Coping with Pain

Relieving pain enhances recovery and quality of life

Insulin Independence
Treating diabetes with diet and exercise

Back to Extraordinary
A story of inspiration

The Brain’s Crossroads
A primer on brainstem stroke

Stroke Connection is underwritten in part by Bristol-Myers Squibb/Sanofi Pharmaceuticals Partnership, makers of Plavix.

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

If you’ve had a stroke, you may be facing a major risk of having another. You may also be at increased risk for having a heart attack.

**PLAVIX is the only prescription antiplatelet medicine that helps protect against both.** Recovering from a stroke can be difficult and you’ve worked hard to make progress. If you’ve recently had a stroke, you should know PLAVIX can help protect against another stroke or even a heart attack. PLAVIX may be right for you. Be sure to talk to your doctor to find out.

**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.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

**PLAVIX offers protection.** PLAVIX is proven to help keep blood platelets from sticking together and forming clots, which helps keep your blood flowing. Since clots are the leading cause of strokes and heart attacks, PLAVIX helps you stay protected.

**MAJOR RISK OF ANOTHER STROKE | INCREASED RISK OF A HEART ATTACK**

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Blood platelets can stick together and form clots.

PLAVIX helps keep blood platelets from sticking together.

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Talk to your doctor about PLAVIX.

For more information, visit www.plavix.com or call 1-800-905-1921.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Please see important product information for PLAVIX on the following page.
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?
Take PLAVIX exact 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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Therapists Are Dedicated

I appreciated the article on Dr. Jill Bolte Taylor (January/February 2009). However, I believe a “conventional” rehab center provides the comprehensive, intensive therapeutic setting that most survivors need during the initial stages of their recovery. In my 20+ years of rehab experience, I have found most staff to be encouraging of patients in working toward their individual goals and dreams.

Diana Caughron, Rehabilitation Therapist
Tulsa, Oklahoma

Help with Spasticity

I am 51 years old and six years post-stroke. I have always said my stroke was life-changing, not life-ending! I often tell people who question my sense of humor and survival attitude, “I have a choice. I can choose to cry or to laugh. Today I choose to laugh!” I love Stroke Connection because I get to read about people who are so inspiring. I wish I had been getting it during the first five years after my stroke.

I need to decrease the spasticity in my left leg so that I can get a more technologically advanced ankle-foot orthotic. I have tried therapy, medication, water exercises, Jazzercise and acupuncture, but nothing has worked. Are there other readers who have been able to conquer spasticity and achieve a more normal gait and ability to walk without an ankle-foot orthotic? What else should I try? As difficult as it is to live with one arm and hand of limited function, I believe it is my limited walking ability that limits my quality of life the most.

Paula Marks, Survivor
New Hartford, Iowa

Thanks for the Encouragement

It’s 18 months since I had a stroke. In rehab, I picked up a copy of Stroke Connection, and I’ve been reading it ever since. I thank you for the stroke education you’ve given me. In each issue, I learn something new. I really love the magazine.

The people around me don’t understand what I went through. Sometimes I get really emotional, but it doesn’t bother me because I read about that in your magazine. I have learned about what to eat, and I’ve read about people who are not being held back by their strokes.

I am grateful for the encouragement that the stories give me because I’m planning to go back to work soon to get my life back on track. Keep writing those stories because they are encouraging people everywhere and lifting the spirits of all of us in this situation.

Bridget Harris, Survivor
Donaldsonville, Louisiana

A Little Late

I am a little late in writing. I just wanted to thank you for the article on Mark McEwen. He’s one of my favorite people, and I wondered what happened to him. Thanks again.

Lorraine Prince, Survivor
St. Paul, Minnesota
WalkAide is the biggest name in the treatment of foot drop. WalkAide can help you step up your mobility significantly and live life on your terms again. With its compact, single-unit design, WalkAide leverages functional electrical stimulation to improve brain reaction and restore mobility. Many health insurers are now covering the Walkaide. Now is the time to take the big step forward by taking advantage of a free WalkAide trial. For more information or to request a free patient kit, call 866-909-WALK (9255) or visit walkaide.com.

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Men and women who have experienced a first stroke report suboptimal use of healthcare services to prevent a second stroke, researchers reported in Stroke: Journal of the American Heart Association.

“Alarmingly high numbers of adults did not receive stroke prevention services,” said Joseph S. Ross, M.D., M.H.S., the study’s principal author and assistant professor in the department of geriatrics and adult development at Mount Sinai School of Medicine in New York City. “Most usage rates for prevention services were between 50 percent and 70 percent. That’s a lot of people not getting recommended care.”

