Stroke In Children

It's not the same as in adults

S **troke in children is not as rare** as once thought, and the symptoms do not mirror stroke in adults. In its first scientific statement on the topic, the American Heart Association/ American Stroke

Association addresses treatment, symptoms and risk for stroke in infants and children.

“Children and adolescents with stroke have remarkable differences in presentation compared with adults,” said E. Steve Roach, M.D., chair of the statement writing group and professor of pediatric neurology at the Ohio State University College of Medicine. “In newborns, the first symptoms of stroke are often seizures that involve only one arm or one leg. That symptom is so common that stroke is thought to account for about 10 percent of seizures in full-term newborns. Seizure is a much less common stroke symptom in adults.”

A major treatment difference between adult and child stroke is the use of tPA. The clot-busting agent is the cornerstone of treating adult ischemic stroke but, in the new statement it's not generally recommended for treating young children, especially newborns.

“Stroke in children is uncommon but not as rare as we used to think,” said Roach. “Even as recently as 20 years ago, stroke was an unlikely diagnosis in a child because it was so strongly associated with adults with atherosclerosis.”



Symptoms of stroke in children vastly differ from those in adults.

The risk of stroke from birth through age 18 is 10.7 per 100,000 children per year. The risk of stroke in children is greatest in the first year of life, particularly in the first two months. It decreases after that. Data from the statement shows that stroke in the first month of life (neonatal stroke) occurs in about one of every 4,000 live births. Stroke also can occur before birth.

Improved diagnostic techniques such as magnetic resonance imaging and vascular ultrasound have made it possible to confirm that a stroke has occurred when it was only suspected before. Because of these advances, experts now believe that a significant number of cerebral palsy cases may be due to strokes before or right after birth.

The most common underlying risk factors for childhood stroke are sickle cell disease and congenital or acquired heart disease. The incidence of the two main types of stroke (ischemic and hemorrhagic) is different in adults and children. According to the statement, 80-85 percent of adult strokes in Western countries are caused by a blood clot (ischemic). In contrast, in children about 55 percent of strokes are ischemic and the other 45 percent are hemorrhagic (bleeding in the brain). **SC**

Healthy People and 'Silent Strokes'

In a study of apparently healthy middle-aged people with no symptoms of stroke, about 10 percent of participants were injured from “silent strokes,” researchers reported in *Stroke: Journal of the American Heart Association*.

Silent cerebral infarction (SCI), or “silent stroke,” is a brain injury likely caused by a blood clot interrupting blood flow in the brain. It’s a risk factor for future strokes and a sign of progressive brain damage.

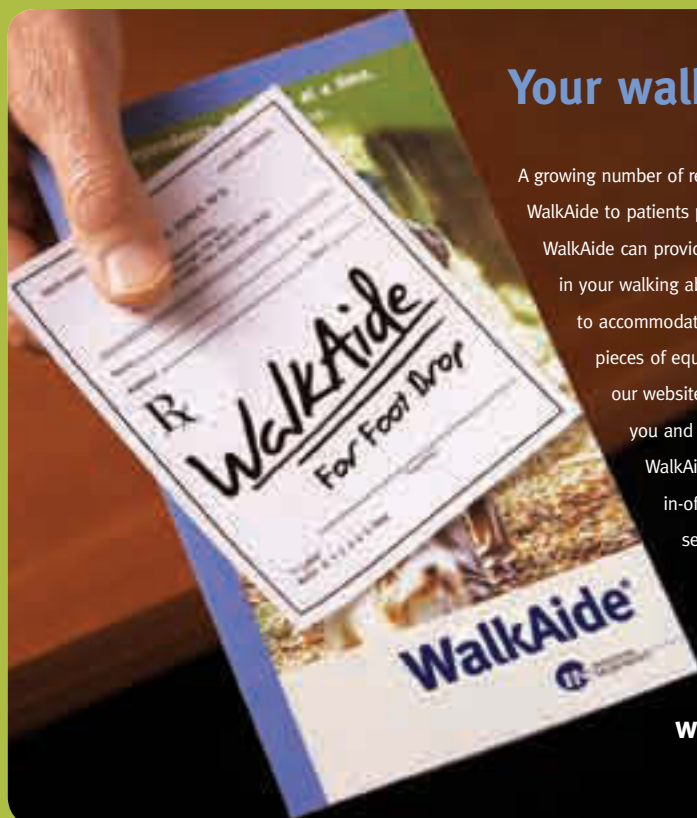
Researchers evaluated magnetic resonance imaging (MRI) from about 2,000 people, average age 62, who are part of the Framingham Offspring Study (children of participants in the original Framingham Heart Study). Among patients who displayed no symptoms of stroke, 10.7 percent had SCIs on routine brain MRI.

Researchers found a significant correlation between atrial fibrillation (AF) and silent strokes. AF is the most common form of irregular heartbeat in people older than 65. AF increased the risk of SCI more than two-fold. Hypertension and systolic blood pressure were also associated with an increased prevalence of SCI.

