Getting Active, Staying Active

Even a little exercise has huge benefits for survivors

Bleeding in the Brain
Surviving a hemorrhagic stroke

Recreational Therapy
Healing body and spirit

Life at the Curb
Anything you can do I can do better

Getting Active, Staying Active
Even a little exercise has huge benefits for survivors

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Cover Story

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Surviving a stroke is no excuse for not exercising — but it may require some changes in how you do it. We talked to a survivor, a physiatrist and a physical therapist about getting active again.

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Keep It Coming!

Please never discontinue this magazine; it has saved me on many occasions. There were issues I talked to no one about, some I didn’t even know I had till reading articles in your magazine. Just when I would be despondent, there would be some articles that would help so much because I realized I was not alone with whatever problem I was having. Thank you so very much. Whenever someone expresses a need, I recommend Stroke Connection. In the article “What’s Wrong with Me?” (May/June 2008), it says that long-term survivors continue to experience increases in function. I was so excited to see this statement because it has been so true for me and I want others to know this.

Donna Rumlow, Survivor
Omro, Wisconsin

Surviving a Snafu

I’m sure that your statistics, already gripping (“When NOT to Call Your Doctor,” May/June 2008), didn’t include those of us who must go to our doctor’s office even before going to the ER. Our insurance plan has a clause that says if you don’t go to the ER with your doctor’s referral, you’re liable for a bigger ER bill and, if necessary, hospital charge.

Years ago this insurance snafu led me to leave my devoted doctor out of embarrassment. His wife, acting as his receptionist, didn’t know my insurance plan had changed, and she had my husband bring me in to the office first. My doctor practically yelled at her in front of me that I should have been picked up at home by an ambulance and rushed to the ER.

I survived, but without a national healthcare system, how many of us haven’t?

Joyce Rinehart
Ocala, Florida

Finding a Physiatrist

As a stroke survivor and advocate, I participate in many Internet message boards. I am constantly amazed that survivors and caregivers are not aware that there are medical professionals who specialize in coordinating stroke rehabilitation. I encourage Stroke Connection to publish an article about physiatrists to notify readers that they can find one in the United States at www.aapmr.org/ or a Canadian physiatrist at capmr.medical.org/public_info.htm.

Rene Williams Larson
Tempe, Arizona

Getting a Leg Up

The article by Walter Kilcullen (“Therapy on Horseback,” March/April 2008) was so true to me. As a survivor without the use of my left arm and with limited use of my left leg, I was curious how they mounted and dismounted the horse. A couple of years ago, I did the overnight mule trip into the Grand Canyon. Two big guides had to pick me up and put me on the mule and take me off. The same thing happened four years ago when I did the eight-day raft trip in the Grand Canyon. Two of the other guys on the trip would lift me in and out of the high raft. I guess my point is, where there is a will, there is a way.

Gary Willmart, Survivor
Navajo Dam, New Mexico
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.

**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.

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**Talk to your doctor about PLAVIX.** For more information, visit www.plavix.com or call 1-888-352-7531.
**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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listening to music in the early stages of recovery from stroke can improve recovery, according to new research in the medical journal *Brain*.

Researchers from Finland found that if stroke patients listened to music for a couple of hours a day, their verbal memory and focused attention recovered better and they had a more positive mood than patients who did not listen to music or who listened to audio books.

“As a result of our findings, we suggest that everyday music listening during early stroke recovery offers a valuable addition to the patients’ care by providing an individually targeted, easy-to-conduct and inexpensive means to facilitate cognitive and emotional recovery,” said Teppo Särkämö, the study’s lead author.

The researchers started working with the survivors as soon as possible after they had been admitted to the hospital.

“We thought that it was important to start the listening during the acute post-stroke stage, as the brain can undergo dramatic changes during the first weeks and months of recovery, and we know these changes can be enhanced by stimulation from the environment,” he said.

The researchers randomly assigned them to a music listening group, a language group or a control group.

During the next two months the music and language groups listened daily to music they chose themselves or to audio books, respectively, while the control group received no listening material. All groups received standard stroke rehabilitation.

Three months after stroke, verbal memory had improved by 60 percent in music listeners, by 18 percent in audio book listeners and by 29 percent in nonlisteners. Similarly, focused attention, the ability to control and perform mental operations and resolve conflicts among responses, improved by 17 percent in music listeners while no improvement was observed in audio book listeners and nonlisteners. The researchers also found that the music listening group experienced less depression and confusion than the patients in the control group.