The study included 11,862 adults age 18 years and older (54 percent women) who reported ever having had a stroke. The study examined use of 11 stroke secondary prevention services and found use varied widely.

The outpatient measures included:
• vascular risk reduction, such as taking aspirin regularly, exercising regularly and annual cholesterol testing and management;
• management of high blood pressure;
• management of diabetes; and
• infectious disease prevention.

The study found:
• 31 percent of patients received outpatient rehabilitation services;
• 52 percent reported influenza vaccination and 53 percent received pneumococcal vaccination;
• 57 percent exercised regularly;
• 77 percent used aspirin regularly;
• 66 percent received counseling to quit smoking;
• 62 percent with high blood pressure received low-fat diet counseling;
• 91 percent with high blood pressure reported currently taking hypertensive medication; and
• 89 percent of those with diabetes reported having annual glycosylated hemoglobin measurements for diabetes management. (This measures the amount of sugar attached to the hemoglobin in red blood cells and shows the average blood sugar for several months before and can help regulate diabetic behavior.)

“Suboptimal care has important implications for the care of adults who have had a stroke,” Ross said. “Regular exercise, reported by 57 percent in our study, is among the most straightforward stroke prevention strategies, even if limited to modest, leisure-time physical activity. It needs to be prioritized for counseling by primary care physicians and neurologists.”

The study found no significant differences in possible disparities by race, age or gender, even though nearly one-quarter of the post-stroke adults lived in a Stroke Belt state (Alabama, Arkansas, Georgia, Indiana, Kentucky, Louisiana, Mississippi, North Carolina, South Carolina, Tennessee or Virginia), and 13 percent were non-Hispanic blacks, groups traditionally identified as at higher risk.

“We were surprised not to find any consistent disparities,” Ross said.

Ross noted the healthcare services highlighted in this study have been recommended by the American Heart Association/American Stroke Association, based on scientific evidence.

“In the future, improving secondary prevention services means we need to focus on everybody, since it is not possible to focus on one particular group to lift up the level of care,” Ross said.
Younger Adults Are Not Immune
Ischemic stroke rate increases dramatically in mid-40s

Rates of ischemic stroke begin to increase sharply after age 44, particularly in men, researchers reported in Stroke: Journal of the American Heart Association.

In a Finnish study of 1,008 ischemic stroke patients less than 50 years old, researchers also found:

• a high frequency of stroke risk factors in young patients;
• a high percentage of “silent” and multiple strokes;
• the pattern of stroke-causing events begins changing in midlife to resemble that of the elderly.

“We were surprised by the overall high prevalence of modifiable stroke risk factors in these patients, and particularly in men,” said Jukka Putaala, M.D., lead author of the study and a stroke neurologist at Helsinki University Central Hospital. “Furthermore, we did not expect to find so many patients having silent or multiple ischemic strokes.”

Silent strokes cause no obvious symptoms, but medical imaging can detect their residual injury to the brain.

Younger patients have a different risk factor profile for ischemic stroke and a wider spectrum of causes compared with elderly patients. For example, cerebral small-vessel disease, large artery atherosclerosis and atrial fibrillation—common underlying causes of ischemic stroke in the elderly—are relatively rare in the young.

Previous stroke studies in younger patients have involved modest numbers, and often did not consider all stroke risk factors. In this study, researchers analyzed trends in demographics for patients who were between ages 15 and 49 and treated for a first ischemic stroke at Helsinki University Central Hospital.

Among their findings:

• Although males outnumbered females nearly two to one overall, among stroke patients under age 30, females exceeded males 56 percent to 44 percent.
• The number of strokes increased with age until the incidence rate was almost equal at around age 44. At that point, strokes rapidly increased, particularly in men. Among patients ages 45–49, twice as many males as females had strokes.
• The average annual stroke rate for all patients was 13.3 per 100,000 people for males and 7.8 per 100,000 for females. Among patients ages 15–44, the annual rate was 7.5 for males and 5.7 for females.
• Traditional stroke risk factors — high cholesterol, smoking, hypertension and obesity — were more common among males and those older than 44. Heavy drinking was more often found in males, and migraine headaches were more common in females as a risk factor. Illicit drug use and migraines were more frequent among younger patients.
• The leading causes of strokes were caused by a cardiac source (19.6 percent) and artery dissections (15.4 percent). Artery dissections are small tears in an artery’s inner lining that allow blood to seep underneath, push out the vessel wall, and narrow or block the artery.
• Multiple strokes had occurred in 23 percent of the patients, and silent strokes occurred in 13 percent of the patients.