Risk factors for stroke are also risk factors for AF. Hypertension and other factors that make it more likely individuals will experience AF also predispose them to stroke and probably to silent stroke. AF, therefore, may be a simultaneous outcome rather than a cause of SCI, researchers said.

The study also found that high systolic blood pressure, hypertension and elevated levels of blood homocysteine were other risk factors commonly associated with stroke that also raised participants’ chances of having SCI. Hypertension consistently has been implicated as a risk factor.

“The significant relationship between hypertension, elevated homocysteine, carotid artery disease and prevalent SCI underscores the importance of early diagnosis and prevention of hypertension and atherosclerosis and their risk factors,” said Sudha Seshadri, M.D., co-author of the study and associate professor of neurology at Boston University School of Medicine. “This is especially true since SCIs have been associated with an increased risk of stroke and cognitive impairment.” **SC**



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Getting an Attitude Adjustment



Tony Clikas celebrates St. Patrick's day with his pal Connor.

Recently I had the third anniversary of my two brain stem strokes — three days apart — which changed my retirement plans. That week was filled with a million different memories of weeks in the hospital, many lifestyle changes at home and months of arduous therapy to learn to eat, speak, write, walk, etc. All of us survivors struggle with these things, trying to regain some sense of normalcy and a decent quality of life. I had planned to have a positive attitude from the start about this battle; I even wrote an article for *Stroke Connection* titled “Attitude Is Everything,” (January/February 2006) and those are words I strive to live by. However, I set my expectations high, and the reality of my situation on my third anniversary had me wondering why it’s taking so long. My daily workouts at the gym seemed to be more motivational for my able-bodied workout partners than they were for me. I did not want that doubt creeping into my ongoing job of rehabilitation.

We often underestimate the wisdom of children, but a 5-year-old taught me a lot about motivation and hard work.

A recent encounter with a 5-year-old at a St. Patrick’s Day party was an unexpected wake-up call and battery recharge. Using my cane as usual, I entered the party and stood talking with the boy’s mother. While we were talking, 5-year-old Connor came up and touched my cane. “What’s that?” he asked.

“That’s my cane.”

“Why do you have it?”

“It helps me walk,” I said.

“Did you hurt your legs?”

“In a way, but not like you would playing ball.” I could see by his expression that he was confused, I said, “It’s called a stroke and it happens in your brain. The brain tells the muscles not to work. Those muscles were in my legs, and that’s why I need this cane to walk. I probably won’t ever walk as well as you do.”

Connor nodded and started to walk away, but he looked back over his shoulder and said, “You will.”

We often underestimate the intelligence of children, but I choose to believe that Connor’s positive and confident comment about my walking is my attitude adjustment for the work I have ahead of me. I am going to take what this innocent little towheaded boy said as motivation to keep working hard. Why not?

Tony Clikas, Survivor

Daphne, Alabama

Change, It's a Good Thing



Chuck Hofvander *NOT* working at his computer

I was in the hospital when our lives changed. No one prepared us for how much they would be altered. At night, I awoke constantly. During the day, I was never at peace, wondering what would happen next. Sometimes when I spoke, strange words would pop out of my mouth. Was it a stroke? Something even more serious? No, it was life with our first born!

You wake up several times during the night to feed the baby or to comfort a crying child. You spend every waking hour thinking of ways to get to know, teach and soothe this new addition to your world. And you do speak in ways you never thought you would — you say “*gaa-gaa, goo-goo*” or “*he’s a good baby*” in a strange voice.

And the changes go on and on: starting school, going through puberty, leaving for college, getting married, buying your first house, switching jobs. The list is endless. Everything is change.

Recently, two good friends visited. We were colleagues before the stroke. Both complained about their jobs and how their work hadn’t changed in years. They were happy in their home lives but dissatisfied in other aspects of their lives.

That set me thinking about my life. During my working years, I got up regularly at 4:30 in the morning to start my day, which generally ended between 7:30 and 8:30 at night when I sat down and watched TV. Then I started to think about my life after the stroke and realized it isn’t so bad.

I get out of bed between 6:30 and 7:30 a.m., but when I want to sleep in, I can do it! I spend my day writing, reading, sleeping, talking, biking, exercising and eating, and it’s all therapy (OK, not the eating). Overall, life is good. Besides the fact I am partially paralyzed on my right side and have aphasia, I wouldn’t go back to my old life.

I enjoy my new life. I’ve come to realize that after the stroke I wasted time regretting my pre-stroke life and feeling sorry for myself. It took over three years and the help of friends and family, but I finally adjusted.

Chuck Hofvander, Survivor
Prospect Heights, Illinois

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Helen Talley
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SC FEATURE STORY



When
Loved
Ones

LASH OUT

Just because a survivor may not be able to physically hit someone doesn't mean they can't hurt them. **by Jon Caswell**



“Winter is the worst, because then he’s cooped up all the time, so he throws a tantrum almost every day,”

said Jan D., age 59, of her former fiancé and current housemate Harvey, age 65 (not their real names). The couple had moved in together with plans to marry, but then Harvey, a contractor, had a left-hemisphere stroke. Beyond right-side hemiparesis that prevents him from working or driving and some speech difficulty, the stroke also changed his personality. “Before the stroke he had a quirky sense of humor that was entertaining, but that ‘humor’ is now sarcastic, biting, insulting and intentionally hurtful.”