“Our research shows for the first time that listening to music during this crucial period can enhance cognitive recovery and prevent negative mood, and it has the advantage that it is cheap and easy to organize,” Särkämö said.
Stroke Telemedicine
ASA sponsors Congressional briefing

Thanks to new technology, stroke patients at remote hospitals can be evaluated from hundreds of miles away, a fact now catching Congress’ attention. In May, the American Heart Association/American Stroke Association (AHA/ASA) sponsored a briefing on Capitol Hill to highlight ways telemedicine can improve the delivery of acute care to stroke patients.

More than 60 people, including Congressional staff, attended the briefing, which was co-sponsored by the American Telemedicine Association. Dr. Darwin Labarthe, director of the Division for Heart Disease and Stroke Prevention at the Centers for Disease Control and Prevention, kicked off the event by introducing The Atlas of Stroke Hospitalizations Among Medicare Beneficiaries, which includes state- and county-level data about stroke. The atlas can be found at http://www.cdc.gov/DHDP/library/stroke_atlas. Trisha Carney, a stroke survivor from New York, explained how telemedicine helped her receive the timely and appropriate care she needed following her stroke.

Dr. Paul Katz, AHA/ASA advocate and medical director of the Comprehensive Stroke Center of Renown Institute for Neurosciences in Reno, Nev., discussed how telemedicine has improved the quality of stroke care in rural Nevada. He also showed a video of a remote neurological exam conducted through telemedicine technology.

The briefing also demonstrated how the STOP Stroke Act, federal legislation that would authorize grants for states to develop stroke systems of care including telemedicine, can improve care across the country. For the latest information about the STOP Stroke Act, please visit www.strokeassociation.org/yourethecure.

The Human Factor
Survivors walk better after human-assisted rehab

Walking therapy for stroke survivors is significantly more effective when conducted by a physical therapist instead of a robot, according to a report in Stroke: Journal of the American Heart Association.

Physical therapists often assist stroke patients too weak to walk on their own by fitting them in a harness, putting them on a treadmill and helping them move as they would when walking. But this can be physically demanding on a therapist, and robotic devices have been developed as an alternative to relieve the therapist.

“We wanted to know whether using a robotic device that guides the limb in a symmetrical walking pattern would facilitate greater improvements in walking speed and symmetry than more traditional walking interventions with a physical therapist,” said T. George Hornby, Ph.D., M.P.T., the study’s lead author.

Researchers studied 48 survivors who were at least six months post-stroke and still had moderate to severe trouble walking. Patients were randomly divided between robotic-assisted locomotor training, or traditional physical therapist-assisted locomotor therapy. During locomotor training, patients are fitted with a harness and suspended from a frame over the treadmill. All patients received 12 30-minute therapy sessions during the four to five weeks of the study.

“We found that patients improved their walking whether they had the robotic device or the therapist helping them,” said Hornby, an assistant professor in the Physical Therapy Department at the University of Illinois in Chicago. “However, the amount of improvement was greater in the therapist-assisted group.”
I had my stroke about five years ago. I was one of the “lucky ones.” Translated, that means that I did not suffer any physical impairment afterwards, only short-term memory problems. As I am 72 years old, I wonder whether that is due to the aging process more than the stroke.

Over the years I have acted in local theater and commercials and training films. But because of the stroke, I am never sure what day it is, so I did not audition for some roles, frightened that my memory would leave me speechless in front of an audience. Ultimately I decided to give it a chance, hoping to find a small part. In theater there is a saying, “There are no small roles, only small actors.”

I auditioned and was given a speaking part in a production of “Inherit the Wind.” It fit my goal of having a small role, and I managed to get through our run with minimal screw-ups.

Afterwards I decided that it was time to take the next step — a starring role. I auditioned for a one-act play with two characters; it was comparable to the comedy “The Sunshine Boys.” I had to memorize 13 pages of dialogue. In addition it was necessary for me to memorize the other actor’s lines so I could cover for him if something should happen to him on stage. That is one of the skills that actors doing live performances must have. Through a lot of repetition and with my wife Eleanor’s help, I was able to learn my lines and do the live performances.

I’m going to find a T-shirt that reads “I DID IT!”

Cary Cohen, Survivor
Gaithersburg, Maryland

I’d like to share a true story with you. My girlfriend was a caregiver for her husband who had Parkinson’s disease from age 25, for 40 years. She cared for him, raised three boys, took care of the home and worked.

I watched for years as she waited on this man hand and foot. As his health declined, she had to work even harder feeding and showering him, lifting him up when he fell, cleaning him up after an accident, taking care of his medications, pushing him around in a wheelchair and driving him everywhere he had to go. This woman went beyond the call of duty.