The results also demonstrate a need for aggressive strategies to prevent first strokes and recurrence in patients who suffer a stroke. “The most frequent risk factors were all modifiable. Based on our findings, the optimal target age group for primary prevention of ischemic strokes could be 35 to 44.”
t started Dec. 16, 2002, when I was 32 years old. I had a bleeding stroke at work, an AVM (arteriovenous malformation) burst. I didn’t know about it and drove home for lunch. I lost consciousness for a bit and had an accident. I was taken back to work. I got a bad headache at my office and walked, with help, to the clinic.

At the clinic I stopped breathing. They took me to a hospital, where they put me on a helicopter and flew me to a trauma center. There they did brain surgery to stop the bleeding. That surgery was risky, something like a 30 percent survival rate. Afterwards I was in a coma. I remember my family being told I would always be in a coma, and if I came out, I would be a vegetable.

I did come out of the coma but couldn’t talk or move, which made me appear to be a vegetable, although I could understand what was being said. I was alive, but I had something in my head that could kill me at any time – from something as simple as shaking my head “no.”

The AVM was large and too deep in my brain to be removed. It was just left there, though the bleeding stopped. I was only able to move my left side after some therapy. I taught myself to talk. I taught myself how do things with limited movement on my non-dominant side; I was right-handed but I could only move my left. I taught myself how to manipulate the control on my electric wheelchair with my left hand, how to type on the computer with my left index finger and how to write left-handed.

I had worked with babies as an infant development specialist, so I already knew a lot of what to do. It was good that I could talk again because I could tell others what had to be done. I still wondered what kind of vegetable I was, and I would ask others.

In 2004, doctors at Stanford were able to remove the AVM, and I was able to move my right side again. Since then I have been learning to use my right side and do things like typing with both hands. In therapy, I’m doing everything to my right side that was done to my left. Because of my infant training, I was already familiar with how to get development started, which I needed because I couldn’t do anything. Now I just repeat what I remember was done to my left side.

As great as it was to move my right side, the most important thing about surgery is that I no longer have that thing in my head anymore. Nobody expected this kind of recovery: What kind of vegetable can think, talk or write? I still don’t know what kind of vegetable I am.

Angela Ronson, Survivor
Merced, California
Over his dead body was my father going to swallow that fraudulent purple pill.

Dad carefully picked out the purple-striped imposter and scrutinized it. I braced myself.

“Spot,” he said reproachfully. “What? No, yuck” and pushed it aside. “Somebody over there?” he added. Roughly translated this meant, “Take this pill you’re trying to poison me with and shove it, then bring me the usual lovely little pink pill I take every morning with my breakfast.”

“Dad, remember Mom told you? The purple-striped pill is a generic substitute for the pill you usually take. It’s the same stuff, sold in a different style tablet.”

“Yes, but….” Next followed a lengthy and painful discussion of his side of the story. I patiently listened; over his dead body was he going to swallow that fraudulent pill.

Dad pointed to each acceptable pill one by one, saying “One, two, three,” and when he reached the newcomer, he drew an “X” sign in the air.

I reached for the box of markers and paper scraps kept nearby for such emergencies; a picture can paint a thousand words. Here is what I sketched:

Dad contemplated my artwork. He was conflicted, understanding what I was depicting, but still unsettled about the change in his routine. Something in my gaze must have convinced him I was sincere, and he chose for today to let it go. I loved him for that.

He shrugged, rolled his eyes, and swallowed the offending pill. “¡@#$!,” he said, “que sera, sera!”

Alison Joyce, Family Member
Groveland, Massachusetts
Most of the food you eat is turned into glucose, or sugar, that your body uses for energy. The pancreas, an organ near the stomach, produces a hormone called insulin to help glucose enter your cells. When your body does not produce enough insulin, or does not efficiently use the insulin it produces, blood sugar levels rise and build up in the bloodstream, resulting in diabetes and causing other cardiovascular problems.

We talked with endocrinologist Dr. Dan V. Mihailescu, assistant professor of medicine and director of the Diabetes Education Program at the University of Illinois at Chicago, about the role of insulin in the treatment of type 2 diabetes, the most common form of the disease in adults. “Not all forms of diabetes require insulin,” Dr. Mihailescu said. “For example, type 2 diabetes can be treated with diet and exercise, oral medication or insulin.”

Diet and exercise are usually the first step in treatment recommended by physicians and can be used in combination with insulin or other medications. “Medical nutrition therapy is an individualized nutrition prescription that is based on a patient’s caloric needs, lifestyle, type of medication used and other medical conditions,” Dr. Mihailescu said. “All patients with diabetes should see a registered dietician with expertise in this area for a comprehensive evaluation of their dietary needs.”