“This situation of survivors abusing caregivers comes up way too often,” said psychologist Barry J. Jacobs, Psy.D., director of behavioral sciences for the Crozer-Keystone Family Medicine Residency Program in Springfield, Pa., and author of *The Emotional Survival Guide for Caregivers* (Guilford, 2006). “Stroke changes the way the brain works. It can cause neurological damage that leads to decreased function that makes it more likely that the survivor will lash out.”

Defining Abuse

Many people equate abuse with physical violence. Therefore, it might seem counterintuitive that a stroke survivor, who may have multiple physical and cognitive deficits, could harm anyone. But survivor-on-caregiver abuse is typically verbal or psychological. Just because a survivor may not be able to physically hit someone doesn’t mean they can’t hurt them.

Neuropsychologist Dr. Mark Sandberg, a diplomate in rehabilitation psychology and staff physician at the VA Medical Center in Northport, N.Y., defined abuse this way: “Whenever a caregiver feels the survivor’s behavior is designed to hurt, diminish or unnecessarily control them, they should consider that abuse.”

Why It Happens

There’s no way to predict if or how a survivor will become abusive after stroke. “While people with left-brain strokes tend to be more depressed, people with right-brain strokes can be more impulsive,” Dr. Jacobs said. “Both depression and impulsivity can contribute to lashing out.”

“It’s usually the interplay of pre-stroke psychological and stroke-related physiological changes that bring about behavior that could be considered abusive,” Dr. Sandberg said. “Having said that, a person who sustains a right-hemispheric stroke has tendencies toward diminished awareness, which may create insufficient concern about situations as well as impulsive and inappropriate responses. Those types of changes predispose a person to react poorly to frustration, which in turn may lead to behaving in ways that could be considered abusive.”

Typically, survivors lash out at caregivers for two reasons, according to Dr. Jacobs. First, because of a loss of impulse control, which often happens with frontal lobe damage, and makes survivors more likely to lash out when they’re frustrated. (Frontal lobe injury is also associated with loss of empathy.) And second, survivors who are frustrated at their losses and clinically depressed may take those feelings out on those closest to them.

“When Harvey goes off on me, I feel worthless, like what I think

Nearest Target

Ella Parsons, age 70, knows about this firsthand. Her mother, Leona Mortensen, had seven strokes and numerous TIAs over 18 years before she died in 2007 at age 90. “With each stroke she got meaner and meaner,” Ella said. “After the fourth one, I had to place her in assisted living, and when I would visit, she was ready to fight before I could even say hello. She didn’t want to converse, she just wanted to rant. She was always hateful and accusatory and belligerent with me, but she never acted up with anyone in the facility, never argued with the CNA (certified nursing aide).” Her fifth stroke left her with aphasia, but that didn’t make her any more docile



Ella Parsons (left) and her mother Leona Mortensen share a happier moment.

or easy to get along with. “Sometimes she would reach out to hit me or give me a dirty look or make a face like she was going to yell at me.”

Jan has also experienced verbal abuse. “Harvey can lose his temper with me over the

most ridiculous things. For instance, last winter he threw a tantrum because I would not go get garlic when it was 20 below zero. Another time it was because I bought the wrong kind of cat litter. Then I bought the wrong size. When I got the right kind in the right size, I bought it at the wrong store and paid too much. With each ‘mistake’ he got completely out of control.”

Our experts’ advice about this type of behavior is not to tolerate it. “First and foremost, leave the room,” Dr. Jacobs said. “Caregivers have to be very clear that they will not tolerate being abused. The more a caregiver puts up with maltreatment, the more they encourage the survivor to behave that way.”

Before and After

Often, how survivors and caregivers related to one another before the stroke is a factor in how they relate afterward. If they had a rocky relationship before, their post-stroke relationship may be rockier still. After all, frustration, depression, grief and disappointment coupled with physical disability rarely bring out the best in people.

Even before his stroke, Harvey could be difficult and overbearing and didn’t seem to care much about other people, Jan admits. “Even then I thought he was overly opinionated

and seemed to need to be the center of attention all the time,” Jan said. “He definitely had a temper, but he could stop himself before it got out of control. Now it’s impossible to have a normal conversation with him because he cuts off whoever is speaking. He only wants to express his opinion and doesn’t seem to care what anyone else has to say. With his family, he constantly brings up past issues and provokes arguments.”

Personality styles are another factor in how people respond to frustration and disappointment. For instance, a psychologist might label a person who doesn’t care about the feelings of other people and even exploits them as a narcissistic personality; an antisocial personality is characteristically insensitive, irritable and aggressive and may disregard their own safety or that of others. “The association between personality style, area of neurological damage brought on by the stroke and how the loss of function is being experienced by the survivor are all critical to consider in understanding why certain behaviors are present and how best to treat issues that might require intervention,” Dr. Sandberg said.