After her husband passed away, I was visiting with her and she said, “That man gave me everything material, I wanted for nothing.” Then she broke down in tears and said, “Zenta, not once did he ever say ‘thank you.’ All I ever wanted from him was a thank you.” That got me thinking how thankful I am to my caregiver. I now make sure I thank my caregiver for everything he does for me, no matter how big or small, whether it was a good day or not. Unless I forget, I make sure each night before I go to sleep to tell my caregiver, “Thank you for a nice day. I love you and good night.”

Survivors, don’t take anyone for granted — no one owes you a thing. Be thankful to your caregiver because they’re the ones that help you get through each day, as well as all those who cross your path each day with a helping hand, a warm smile or a gentle hug. Give thanks.

Zenta Sheehan, Survivor
Taunton, Massachusetts
Over time my weight has gone up and down like the New York Stock Exchange index. In later years, significant weight change has been coupled with a doctor’s dire warning and two or three pages of indecipherable test results. However, here’s my gripe: When I need to trim a little fat, I work my tail off, so to speak, to get my weight down to where it should be. But the problem takes place after I’ve plowed through two or three issues of *National Geographic* waiting to see the doctor, then the nurse’s assistant asks me to step on the scale. “Wait!” I say, “Before I do that, shouldn’t I take off:

a) my jacket?  
b) my hat?  
c) my shoes?  
d) my hearing aids?”

And what about the rest of my clothes? I can see it now — I’m standing in the hallway of my doctor’s office stark naked, but with a smile on my face.

Why a smile? Because this weight — stark naked, first thing in the morning in the privacy of my bathroom — is what I’ve been striving for months to attain. For me, this is going for the gold, accompanied by numerous trips to the gym and reading hundreds of food ingredient labels in the supermarket, all aggravated by countless discussions with my wife about what to buy or eat for the next few meals. Not to mention the endless waiting for one pound to ungraciously depart.

The nurse’s assistant simply addresses the issue by saying, “Well, it really doesn’t matter. We’re just trying to get a rough estimate of your weight.” Rough estimate?

I feel like saying to her, “Well, let’s make a rough estimate of your property taxes. Let’s make a rough estimate of how much is left on your mortgage or of how much money the doctor intends to pay you this month.”

In summary, I’d like to say that a pound shaved is a pound earned. And that’s all I have to say about that!

**Bob Guns, Survivor**  
Mooresville, North Carolina

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for anyone challenged regarding the need to be at the hospital every day while a family member is hospitalized, let me tell you our tale. My father, who had a stroke in March 2006, was recently hospitalized. He has expressive aphasia and is not able to communicate effectively. He had an elevated white blood cell count, and in addition to his antibiotic dose, he was given what we thought was his usual dosage of Lamictal, an anti-seizure medication. Over the course of his 11-day hospital stay, my mother and I noticed his unresponsiveness, lethargy and desire to keep his eyes shut. We kept questioning the nurses as to why he was behaving this way. Their canned responses were “Oh, this is typical for stroke patients” and “He probably didn’t get enough sleep last night.” He was subjected to another CT scan because his doctor thought a mini-stroke might be causing this extreme sleepiness.

I’ll cut to the chase: When my father was discharged, I picked up all his prescriptions from the pharmacy, and as I portioned out his pills, I saw that the Lamictal pill was four times the dosage he should have been getting. The nurses had been giving my father 200 mg in the morning and 200 mg at night. He normally took 50 mg twice a day. Who wouldn’t be lethargic and sleepy!

My point is that it is essential that family members persist in questioning and remain an ever-vigilant presence when a loved one is hospitalized. By the way, the doctor admitted his mistake, and my dad is back to normal and no longer keeps his eyes shut during the day.

**Beth Rose Feuerstein, Caregiver**  
Long Beach, New York

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**Rough Estimates**

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**Bob Guns, Survivor**  
Mooresville, North Carolina
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— Daryl Holt, OTR/L

“To try on the SaeboFlex® was amazing! I was so excited to see my arm move, and that I could grasp and release… was amazing.”

— Mary Graham, Stroke Survivor
Getting Active, Staying Active

Even a little physical activity has far-reaching benefits for stroke survivors

by Jon Caswell
We know that physical activity is good for human bodies. That goes double for stroke survivors.

The benefits of exercise are remarkable and wide-ranging: Physical activity improves heart function and lipid profile by lowering total cholesterol while raising HDL (good cholesterol). It lowers blood pressure and resting heart rate. Being active reduces the risk and severity of diabetes by increasing insulin sensitivity, and it improves strength, balance and endurance. For stroke survivors, these benefits can spell the difference between dependence and independence.