Generally, patients with diabetes should:

- Monitor their carbohydrate intake. Carbohydrates become sugar in the body.
- Reduce their intake of saturated fat, which is found mostly in foods from animals and is the main cause of higher LDL (“bad” cholesterol) levels. Saturated fats should make up less than 7 percent of total calories.
- Minimize intake of trans fats, the manmade fats used in processed foods.
- Get regular physical activity.
- Decrease their total calorie consumption to lose weight, if obese or overweight.
- Keep their blood pressure in check.
- Not smoke.

“There are numerous forms of insulin available for the treatment of diabetes but at the present time all require subcutaneous (below the skin) or sometimes intravenous administration,” Dr. Mihailescu said. (Intravenous administration should only be done in a hospital.) “For outpatient treatment of diabetes, insulin can be taken as an injection with a syringe or a pen, or it can be delivered as a continuous subcutaneous infusion via an insulin pump.

“For patients with type 2 diabetes, lifestyle changes including diet, exercise and weight loss can have a profound effect on the number of medications required as well as the amount of medication used. I have seen patients with type 2 diabetes who were able to come off insulin completely through lifestyle changes and weight loss.”

Discover your personal risk of developing cardiovascular diseases within the next 10 years by taking the My Diabetes Health Assessment from the American Heart Association’s Heart Of Diabetes program. You’ll also uncover steps you can take to reduce your risk of developing CVD, including lifestyle changes like adding physical activity to your daily routine, losing weight and controlling your blood pressure, blood glucose and cholesterol. It only takes a few minutes to change your life. Visit IKnowDiabetes.org today.
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Helen Talley
Caregiver

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Stroke survivors often experience pain after their strokes. This spans a spectrum from irritating headaches to crippling joint pain to shoulder subluxation to the often-difficult-to-treat central post-stroke pain (CPSP). For some patients, post-stroke pain may be serious enough to jeopardize their recovery by preventing them from participating in therapy. Whatever the level of pain, it compromises quality of life for patients and caregivers. by Jon Caswell
Shoulder Pain

“Shoulder pain is one of the most common pain issues following a stroke,” said physiatrist Dr. Trevor Paris at Brooks Rehabilitation in Jacksonville, Fl.

According to physiatrist Dr. Diemha Hoang, there are two types of shoulder pain; one is caused by limited range of motion, the other is due to muscle weakness. Limited range of motion in the shoulder and the related immobility can cause “frozen shoulder.” “That’s called ‘adhesive capsulitis,’ and it’s really scar tissue that forms in the joint and limits motion. It can be very painful.” Dr. Hoang specializes in stroke and brain injury rehabilitation in Long Beach, Cal.

“The second type of shoulder pain is ‘subluxation secondary to muscle weakness,’ which basically means the arm falls out of its socket because the shoulder muscle is no longer strong enough to hold it in,” Dr. Hoang said.

Physical therapist Stephanie Kaplan is the director of Inpatient Rehabilitation and Physical Therapy at Casa Colina Centers for Rehabilitation in Pomona, Cal. She specializes in neurologic rehabilitation. “In my experience, upper extremity pain is the most limiting and most frequent, and most common in the shoulder, wrist and hand. For many patients that have a flaccid upper extremity, the shoulder joint is being stretched on a regular basis past its normal limits. Thousands of pain receptors located in the shoulder joint are affected by that stretched joint.”

The best way to treat shoulder pain is using range-of-motion exercises of the affected shoulder with the therapist maintaining the correct anatomic position of the shoulder joint as much as possible. “In addition to range-of-motion exercises, there are reports of benefit with muscle block injections with anesthetic and more recently the use of botox,” Dr. Paris said.

Spasticity

“Spasticity is abnormal tone that causes the muscle to contract constantly,” said Dr. Hoang. “It can be quite painful when the muscles are stretched, which they must be so that the patient does not form contractures (permanent shortening).”

“After an extended period of time shortened like that, it is often painful to stretch the muscle into a normal range of motion. Spasticity often impacts a person’s ability to use their upper extremities,” Kaplan said.

Spasticity can also cause restrictions in range of motion. “Due to the restricted range of motion, the joints become stiff and adhesions develop, and they can cause pain when they are stretched,” said Dr. Paris. “The muscles themselves become stiff without repetitive motion, and then they can be a source of pain. In more severe spasticity, muscle spasms can occur periodically, which can be a further source of pain. Medications that specifically address spasticity such as baclofen and botox injections are essential tools in the management of spasticity.”

For survivor Frances Bryant of Sanderson, Florida, persistent pain due to spasticity has been hard to treat. Frances, 70, had two strokes within 24 hours in May 2008. “My arm pain started about a week later,” Frances said. “It’s in my right bicep. Sometimes it’s a stabbing pain, and then subsides to an ache. When it really spasms, it’s very intense and I double over. That happens if it gets cold or I get tired or I sit up too long, like when I go to church. If I’m up for more than three hours, it starts hurting. It feels like I’ve overused that muscle.”