How It Feels

“One shorthand definition of anger is that it’s depression turned outward,” Dr. Jacobs said. Often it is used to control another’s behavior by causing them to feel guilty.

Jan described her feelings this way: “When Harvey goes off on me, I feel worthless, like what I think or feel makes no difference, like I’m nobody, like no matter how much I do for him, it’s never enough.”

According to Dr. Jacobs, Jan’s feelings reflect classic victim thinking: ‘If only I had done it better, he would not be acting this way.’

“What happens in abusive relationships is that the one being mistreated feels responsible for the mistreatment. It often takes women years to leave an abusive relationship because they continue to believe that if they could change, everything would be all right,” Dr. Jacobs said.

But Jan is not doing herself or Harvey any favors by putting up with his behavior. “Staying with an abusive survivor and allowing him to be abusive doesn’t help the survivor,” he said. “People should be held to a certain standard of behavior, and when we don’t hold them to that standard, we do them an injustice.”

Jan has threatened Harvey with putting him out of her house and giving him back to his family. “When I do, he tries to put the brakes on his tantrum, but he just doesn’t have enough self control to stop. He panics when I threaten to call his sons to intervene — he doesn’t want them to know he’s out of control.”



Get the Doctor Involved

Dr. Jacobs emphasized that medical intervention is key to improving the caregiver's situation. There are psychiatric medications that help people gain control over their impulses as well as for depression. "The best thing a caregiver in this situation can do is get their loved one to a doctor because medication can help in most of these cases," he said.



Dr. Jacobs (left) and Dr. Sandberg believe support groups are beneficial.

Jan has suggested this to Harvey, but he isn't interested. "I've talked about his behavior with his doctors," she said, "and they are more than willing to refer him for psychological

evaluation and medications. He even had one tantrum in the doctor's office, but he refuses to take the doctor's advice. He doesn't even acknowledge his behavior is a problem. It's always someone else's fault. He feels it's his right to say whatever he wants, however he wants to, and if you don't like it, that's your problem."

Grief Has a Role to Play

According to both doctors, grieving losses is an important aspect of recovery after stroke. Since both parties in the relationship have experienced losses, both people have to grieve. "Survivors who are able to grieve and thereby accept their losses are less likely to lash out," Dr. Jacobs said. Caregivers also benefit from grieving the loss of the person they knew; accepting the survivor as they are now insulates them when the survivor lashes out.

"Working through the feelings of loss is important," Dr. Sandberg said. "Recovery from stroke includes an acceptance of the limitations that have resulted. Through that acceptance, both survivors and caregivers can realize that new opportunities and possibilities are available."

Ella Parsons found it difficult to accept the person her mother had become, especially since she only acted out toward Ella. "She was always good with the people at both the facilities where she lived, but whenever I showed up, all she wanted to do was fight." Those attacks were so painful that Ella reduced her visits to once a month, but that left her feeling guilty. "I would come home from seeing her and just cry."

For a long time Jan found it difficult not to take Harvey's outbursts personally, but as she has grieved the loss of

the relationship they once shared, she's found it easier to disengage. "I no longer react by feeling guilty," she said. "I understand that a lot of it is the result of the stroke and his forced retirement. I realize that the relationship we had prior to the stroke is gone. He simply doesn't care what I think or feel. He doesn't care one bit how his stroke has affected me or the rest of his family. I don't like or respect him so his negative opinion of me no longer has the power to hurt me."

Support Makes a Difference

Both Jacobs and Sandberg felt that caregiver support groups benefited caregivers, whether or not they are in an abusive situation. "The emotional support and problem-solving opportunities that come about in support groups are very helpful," Dr. Sandberg said. "It's great to know that your feelings and concerns are not unique and that you are not alone."

Ella had a kind of informal caregiver support group among friends in her aerobics class, one of whom was dealing with an extremely ill husband. "We would talk after class," she said. "We called it our 'psychiatric treatment.'" After her mother passed last year, Ella saw a therapist for seven months. "That was very valuable for me because she helped me get through the anger I felt and the sadness that the last two years of mom's life were so difficult. I think if you can get some kind of support while you're going through it, that's the best. It would have helped me so much if I'd known beforehand what was likely to happen."

Unwilling to put Harvey out, Jan copes as best she can. "I tried reason at first, but then I realized he has the emotional maturity of an eight year old, so reason seldom works. Arguing back only exacerbates the situation. Sometimes I just leave the house for a few hours, or simply don't respond at all, but that really gets him going — he can't stand when there's no reaction."

"If a caregiver can see the survivor's anger as a manifestation of the stroke," Dr. Jacobs said, "then they don't have to take the name calling and the anger personally, and it doesn't hurt as much. That doesn't mean they should excuse the behavior. They should require them to get help for their behavior. If a caregiver feels she is being mistreated, she should seek some sort of outside help immediately by reaching out to a physician or a local support group. And she should talk to other family members about getting some relief." **SC**

Editor's Note: For a list of questions that may help you better assess and make decisions about your situation, visit www.strokeassociation.org/strokeconnection.