In addition to those physical benefits, exercise can enhance self-confidence and independence and reduce depression and anxiety. As survivor Lorraine Essig, 87, said, “I can be in a bad mood, but after I’ve done my exercises, that disappears.”

Since Lorraine’s stroke seven years ago, she works out three days a week, despite right-side weakness and challenges with her balance that require her to use a cane.

She starts with 10 minutes of pedaling on a portable exercise cycle she puts in front of her chair. Then she does a balancing exercise — standing on both feet, she raises her arms to shoulder height, closes her eyes and counts to 60. Holding onto her walker, she does 20 steps in place, bringing her knees as high as the handholds on her walker. Then she does a routine of 14 exercises 20 times each; she increases benefit by adding 2.5 lb weights, strapped to her wrists or ankles depending on the exercise. “I started out doing each one 30 times, but it tired me out too much,” Lorraine said.

**Expert testimony**

Survivors should get clearance before starting a physical activity program. “See your doctor first,” said Dr. Dorian Rose, a physical therapist with a Ph.D. in biokinesiology and research assistant professor in the College of Public Health and Health Professions at the University of Florida. “But don’t let that step be a barrier to exercising. Most physicians will be thrilled to hear that their patients are interested in exercising.”

**One size doesn’t fit all**

Many survivors with disabilities are put off by the general physical activity prescription of 30–45 minutes of aerobic exercise most days of the week. Physiatrist Dr. Elizabeth Pegg Frates is assistant director of medical education for the Institute of Lifestyle Medicine and a clinical instructor in the Department of Physical Medicine and Rehabilitation, both at Harvard School of Medicine. She emphasized that most survivors are capable of some activity depending on their functional abilities. “The exercise prescription needs to be individualized for each survivor based on interests, strengths and current level of fitness,” Dr. Frates said. In her book, *Life After Stroke: The Guide to Recovering Your Health and Preventing Another Stroke*, she and her co-authors created four categories to help with selecting an appropriate type of physical activity. The four categories are:

1) Severe functional limitations
2) Moderate functional limitations
3) Mild functional limitations
4) No functional limitations

(continued)
Those with severe limitations (e.g., paralyzed on one side of the body and spending significant amounts of time in bed) may do their exercises sitting in a chair and get assistance doing range of motion exercises with their affected limbs. They may be able to do neck stretches, knee lifts, ankle rotations, and flexing and extending their elbows and wrists on the unaffected side of their body.

Those with moderate limitations (e.g., significant weakness in a limb) may be able to engage in physical activity in a pool where their affected limbs are lighter or use a recumbent stationary bike with assistance from a friend or family member or even a Velcro strap to keep their affected foot on the pedal.

Those who can move all four limbs despite weakness in one or two of them (mild limitations) have even more options, including swimming and walking or using a recumbent stationary bike or stair stepper.

Those with no functional limitations have no excuse for not participating in some form of physical activity. The trick is finding one you like. (To read the full interview with Dr. Frates, visit www.strokeassociation.org and type “Dr. Frates interview” in the search box.)

Recipe for physical activity

There are three main ingredients in aerobic physical activity: intensity, duration and frequency. Whether you engaged in physical activity before your stroke or not, begin any new physical activity regimen slowly. “An exercise session that is completed at a low intensity is better than no exercise session at all,” Dr. Frates said. “Moderate intensity, when you can talk but not sing, might be possible for some survivors, depending on their level of heart health and overall fitness.”

Many survivors come to post-stroke physical activity after a long period of convalescence during which their muscles have atrophied and they have lost aerobic capacity. “A reasonable goal for someone in that condition is accumulating 10 minutes of physical activity each day or over the course of a day,” Dr. Frates said. “That can be broken into two five-minute segments. With the guidance of their physician they might be able to add five minutes after a week or so depending on how things are going.”

Frequency is also important. The exercise prescription is to be active most days of the week. Lorraine Essig goes through her 40-minute workout three days a week. As survivors increase their strength and endurance, they may be able to increase the frequency. “It is best to progress at a slow and steady pace that is comfortable,” Dr. Frates said.

“The most important thing is to start,” said Dr. Rose. “Five minutes of physical activity is better than zero minutes of physical activity. Survivors should do what they can, what their physician has given them permission to do. Five minutes can turn into seven minutes can turn into 10 minutes.”

Resistance training

Resistance training — either with weight machines or exercise bands — is another important component of physical activity. “Often survivors have secondary weakness,” Dr. Rose said. “This results from inactivity since the stroke. A strengthening program benefits this secondary weakness. I recommend consulting a physical therapist to establish a proper resistance training program.”