She started using the muscle relaxant baclofen while still in the hospital, but her arm remained contracted so tightly that her hand, constantly clenched in a fist, was under her chin. In December 2008 she had botox injections in her right side, and the tone relaxed considerably, allowing her to rest her arm near her hip. This past March she started doing electrical stimulation (e-stim) of her contracted muscles with a physical therapist who treats her twice a week. “The e-stim treatment feels a little like a bee sting on the skin and then I can feel the current flowing through the muscle—it feels like a knife going through the muscle. It only lasts a few seconds, but I’ve really noticed a difference. Now I can relax my arm to my side when I’m resting, and my fingers are starting to open, too.”

Immobility and Muscle Weakness

Immobility and muscle weakness can also cause pain for survivors. “Immobility often results in a reduction in both the active range of motion of joints and in the muscle stretching that typically occurs in normal activity,” Dr. Paris said. “As a result of this decreased activity the muscles become stiff as do the joints, which restricts a patient’s movement either for walking or activities-of-daily-living (ADL) tasks, and that, in turn, can result in pain.”

Headaches

All three experts said that headaches are common in the months following a stroke. They also agreed that headaches generally resolve themselves and are not a source of long-term incapacitating pain.

(continued)
Beyond the Pain

Post-stroke pain produces consequences beyond physical discomfort. Frances Bryant’s spasticity and pain limit her activity and the amount of time she can be away from home. “I used to take care of the children at church, I organized the food for all the events. I cooked and cleaned my own house, and took care of my 82-year-old husband Millard, but now I can’t do any of that. Millard has become my caregiver.”

Pain, of course, limits function with regard to ADLs and mobility and most other areas of life. The more severe the pain the more impact there is on therapy participation, sleep and overall sense of well being, which can certainly affect a patient’s quality of life. “When you are in pain, you don’t want to do activities that would increase your pain,” Dr. Hoang said. “And if you are cognitively impaired as well, then you can’t or won’t work through the pain in order to lessen it in the long term because you can’t understand the reason behind the painful activity or therapy.”

Post-stroke pain is often a source of depression in survivors. “People who experience pain for long periods of time must be closely monitored for developing depression and stress syndromes, such as chronic fatigue because sleep is consistently interrupted,” Dr. Paris said.

“Chronic pain is a significant medical issue, which can be linked to depression,” Kaplan said. “It can also increase irritability and create additional stress for survivors and their caregivers or family members.”

Of course, it is hard on caregivers who often feel helpless as their loved ones suffer. This may result in irritability and depression, which in turn can have health consequences for the caregiver. If the pain is affecting the survivor’s sleep patterns, it will almost certainly cause the caregiver to lose sleep, with all the attendant problems that arise from that. Because pain limits a survivor’s activities, a family caregiver’s social and community interactions may also be limited.

Decreasing the Pain

Unfortunately, the old adage “no pain, no gain” often applies to treatment approaches that address post-stroke pain. Exercise can increase or decrease pain depending on the type of pain and type of exercise. “If the limb is tight and needs to be stretched, this can cause immediate pain during the activity, but increase function or decrease pain after the activity has been completed,” Kaplan said.

“Range-of-motion exercises should be done gently and with careful attention to avoid trauma,” Dr. Paris said. “But even then they often cause pain because spastic muscles and tight joints are tender and will be painful. Steroids and analgesics (painkillers) may help with this type of pain.” All three experts emphasized that this stretching is essential for maintenance and improvement of functioning. Positioning splints may also be required, which may be inconvenient and uncomfortable.

Of course, medication is the most common method for treating pain. Both doctors were clear that the type of drug used depends on the type of stroke. “If the patient had a hemorrhagic stroke, they should avoid NSAIDs (non-steroidal anti-inflammatory drugs) because of the risk of bleeding,” Dr. Hoang said. “Also, ischemic stroke survivors should be careful about taking aspirin in conjunction with NSAIDs because of the increased risk of bleeding.” Narcotic painkillers, commonly used for many types of pain, can cause sedation. If the stroke has had an impact on the survivor’s cognitive ability, these drugs are likely to impair cognition further. There is also a risk of addiction with narcotics.

Frances Bryant has chosen to avoid painkillers. As noted earlier, she has used the muscle relaxant baclofen since she was hospitalized; she also started taking zanaflex (another muscle relaxant) in December. Respecting her limits helps limit her pain. “If I’m exercising my arm and it starts to hurt, I stop,” she said. She plans her outings so that she doesn’t get tired, which aggravates the spasticity in her bicep. “When it gets bad I rub it with a topical gel called Freeze-It that I get at the drug store.”