I've had a Stroke:

Important questions to ask your doctor

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share your story
support your friends & family

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– Mary Graham, Stroke Survivor

WAITING TO SEE HOW THE STORY ENDS

by Patricia Smith, Survivor | Buffalo, New York



“Ellen, Ellen!” I called as I grabbed my sister’s hand. “I have Kelly Ripa’s baby in my belly and I don’t know how I’m going to give him back.”

“No, honey, that’s not a baby,” she replied. “It’s your skull.”

That was the first conversation I, Patricia Smith, a 42-year-old public relations professional from Buffalo, N.Y., had after emerging from a days-long, drug-induced coma in July 2004.

It provided Lesson No. 1 about stroke survival: Never leave morning TV on in the room of a patient in a coma. I’m surprised I didn’t think I was Diane Sawyer.

The next thing I knew after that brief conversation with my sister, I had fully regained consciousness and gotten my bearings only to learn that I had had a massive stroke and had already

undergone surgery. To relieve the swelling in my brain, doctors performed a craniectomy, which involves the temporary “relocation” of a portion of the skull to the fatty part of the abdomen — in my case, for about six months. They also removed about a third of my brain. I was blessed to have cheated death not only by surviving the stroke, but by surviving the surgery, thanks to the prayers of my family and friends.

The stroke left my left arm and leg paralyzed. The doctors told me that if I were able to stand up from my wheelchair and take a few steps in a year, that would be great. But I wasn’t that patient (pun intended), and just four months later, I could walk without a cane. What got me there were nine weeks of torturous inpatient medical rehab followed by six months of grueling home care that included

“Ms. Smith, you’ve had a stroke, and we’re going to give you something to thin your blood.”
I responded, “Got anything for my thighs?”

physical, occupational and speech therapy. I had to learn to dress and shower again, as well as to do important things like empty the dishwasher, bake brownies and write a check. One of 10 children, I moved in with a brother and his family. There I received therapy, relying on my sisters, sisters-in-law and cousins to help me shower and dress for the next 15 months. Rehab was, in short, traumatic. If not for the support and humor of my family and friends, I wouldn’t be alive and using the two-thirds of my brain I have left.

Being a Buffalo resident and the sister of a dietitian, it is very important to me that everyone who hears my tale understand that mine wasn’t a “chicken-wing stroke.” It was not the result of years of eating the spicy, fried delight. It was the result of an undetected blood clotting disorder known as anticardiolipin syndrome.

For me, humor proved to be a safe coping mechanism from the start. When I arrived at the ER, a doctor said, “Ms. Smith, you’ve had a stroke, and we’re going to give you something to thin your blood.” I responded, “Got anything for my thighs?”

While staying with my brother and his family, I tried to keep the mood playful, calling myself “the cripp.” I could laugh at things with my caregivers — things such as being told by Amy, my nurse, that I needed to “sit up straight.” I replied, “I don’t have to. My mother named me Patricia *Eileen* Smith, and I’m going to take full liberty with that moniker and lean to the left until I can get out of this bed without the use of a humiliating Hoyer lift.”

The long road to recovery, while including a much-needed laugh every day, also contained a devastating bout with clinical depression and a new “habit,” obsessive-compulsive disorder. Since the stroke, I keep counting in my head — no rhyme or reason to it, I just count. Despite the fact I was never good in math.

Throughout my treatment, both as an inpatient and in home care, I cried enough tears to fill the Atlantic. I was so sad and traumatized, I couldn’t even get through the Lord’s Prayer because I’d cry at the words “Thy will be done.” I couldn’t believe it was God’s will that I lose the use of my left arm, my career, my privacy and all control over my emotions.

There was also a period of several weeks when I was too depressed to eat and the very thought or smell of food produced a violently nauseated reaction. I don’t know how my



Patsy vacationing in Mexico

family and friends put up with me. They tried all my pre-stroke favorites, but I had absolutely no appetite. To her credit, Linda, my sister-in-law, continued to cook my favorite foods. One night at dinner, roast turkey was on the menu and I actually ate it. When I did, Victoria, my 12-year-old niece, exclaimed, “Look, even the cripp is eating turkey!”

Lesson No. 2: If you happen to wake up one day and a piece of your brain is gone, relax. While you may never be good at math, there is an upside: You don’t get asked to think on your feet too often.

Four years later, I still have left-side paralysis and I’m still horrible at math, but I’m living independently in my own home.

I walk with the help of an ankle-foot orthosis (AFO) and, when I’m outside my home, a straight cane. While I cannot work, I have found a new calling as a professional volunteer. I volunteer one day a week at an all-girls Catholic academy where I, a public school kid, take great pride in correcting the nuns’ grammar. I also serve on the board of directors of the Western New York affiliate of the Susan G. Komen Breast Cancer Foundation. I am on the board of a nonprofit literary arts center, volunteer in the library of a local elementary school once a week, and am an advocate for the use and promotion of advanced care directives.