Lorraine Essig works out three days a week in the comfort of her home. “I can be in a bad mood, but after I’ve done my exercises, that disappears.”
Resistance training can increase strength and muscle mass, and those changes can mean increased mobility, greater independence and better function with daily activities. As with aerobic exercise, resistance training involves intensity, duration and frequency. Again, check with your doctor before engaging in a weight training program, and talk to your physical therapist as well.

A weight workout should work eight to 10 areas of your body — arms, shoulders, chest, trunk, back, hips, legs and ankles. Dr. Frates suggests choosing a weight that is not too heavy (one that you can lift only six times) and not too light (one that you can easily lift more than 15 times).

It is generally recommended that you start with 10–15 repetitions of a weight-bearing exercise — considered a set. The goal is three sets of each exercise, with a 15-second rest between sets. But again, do what you can, starting slowly, perhaps working only two or three muscle groups a day and building toward three sets.

Do resistance training twice a week, not on consecutive days so the muscles have time to recuperate.

(For more on post-stroke weight training, read “Resist This!” in our January/February 2004 issue, or visit www.strokeassociation.org and type “weight training” in the search box.)

Motivation

Motivation can be a huge issue. To find out what motivates you or the person in your care to engage in physical activity, go over the benefits — weight loss, lower blood pressure, more strength, better mood, more independence and better overall health. What gets you excited? Is it the thought of losing weight or having more energy or better balance or the independence that comes with greater strength?

Then set a three-month goal such as exercising for 30 minutes five days a week. “Realizing it will take three months to get there, set a concrete goal for the first week,” Dr. Frates said. “For example, a reasonable goal for a survivor who has mild functional limitations and has been sedentary for years would be to exercise for 10 minutes three days a week. Selecting the time of day and putting it in a calendar helps.”

Keeping a physical activity log where you can chart progress is another way to stay motivated. Working out with a friend or joining an exercise group makes it more fun and keeps you accountable. The social support of family and friends is also important. Dr. Rose’s advice to family members: “Encourage small steps and be supportive in...” (continued)
any small step that is taken. Family members should realize that it can be intimidating to exercise in public. Since everyone can benefit from physical activity, family members can be supportive by joining the exercise class or the gym and exercising with their survivors.”

And just as there are ways to encourage survivors, there are ways to discourage them. “Doing too much too fast is a sure way to de-motivate someone,” Dr. Frates said. “It’s a set-up for failure. Successful small steps are the way to produce long-lasting change.”

Selecting a physical activity the survivor doesn’t like is another de-motivator. Just because a caregiver or therapist thinks water aerobics is a good idea doesn’t mean the survivor will. Remember to keep the physical activity regimen engaging and interesting to prevent boredom. “Varying the type of physical activity can be one way to keep survivors motivated,” Dr. Frates said.

**New horizons**

Visual reality devices like the Nintendo Wii (pronounced “wee”) may give survivors with disabilities a fun way to exercise. “Any time physical activity doesn’t ‘feel’ like exercise, people are more apt to stick with it,” Dr. Rose said. “Anecdotally, physical therapists report their patients enjoy exercising with the Wii, and that they are getting a workout. Research is currently underway to understand the potential specific benefits.”

Besides fun, these devices provide a variety of activities and give instant feedback on a player’s skill. “There are anecdotal benefits, including enhanced compliance with training sessions and increased training time,” Dr. Frates said. “Visual reality rehabilitation will become more and more popular as more devices are invented. These devices seem to enhance motivation, provide active movement around joints, allow for repetition in an engaging setting and create an interactive interface for the survivor. It will be interesting to see what scientific research tells us about their usefulness in terms of improving function.”

Lorraine Essig knows that her physical activity regimen has made a difference. “I had exercised prior to ‘D-day,’ but not with as much dedication as I have now,” she said. “I can see what a difference it makes.”

Dr. Rose said that it’s important for survivors to realize that they can choose to be healthy or unhealthy. “Yes, you’ve had a stroke but you can still be healthy. Individuals — disability or no disability — can make the choice to be physically active.”

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**Know THE WARNING SIGNS OF STROKE:**

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

If you experience some or all of these warning signs, don’t wait. Call 9-1-1 right away.

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Caregiver


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It’s never too late—or too early. Start Today!
It’s common for a stroke survivor to face a communication disorder that causes changes in speech production and language function. What’s expected of the survivor in the treatment process, which often includes a speech-language pathologist (SLP)? And what resources are available to help?

SLPs consider current research, their clinical expertise and the stroke survivor’s and family’s concerns when treating a communication disorder. Survivors and their families should play an active role in the process and know about treatment options. The Internet provides a wealth of information for survivors and clinicians. The challenge is knowing where to look.