“The treatment of post-stroke pain is often complex,” Dr. Paris said. “It is likely to involve a combination of drugs and physical and occupational therapy techniques as well as other medical interventions to address the various issues that are causing the pain. Unfortunately, the path to recovery can be slow and often requires a commitment to a maintenance exercise program to provide long-term benefit.”

“Chronic pain is a significant medical issue, which can be linked to depression.”
Central Post-Stroke Pain

There is another kind of pain that may occur after stroke. It is called central post-stroke pain (CPSP), and it is the result of injury to the brain itself. Clothing, sheets, wind on the skin or a light touch are often enough to trigger episodes of unrelenting pain.

It can be a steady, sometimes deep burning, aching, cutting or tearing sensation; it may be mixed with sudden, excruciating shots of pain or with other distracting sensations like cold, tingling, a “pins and needles” effect, a ballooning sensation, throbbing or the feeling of a dental probe on a raw nerve.

Mary Simpson, 64, of Grand Junction, Col. has CPSP from a hemorrhagic brainstem stroke 14 years ago. It was two years before she got a diagnosis, but that doesn’t mean she got the pain under control. “It still affects my life every day because of the sensations in my affected foot and hand. It often feels like I’m walking on a balloon, so my stability is off. I don’t go out into the wind, cold or snow because it’s too painful, especially on my hand. I don’t do as much rehab or exercise as I should because movement triggers it.”

“CPSP commonly results from damage to or involvement of the thalamus (the brain’s pain center),” Dr. Paris said. “This can be a very difficult disorder to treat effectively and can result in severe pain. Numerous medications have been tried. Narcotic analgesics are generally not effective. Tricyclic antidepressants and anti-seizure meds have shown some benefit.” Anti-convulsants like neurontin have also been effective for some patients. Survivors with CPSP often take anti-depressants as well to help with the emotional trauma of intense and unrelenting pain. Mary Simpson has found relief from light bouncing on a mini-trampoline.

Dr. Paris mentioned epidural motor cortex stimulation, a new treatment option that has shown promise in treating CPSP. It involves attaching electrodes to the skin over the motor cortex of the brain and then stimulating that area with electrical current. Researchers theorize that it is effective because it increases blood flow to that area of the cortex.

Mary Simpson has found that peer support also helps. She maintains the Web site centralpain.org, an online support group for survivors with CPSP. “Just knowing that you are not alone, that there are others who understand and validate what you live through each day, is a very big thing,” Mary said. “We share ideas on how to educate the people around us, family and doctors alike, about CPSP.”

Editor’s Note: For more information on CPSP, visit StrokeAssociation.org/strokeconnection.
Directing a film about her stroke gave Beth McElhenny a new direction in life.

by Jon Caswell

AS A KID, BETH MCELHENNY
LOVED TO ESCAPE TO THE MOVIES.

Sci-fi movies were particular favorites. Then as an adult, she made a movie about a subject she couldn’t escape. Beth is a stroke survivor, and her 20-minute film “Still Me” is the moving story of a survivor’s struggle to be seen not for his disability, but for who he really is.

Beth’s stroke was a little like one of those sci-fi films where the character wakes up in another world. At 35, she lived alone and was home when the stroke started. In severe pain, she went to her neighbors. They didn’t know Beth; in fact they thought she was on drugs and called the police, who called the EMTs. She was taken to the hospital where she was unconscious for several days.

Meanwhile, family members and co-workers had no idea where she was or what had happened. After 48 hours, Debbie Landis, a co-worker, knew something was wrong: “My little voice all but beat me over the head,” she said. Debbie called the Los Angeles County sheriff’s department, who met her at Beth’s house. They found the oven on and TV blaring, the dog not fed and the telephone on the front porch. A day and a half later, they found Beth had checked into a hospital as a “Jane Doe.” “She was battered and bruised, with no memory of herself, her life, her friends, her family or how she had gotten where she was,” Debbie said. She had awakened in another world as the result of a stroke.

A few days later, after her mother arrived from across country, Beth was allowed to go home, but she was still very sick. Within 24 hours she
Beth was back in the hospital with a second stroke. “She crossed over once, more likely twice, that night as we waited outside intensive care,” Debbie said. “We did the best we could to stay optimistic. Through prayer, or strength, or sheer willpower, she survived the night.” That was December 2002.