As with anyone who receives this magazine, my life is completely different after stroke — not awful, but certainly different than I’d planned. What’s different? Specifically, I don’t get up every morning to shower, don a suit and heels and bound downstairs to start the car and head off to a 12-hour workday in my 20-year career in public relations. Now I linger in bed a few minutes, say a few extra prayers, especially those of thanksgiving that I have my life and another day to put my feet on the floor, and the rest is in God’s very capable hands. I do some bedside yoga, glide downstairs in my elevator chair, make breakfast and limp into the family room to make morning phone calls to family and friends. Sometimes I don a denim skirt and a sassy pair of velcro shoes and use the shuttle service offered to disabled people by the Niagara Frontier Transportation Authority, heading off for a four- or five-hour day of volunteering.

I can’t think as quickly as I once did and I’m not as competent as I once was. I have more faith than I had pre-stroke, and I am just as busy as before. I’m busy waiting to see how this story ends. **SC**



Reaching out for the Help You Need

Why is it so hard to ask for help?

What's a good response to the statement, "Call me if you need me?" Despite the fact that family caregivers are drowning in responsibility or are really confused about what the next step ought to be, they often respond "no thanks" when help is offered. Asking for and accepting help is a complex issue. Obviously you first need to admit that having some help will make a real difference in your loved one's quality of life, and therefore yours as well. Then you need to define what help you need. Which tasks or chores would be the easiest to ask others to do? Which do you really want to do yourself? And which, if any, can you afford to pay others to do? If this just sounds like more work, know that it doesn't have to be an overwhelming task but rather just a way to organize the thoughts and information you already have. Are you ready to give it a try?



Here are SIX STEPS to getting help...

1. Recognize that caregiving, like any job, is made up of lots of individual tasks, not all of which are of the same importance. Some tasks take a few minutes; some may take many hours. Some tasks are easy; others require some skill and fortitude. The challenge is to know the difference.

2. Recognize that asking for help is a sign of strength, not weakness. It means you truly have a grasp on your situation and have come up with a proactive problem-solving approach to making things easier and better.

3. Create a list of the tasks that need to get done in any given week, or at least those you are most concerned about, such as balancing your responsibilities at work with taking Mom to the doctor and Susie to soccer practice, bathing and dressing your husband, cooking, cleaning, etc. When you see how long the list is you'll quickly understand why you are so tired and don't have time for yourself.

4. Group your tasks into categories such as personal care tasks for your loved one, transportation, household chores. You can group your tasks into only a few broad categories, or many specific ones. There's no right or wrong way. It's all a matter of personal preference.

5. Write down your caregiving worries. Where will we get the money to pay for John's medications? Who will care for Mary if I get sick? Where can I find an adult day facility that provides transportation? Seeing them in black and white helps diffuse some of their emotion. It also allows you to think more rationally about your concerns and understand how getting help with some of your tasks might lessen the stress. It can provide the basis for deciding which tasks you might ask a neighbor, family member or the church to help out with, which you are willing and able to pay someone else to do, and which there might be a public program for.

6. Share your lists with someone you trust before you actually reach out for help — a friend, therapist, or clergyman, perhaps. The intent is to first get comfortable with the idea of talking about your need for assistance and hopefully get some encouragement and good ideas in the process. Then take a deep breath and actually ask someone to help with one of the tasks on your list, or ask for guidance in resolving your most persistent worry. Start with something small, especially if you are looking for hands-on assistance or something that requires someone doing you a favor. Don't get discouraged if you get rejected at first. It sometimes takes perseverance. Just remember — the effort is worth it because the goal is better care for your loved one and yourself. **SC**

Source: Reprinted with permission of the National Family Caregivers Association, Kensington, MD, the nation's leading organization for all family caregivers. 1-800-896-3650; www.thefamilycaregiver.org

Free Class for Caregivers

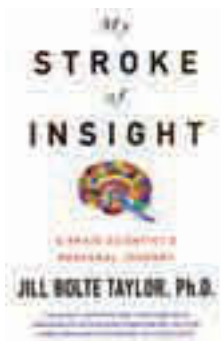
November 6 and 13; 2 p.m. ET: A FREE national TeleClass will be hosted by the National Family Caregivers Association. The purpose of the TeleClass is to improve the ability of family caregivers to communicate more effectively with healthcare professionals so they can become better healthcare advocates for themselves and their loved ones. For more information visit: www.thefamilycaregiver.org or call 800-896-3650.

Books for Survivors

My Stroke of Insight: A Brain Scientist's Personal Journey

By **Jill Bolte Taylor, Ph.D.** | Viking Press
ISBN 978-0-670-02074-4

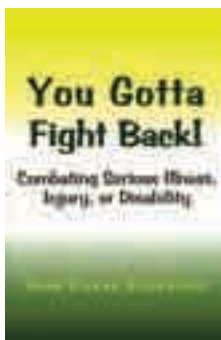
Dr. Jill Bolte Taylor is a Harvard-trained neuroanatomist who experienced a massive hemorrhagic stroke while home alone. As she experienced her stroke, she observed her own mind completely deteriorate until she could no longer walk, talk, read, write or recall her life. Dr. Taylor shares the details of her stroke as seen by a scientist as well as the eight years it took her to repair her mind and understand her insights.