**The Internet**

Many Web sites help stroke survivors evaluate and treat communication deficits. Here are a few suggestions.

**www.aphasia.org**

The National Aphasia Association (NAA) provides useful information about aphasia to survivors and their families. The site lists books and pamphlets you can buy and research and review articles that discuss how aphasia affects a survivor’s ability to cope and participate in social activities.

**www.asha.org/public/speech**

The American Speech-Language-Hearing Association (ASHA) gives an overview of the language and speech deficits that may result from stroke. ASHA publishes several scholarly journals with research articles on managing communication deficits after stroke. You can access article abstracts and get copies of the article through your SLP. ASHA also publishes summaries of treatment effectiveness that describe how treatments can help specific disorders at www.asha.org/public/EfficacySummaries.htm.

**www.aphasiahope.org**

The Aphasia Hope Foundation links to articles about stroke and communication disorders published in the public media and to active research projects and aphasia research centers. This Web site also provides a forum to ask questions of professionals who are experts in neurological communication disorders.

**www.ancds.org**

The Academy of Neurogenic Communication Disorders and Sciences (ANCDS) is developing practice guidelines for evaluating and treating communication disorders that may result from stroke, including aphasia, apraxia of speech and dysarthria. The Web site links to other sites and published full-text articles about the latest research findings for each disorder.

**http://pubmed.gov**

PubMed is a digital archive sponsored by the U.S. National Library of Medicine. It includes thousands of citations of published research and review articles about managing communication disorders following stroke. Each citation includes the abstract for the article (if available), but access to the full-text journal articles is limited to those with personal or institutional journal subscriptions.

**www.scholar.google.com**

Google Scholar is a free Web search engine that helps find citations for scholarly articles, papers and books from many databases. Similar to PubMed, access to the full-text article is based on subscription.

**www.aphasiology.pitt.edu**

The proceedings from the Clinical Aphasiology Conference (CAC), which include articles on the assessment and treatment of communication disorders after stroke, are available on the CAC Web site through the University of Pittsburgh. The full-text articles are available to the public.

**Ask your speech-language pathologist**

If the full article you want isn’t available, talk to your SLP. Most certified SLPs are members of the ASHA and can access the ASHA journals. SLPs who work in medical centers or are affiliated with a university may have access to other scholarly journals that publish research articles about communication disorders after a stroke.

During your treatment program, feel free to ask your SLP for references about treatment options. Then discuss the treatment and the expected outcome.

To find an ASHA-certified speech-language pathologist near you, go to www.asha.org and click on “Find a Professional” or call (800) 638-8255.
In January 2003, a bleeding stroke changed Lori Vober’s life. She was 29 years old.

“I was young, very active in my career, as well as in our church, healthy, and happily married to Dainis, the man of my dreams,” said Lori from her home, in Phoenix. She was living in Minnesota and had just started a new job as the office manager of her church. She was at work when her arm started feeling numb and heavy.

“We called 9-1-1, and while we were waiting, my left leg went numb, and I fell out of my chair. I began slurring my words,” she remembered. She was having trouble breathing and was unconscious by the time the ambulance arrived. Paramedics worked to save her life on the way to the hospital, where a CT scan showed an arteriovenous malformation (AVM), which caused a blood vessel to burst in her brain. She underwent five hours of emergency brain surgery to stop the massive bleeding. “The amount of blood that had flooded the right side of my brain was the size of a fist.”

After the surgery, which stopped the bleeding, Lori spent the next 17 days on life support in a drug-induced coma. Doctors and nurses tried different medications to stabilize her and worked to get her blood and brain pressures under control. Lori also battled pneumonia. “My family said I was surrounded by machines, including a ventilator, and the room was kept very dark and quiet. No one was allowed to talk to me or touch me.”

When she came out of the coma, she was transferred to a regular medical unit to continue her recovery. There she confronted the deficits the hemorrhage had left behind: loss of her left side and the ability to swallow. About a month after her stroke, she underwent a successful, 10-hour surgery to remove the AVM, and she was admitted to the inpatient rehab center. “At first, all I could do was lie there while the therapists worked my muscles,” Lori said. “I was like a baby and had to start at the beginning. First, I learned to sit up and stay balanced, then stand, and eventually walk a few steps with assistance, an AFO (ankle-foot orthotic) and a cane.” In March, three weeks after the surgery, she left the hospital in a wheelchair, and she and Dainis moved in with her parents.