**PLANT RECOVERY**

Beth was released from the hospital with severe physical, cognitive and emotional deficits. “Physical therapy helped me regain strength and balance,” Beth said. “I had overcome physical challenges in the past, and I figured as long as I could get one foot in front of the other, I would master a normal walk again. It took many weeks, but I got there. I learned to be more careful, one, to protect myself physically, and two, to hide the deficit and protect my emotional state.”

Before the stroke, Beth had been a computer networking systems engineer with a photographic memory, who didn’t need to write things down. “That memory was a bit out of focus,” she said. “It’s been a challenge to journal the details of my daily activities and health issues and to track headaches, doctors appointments and medications.”

After 18 months, she entered a vocational rehab program. After six months, she found a full-time job as a software engineer, at a fraction of her former salary. A year later she took an entry-level position in the network testing industry where she had previously excelled. “That was quite a blow to my ego.”

Beth worked diligently to regain her skills. Along the way, she renewed her standing as a Microsoft Certified System Engineer and gained certification as a Cisco Certified Network Associate. Her diligence paid off. Since she returned to work three years post-stroke, she has received two promotions.

**MOVIE MAKING**

There’s more to Beth than her left brain, however. Her college degree is in filmmaking, and before her stroke she worked part-time as an assistant instructor in the film school at the UCLA Extension, and she’d almost finished editing her fourth film.

In the first few months after her stroke, Beth realized that people were reacting differently to her. Sometimes they wouldn’t wait for her to answer because her responses weren’t as quick as before. They made decisions for her based on what they thought would be best for her, or what would be best for them. “I could see...
that they could not see past whatever physical or cognitive hindrances I was experiencing,” she said. That’s when the idea for “Still Me” came. Originally conceptualized as a one-minute public service announcement, it evolved into a 20-minute movie filmed in Ohio in 2007.

“Still Me” is the story of Jack and Roseanne and what happens to them after Jack’s stroke. Roseanne struggles with accepting the way stroke appears to have changed Jack. Three months after his stroke, she has a dinner party for a dozen friends, but their interactions with Jack cause him to feel more isolated. After everyone has gone home, Jack demands his wife look at him. When she can’t, he mischievously slings cake at her. The tension breaks and they share their true feelings—on the kitchen floor, covered in cake. The funny encounter ends in tears. In the end, Roseanne looks her husband in the eyes and realizes that he is still himself despite his disabilities.

I wanted to appeal to a broader audience,” Beth said. However, one scene is taken directly from her experience. Right after Jack’s stroke he awakens alone in a hospital room, not understanding that he has had a stroke. Beth described her experience: “I woke up in the hospital and got out of bed. As I tried to undo the IV, a nurse rushed in and asked what I was doing. I said, ‘I’m going to work,’ which I thought I needed to do. She said, ‘No, you’re not,’ and something in her tone convinced me I could call in sick. She put me back in bed and put something in my IV tube and I passed out.”

In addition to two executive producers who financed “Still Me,” Beth sank all her savings into the production. So far the film has been shown at a number of film festivals and has garnered awards at many of them, including a best actor award for Scott King. Scott, who is not a stroke survivor, studied Kirk Douglas and Dick Clark to prepare for his role as a survivor of a left-brain stroke. Currently Beth is screening the film with stroke support groups in Southern California and is talking with groups across the country, encouraging them to use the film as a fund raiser.

Beyond raising money for stroke groups, she wants to raise awareness. “I want people to better understand that people aren’t always who they are on the outside,” Beth said. “We must look beyond disability.”

For survivors, Beth has an additional message: “Just because therapy is over doesn’t mean the problem is gone. Therapy is my way of life now. I am working with a trainer at the gym who is helping me push my physical limits. We focus on areas that support residual strength and balance issues. And I use various memory games to flex my brain muscle. The important thing is to never give up.”

Debbie Landis thinks Beth is too modest about her recovery and how hard she has worked to achieve it. “I think she underestimates the strength it took to come back this far,” Debbie said. “While Beth considers herself ‘back to normal,’ everyone who knows her agrees that, in reality, she’s ‘back to extraordinary.’”

Editor’s Note: DVDs of “Still Me” are available for $14.99 at brookwoodfilms.com. Group discounts are available for support groups that want to use it as a fund raiser.
The brainstem is a very important part of the brain. Some call it “primitive” because it developed early in our evolution. Scientists know this because it controls our involuntary “life-support” functions, such as heart rate, breathing, swallowing and blood pressure.

The brainstem is a crossroads of the nervous system. Impulses generated in either side of the cortex can only get to the arms, legs, heart and diaphragm by going through the brainstem. In “My Brainstem Stroke,” published in the British Medical Journal, Dr. G.F. Grant described his experience: “Essentially the bridge between my brain and my body blew up. This left me mentally undamaged, my memory intact, my intellectual ability undiminished, and, so my family and friends assure me, my sense of humor in no way altered, but the only parts of me that could move initially were my eyelids. I was classified as tetraplegic with no speech.”