You Gotta Fight Back! Combating Serious Illness, Injury or Disability

By **Dirk Chase Eldredge** | Loving Healing Press
ISBN-13: 978-1-932690-34-7

This book contains 13 stories of people who fought back with courage, humor and a positive attitude. Learn how others successfully played the hand they were dealt and managed to live successful, fulfilling lives.



A Brain's Battle against a Stroke: Refocusing My Memory on Earlier Medicine

By **Robert Sussler** | Authorhouse
ISBN 978-1-4259-9785-4

This book is the story of the battle to recover from a stroke. It follows the treatment history of a patient and compares two eras of medical practice separated by 50 years. This book illustrates the importance of treating the whole patient and how important their knowledge and attitude are in recovery.



Conquering Stroke How I Fought My Way Back and How You Can Too

By **Valerie Greene** | John Wiley & Sons
ISBN 978-0-470-13792-5

In this book, survivor Valerie Greene shares her remarkable story of recovery from two brain-stem strokes through a combination of cutting-edge medical treatments and sheer determination.



These book summaries are provided as a resource to our readers. They have not been reviewed or endorsed by the American Stroke Association.

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Those Were the Days

The temperature hovered at freezing on our first night out since my stroke when the Cort Theater usher approached us. She said sweetly, “Now dear, it’s way too cold for you to stand out here in line. Follow me, and I’ll show you to your seats.”

My response was like Travis Bickle minus the gun. “You talkin’ to me?” I asked as I turned around expecting to find the pope, or at least the mayor behind me. Nope, she was talking to me. Apparently the guy manning the ticket booth noticed my disability and notified the manager, who ordered the usher to pluck us from a line that seemed to extend into infinity. Marilyn and I were as grateful as a couple of puppies being rescued from the pound. However, to the people still waiting, we looked more like spoiled royalty. “Guess the upper crust can’t take it,” I heard someone snarl. Their eyes followed us like lasers as we were escorted through the front doors into the welcoming warmth of the theater. We settled into prime orchestra seats, for an unobstructed view of John Leguizamo’s award-winning show “Freaks.”

Ah, those “Heady, A-List, Red Carpet, Just-Out-of-the-Hospital” days. I remember them well.

I must have been sprinkled with special-treatment fairy dust because I bought a Christmas tree from a street vendor and enjoyed it. In New York City this is an activity that usually involves dangerous negotiations with an angry Canadian woodsman who looks like he’d much rather be butchering a deer carcass than selling anything to pampered city folk. But after seeing

me, Paul Bunyan magically transformed into Bob Barker from “The Price Is Right”: “Here we have a beautiful Canadian balsam fir, the most desirable Christmas tree to emerge from the fertile Ontario soil. An \$80 value (hey, this is New York) but for you, only \$39.99! I’ll even throw in the stand!”

Ah, those “Heady, A-List, Red Carpet, Just-Out-of-the-Hospital” days. I remember them well. Unfortunately, they crashed and burned faster than the Hindenburg.

At family get-togethers following the stroke, I was Sir John, the Patient Prince. I never had to leave my seat to get to the buffet. It was always relatives fighting over me: “Don’t move a muscle. I’ll fix you a plate.”

Now? I’m just a regular Joe at the smorgasbord exhausted from going back and forth to get cold cuts. Instead of “Sweatin’ to the Oldies,” Richard Simmons should do “Sweatin’ to the Buffet Table”! I’m also starvin’ at the buffet table because having the use of only one hand is a major disadvantage. It’s like trying to win the Indy 500 in a Honda Civic. Uncle George is passing me saying, “Hey buddy, the salami’s goin’ fast!” It’s a do-it-yourself do-or-die meal. Grab a plate, put food on the plate, pick up utensils, pour a beverage, pick up the beverage and balance all that back to your chair. Definitely a two-handed operation. I say leave it to the professionals and give me a waiter. While everyone’s chowing down on seconds, I’m scanning the table for scraps. I know the goal of rehab is to make you independent, but would anyone mind if I just pull my chair up to the buffet table?

Even though I now have to wait in line, pay full price and work myself up the family food chain, people are finally seeing me and not my disability. And nothing beats the feeling of being accepted for who I am today. **SC**



**Learn More
About John...**

Read John’s personal stroke story, “**Life is at the Curb**,” from the September/October 2003 issue of *Stroke Connection* at StrokeAssociation.org/strokeconnection, or book his one-man show about stroke recovery, “**Brain Freeze**,” by contacting him at jkawie@aol.com.

WHO IS PLAVIX FOR?

PLAVIX is a prescription-only medicine that helps keep blood platelets from sticking together and forming clots.

PLAVIX is for patients who have:

- had a recent heart attack.
- had a recent stroke.
- poor circulation in their legs (Peripheral Artery Disease).

PLAVIX in combination with aspirin is for patients hospitalized with:

- heart-related chest pain (unstable angina).
- heart attack.