Just five weeks later, Dainis was laid off from his job in the airline industry. Although he quickly found another position, it required a move to Phoenix. “With my parents’ help, we sold our house and theirs, and bought two new houses in Arizona,” Lori said. “Looking back, I don’t know how my family did it all, both physically and emotionally.”

In September, Lori’s brain threw the family another curveball when she developed epilepsy as a result of the scar tissue from the two surgeries. At first, the seizures were just 30-second stares, but over time they progressed to eight-minute convulsive seizures. It took two years of trying different medications and battling side effects before the seizures were brought under control.
“We can’t get back what we have lost, but we still have each other, and that is the most important gift of all.”

“Between the challenges of my disability and the epilepsy, we had no life,” Lori said. “I couldn’t assist with any daily chores or activities, and social functions were out of the question. To survive, my parents and Dainis and I sold both our new homes and bought one larger one where we could all live together.”

Lori and her husband discovered an intensive neuro-therapy program at Southwest Advanced Neurological Rehabilitation (SWAN) in Phoenix. At that time, Lori was still only able to walk with assistance, an AFO and a cane. After many months of therapy, she can walk without assistive devices, and has recovered significant movement in her shoulder and considerable hand function.

“I have learned so much during my time at SWAN. They instilled in me the self-confidence and tools I needed to get back to the life I had before the stroke. Thanks to them, and my own perseverance, I have made great progress. I can do household chores, and Dainis and I can now go out to dinner, go to church and get together with friends. We are even beginning to travel again.”

Lori is, indeed, fortunate. Hemorrhagic strokes are both more lethal and harder to recover from (see “Bleeding Strokes”). Intracerebral hemorrhages, the kind of hemorrhagic stroke Lori survived, result in death as much as half the time, and only about a fifth of those who survive can function independently.

“As each day passes, I am getting stronger, and all of our lives are getting easier,” said Lori. “We can’t get back what we have lost, but we still have each other, and that is the most important gift of all. My gratitude for my parents’ and my husband’s help, love and devotion through this journey goes beyond words. This isn’t how any of us planned for life to be, but we have all come together as a family, and a team, to get through it.”

BLEEDING STROKES

Hemorrhagic (bleeding) strokes account for 13 percent of all strokes. There are two types of bleeding strokes: 1) intracerebral hemorrhage (ICH) occurs when a blood vessel inside the brain bursts and bleeds into the brain, and 2) subarachnoid hemorrhage (SAH), which occurs when a blood vessel breaks and bleeds into the space between the brain and the skull. ICH is about three times more common than SAH and comprises about 10 percent of all strokes. ICH tends to be more lethal, with 35–52 percent of patients dying within a month. Of the estimated more than 60,000 patients a year who have an ICH, only 20 percent are expected to be functionally independent six months later.

High blood pressure is the leading cause of ICH. Smoking, alcohol use and cocaine use are also implicated. In a recent study published in Stroke: Journal of the American Heart Association, investigators determined that smoking boosts the increased risk of hemorrhagic stroke already faced by people with high blood pressure. Analysis of the data collected on more than a half million people revealed that for every 10mm/Hg increase in systolic blood pressure (the larger number in your blood pressure reading), smokers faced an 81 percent increased risk of hemorrhagic stroke, compared to a 66 percent increased risk for nonsmokers.

It is thought that smoking weakens blood vessels, and weakened vessels are more prone to rupture. Smokers with the highest systolic blood pressure readings (150 mm/Hg or greater) were more than nine times more likely to suffer a bleeding stroke than smokers with the lowest readings (120 mm/Hg or less).

This added risk of smoking in people with high blood pressure appeared to be specific to hemorrhagic stroke. The researchers theorized that smoking may further damage blood vessels in the brain that are already weakened by hypertension.

INTRACEREBRAL HEMORRHAGE

An intracerebral hemorrhage occurs when a blood vessel (or vessels) bursts, spilling blood into the surrounding tissues of the brain.

SUBARACHNOID HEMORRHAGE

A subarachnoid hemorrhage occurs when a major blood vessel bursts on the surface of the brain, underneath the skull. This results in abnormal pressure on the brain.
Difficulty speaking or impaired memory and physical mobility can make stroke survivors feel like they can’t participate in fulfilling activities. But finding ways to contribute to society can be an important part of surviving — and thriving.

In fall 2007, the recreational therapy students interning at The Center for Life Skills at Ithaca College (Longview), a retirement and independent living community, planned a community service project that engaged stroke survivors at Longview with students and faculty.

Community service projects offer many benefits, including learning computer skills, practicing speech and writing, developing fine motor skills, problem solving and doing something useful for the community. Students discussed these at their first meeting with Longview survivors.