Dr. Richard Zorowitz, chairman and associate professor of physical medicine and rehabilitation at the Johns Hopkins Bayview Medical Center in Baltimore, pointed out that brainstem stroke is relatively uncommon, accounting for 10–15 percent of all strokes. As with cortical strokes (strokes in the cortex of the brain), brainstem strokes can be ischemic or hemorrhagic. “And just as with cortical strokes, brainstem strokes span the spectrum of consequences,” Dr. Zorowitz said. “It’s as much the location as the size of the area affected.” The more area affected, the worse for the patient.

The brainstem comprises three parts — the midbrain, the pons and the medulla — and which nerves are affected determines the symptoms a person will have. In addition to breathing, blood pressure and heart rate, a brainstem stroke can compromise many other functions. “For instance, if the stroke is in the midbrain, at the top of the brainstem, patients may lose the ability to move their eyes or open their eyelids,” Dr. Zorowitz said. In other brainstem strokes, patients may develop involuntary “dancing” or “jerking” eye movements known as “nystagmus.” A stroke lower in the brainstem will result in facial weakness; lower still the muscles that allow us to chew are affected; a stroke below that may injure the muscles of the throat, affecting swallowing and the voice. Injury to the pons may result in “locked-in syndrome,” a condition in which a patient is aware and awake, but cannot move or communicate due to complete paralysis of nearly all voluntary muscles.

A brainstem stroke can impede messages sent to the cerebellum, which is located behind the brainstem. The cerebellum tells muscles how to work together for coordination and balance. Ataxia, the body’s inability to coordinate how muscles move together, can affect arms, legs and chest muscles and may be associated with tremors.

Brainstem strokes are not more common in any demographic group, and ischemic brainstem strokes may be treated with tPA, a medication that dissolves blood clots, as long as the patient arrives at the hospital within three hours of symptom onset.
Floor coverings

Floor coverings are a problem when they require too much effort to walk or wheel over. Low-pile carpeting or vinyl or laminate flooring are good choices whether you walk (with or without a cane or walker) or use a wheelchair. They can replace thick or textured carpet (which create “drag”) or hardwood floors (which require waxing and can be slippery). If you use a power wheelchair, consider removing all carpets, as the torque of making turns can stretch or damage carpeting.

Passageway widths

Passageway widths include spaces between furnishings, hallways and doorways. You can rearrange furniture to allow adequate space. You may have already done this to get to your favorite chair or the bed, but it’s a good idea to evaluate each room for ways to gain adequate passage. This may require removing seldom-used furniture. Keep in mind that if you use a wheelchair or walker, any passageway that involves a turn must be wide enough to accommodate your equipment at the point where you change direction.

It’s possible to get more space from a doorway without widening the door. The first step is to ensure that the door can swing open to at least 90 degrees, preferably to the adjacent wall. This may require moving objects behind the door. If a perpendicular wall or immovable furniture prevents full opening, consider reversing the hinges so that the door opens out (into a hallway) instead of into the room. If this is still not enough space (as for a wheelchair), you could install “swing clear hinges” to allow the door to operate normally but gain the few inches that are usually taken by the thickness of the door when it is opened. The last resort is to widen the doorway, which requires a remodeler or handyperson.

Grade changes

“Grade changes” refers to raised thresholds, steps or stairs. It can be helpful to have a rail or handle installed on the wall at places where you have to step up or over. On stairways, have railings installed on both sides of the stairs, extending just beyond the last step in either direction. This gives additional support for ascending and descending, including your approach to the stairs and as you step away. If you use a walker, consider getting a second one and keeping one upstairs and one downstairs rather than trying to bring it up or down the stairs.

You’ll find that making small changes can make a big difference in reducing the effort and risk of doing daily activities in your home.
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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PLA-OCT07-B-Aa
After surviving a stroke, some of the toughest challenges are the ones you can’t see.

If you’ve had a stroke, you may be facing a major risk of having another. You may also be at increased risk for having a heart attack.

PLAVIX is the only prescription antiplatelet medicine that helps protect against both. Recovering from a stroke can be difficult and you’ve worked hard to make progress. If you’ve recently had a stroke, you should know PLAVIX can help protect against another stroke or even a heart attack. PLAVIX may be right for you. Be sure to talk to your doctor to find out.

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.

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit www.fda.gov/medwatch, or call 1-800-FDA-1088.

Talk to your doctor about PLAVIX. For more information, visit www.plavix.com or call 1-800-905-3430.

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