Doctors may refer to these conditions as ACS (Acute Coronary Syndrome).

Clots can become dangerous when they form inside your arteries. These clots form when blood platelets stick together, forming a blockage within your arteries, restricting blood flow to your heart or brain, causing a heart attack or stroke.

WHO SHOULD NOT TAKE PLAVIX?

You should NOT take PLAVIX if you:

- are allergic to clopidogrel (the active ingredient in PLAVIX).
- have a stomach ulcer
- have another condition that causes bleeding.
- are pregnant or may become pregnant.
- are breast feeding.

WHAT SHOULD I TELL MY DOCTOR BEFORE TAKING PLAVIX?

Before taking PLAVIX, tell your doctor if you're pregnant or are breast feeding or have any of the following:

- gastrointestinal ulcer
- stomach ulcer(s)
- liver problems
- kidney problems
- a history of bleeding conditions

WHAT IMPORTANT INFORMATION SHOULD I KNOW ABOUT PLAVIX?

TTP: A very serious blood condition called TTP (Thrombotic Thrombocytopenic Purpura) has been rarely reported in people taking PLAVIX. TTP is a potentially life-threatening condition that involves low blood platelet and red blood cell levels, and requires urgent referral to a specialist for prompt treatment once a diagnosis is suspected. Warning signs of TTP may include fever, unexplained confusion or weakness (due to a low blood count, what doctors call anemia). To make an accurate diagnosis, your doctor will need to order blood tests. TTP has been reported rarely, sometimes in less than 2 weeks after starting therapy.

Gastrointestinal Bleeding: There is a potential risk of gastrointestinal (stomach and intestine) bleeding when taking PLAVIX. PLAVIX should be used with caution in patients who have lesions that may bleed (such as ulcers), along with patients who take drugs that cause such lesions.

Bleeding: You may bleed more easily and it may take you longer than usual to stop bleeding when you take PLAVIX alone or in combination with aspirin. Report any unusual bleeding to your doctor.

Geriatrics: When taking aspirin with PLAVIX the risk of serious bleeding increases with age in patients 65 and over.

Stroke Patients: If you have had a recent TIA (also known as a mini-stroke) or stroke taking aspirin with PLAVIX has not been shown to be more effective than taking PLAVIX alone, but taking aspirin with PLAVIX has been shown to increase the risk of bleeding compared to taking PLAVIX alone.

Surgery: Inform doctors and dentists well in advance of any surgery that you are taking PLAVIX so they can help you decide whether or not to discontinue your PLAVIX treatment prior to surgery.

WHAT SHOULD I KNOW ABOUT TAKING OTHER MEDICINES WITH PLAVIX?

You should only take aspirin with PLAVIX when directed to do so by your doctor. Certain other medicines should not be taken with PLAVIX. Be sure to tell your doctor about all of your current medications, especially if you are taking the following:

- aspirin
- nonsteroidal anti-inflammatory drugs (NSAIDs)
- warfarin
- heparin

Be sure to tell your doctor if you are taking PLAVIX before starting any new medication.

WHAT ARE THE COMMON SIDE EFFECTS OF PLAVIX?

The most common side effects of PLAVIX include gastrointestinal events (bleeding, abdominal pain, indigestion, diarrhea, and nausea) and rash. This is not a complete list of side effects associated with PLAVIX. Ask your doctor or pharmacist for a complete list.

HOW SHOULD I TAKE PLAVIX?

Only take PLAVIX exactly as prescribed by your doctor. Do not change your dose or stop taking PLAVIX without talking to your doctor first.

PLAVIX should be taken around the same time every day, and it can be taken with or without food. If you miss a day, do not double up on your medication. Just continue your usual dose. If you have any questions about taking your medications, please consult your doctor.

OVERDOSAGE

As with any prescription medicine, it is possible to overdose on PLAVIX. If you think you may have overdosed, immediately call your doctor or Poison Control Center, or go to the nearest emergency room.

FOR MORE INFORMATION

For more information on PLAVIX, call 1-800-633-1610 or visit www.PLAVIX.com. Neither of these resources, nor the information contained here, can take the place of talking to your doctor. Only your doctor knows the specifics of your condition and how PLAVIX fits into your overall therapy. It is therefore important to maintain an ongoing dialogue with your doctor concerning your condition and your treatment.

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After surviving a stroke, some of the toughest challenges are the ones you can't see.



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**HEART
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IMPORTANT INFORMATION: If you have a stomach ulcer or other condition that causes bleeding, you should not use PLAVIX. When taking PLAVIX alone or with some other medicines including aspirin, the risk of bleeding may increase, so tell your doctor before planning surgery. And, always talk to your doctor before taking aspirin or other medicines with PLAVIX, especially if you've had a stroke. If you develop fever, unexplained weakness or confusion, tell your doctor promptly as these may be signs of a rare but potentially life-threatening condition called TTP, which has been reported rarely, sometimes in less than 2 weeks after starting therapy. Other rare but serious side effects may occur.

Please see important product information for PLAVIX on the previous page.

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