Participants brainstormed what types of community agencies would benefit from their work and decided to conduct a canned food and supplies drive for the local animal shelter.

Planning the Project

The survivors and student therapists made a list of essential jobs needed to complete the drive for the shelter. Tasks included:

• Asking the director for permission to proceed and inviting her to talk to the group about the shelter’s needs;
• Making a list of potential places where collection baskets could be placed and securing permission from managers to do so;
• Creating posters that described the project;
• Distributing and monitoring the collection baskets;
• Developing public relations releases on the computer; and
• Developing a speech to make when presenting the collected items to the agency.

Survivors were matched with tasks based on their need to practice certain skills. For example, those who had trouble speaking would call collection sites and the animal shelter by Janice Elich Monroe, Ph.D. Associate Professor, Department of Recreation and Leisure Studies, Ithaca College

What is Recreational Therapy?

Recreational therapy uses a holistic approach that involves assessment and intervention into the physical, social, cognitive and emotional functioning of people with disabilities. Recreational therapists help clients improve their functional skills, adapt and teach recreational skills to enable full participation in activities that enhance quality of life, and provide community-based resources for independent functioning.

Recreational therapists use the arts, crafts, music, dance, drama, relaxation, horticulture, movement, volunteer activities, sports and games that are specifically chosen to improve functional deficits in a safe, fun and non-threatening environment. They focus on helping people with disabilities transfer their new skills to work, social relationships and activities of daily living.

An underlying principle of recreational therapy is that when
suffering. Participants who had difficulty writing made posters or collages that were placed with the baskets to explain the project. Those who wanted to learn to use the computer wrote letters and developed copy for the posters. Some survivors collected and cut out manufacturers’ coupons to use their affected hands and practice cutting.

The Result — Everybody Wins

The project was a great success. The survivors stretched and grew, producing a meaningful result that they could each feel good about. And more than 10 laundry baskets of food and supplies were collected for the shelter.

As one participant reported, “It was a good idea to encourage us to be very active in this project because it made us feel useful. I really enjoyed making the collages. The speech I did was a bit scary, but I’m glad I had to do it.”

In satisfaction surveys, survivors reported that they made the most significant gains in working together to make a difference and giving back to the community. They also became more comfortable communicating with people in the community and enjoyed the interaction with the students. Many shared the desire to do more projects; the Longview group embarked on a similar project the following semester.

Recreational therapists play a significant role in the rehabilitation process by using purposeful interventions to enhance the quality of life for survivors. These activities, matched to their functional disabilities, let survivors engage in meaningful activities that heal the body and the spirit.

Recreational therapy is a win-win for the Ithaca/Longview crew

people with disabilities discover that they can continue to live a full and productive life, they will work hard to achieve their treatment goals.

An example of an intervention that a recreational therapist might use would be if a survivor has short-term memory deficits, fine motor deficits and poor endurance, the therapist could play the card game Concentration and have the survivor use his or her affected hand to turn the cards while standing.

Therapeutic recreation is provided by professionals who are trained, certified and licensed to provide therapeutic recreation. For more information, visit the American Therapeutic Recreation Association Web site: www.atra-tr.org.
I was sliding my right hand into the left sleeve of my coat where the hand normally comes out. This allows me to grab my affected left arm and pull it into the sleeve so I can get my coat on. Just as I accomplished this convoluted maneuver the phone rang. I recognized the voice of my wife’s brother, Chris. “I think about you every day, man,” he said. Before you run off and submit “Brothers-In-Law In Love” as a topic for an upcoming Jerry Springer Show, let me explain.

You see, Chris had a very serious circulation problem in his left hand that required emergency surgery. The operation was successful, but until it healed he was without the use of his left hand.

“Yeah, but can he tie his shoe one-handed?”

Even after being on the receiving end of an infinite amount of noogies growing up, my wife Marilyn sprang into action to support her sibling and caught the next train to Greenwich, Conn. Several weeks (not days) later she came home more excited than Marco Polo was on his return from the court of Kublai Khan. She couldn’t wait to tell me tales of postoperative adventures. “You should see what Chris can do with one hand!” she exclaimed. “Cooking? He made Julia Child look like a short-order chef. He maneuvered the Electrolux like Mario Andretti at Monte Carlo, sprayed Pledge like a graffiti artist, and you could bounce a quarter off his bed. Plus, he actually uncorked bottles of ’89 Chateau La Dominique by himself.”

“I’ve been opening bottles of wine for a while now,” I said defensively. For me, it had been right up there with putting your pants on as a priority post-stroke activity to learn.

The more Marilyn bragged about Chris’ accomplishments the more competitive I felt. Then it happened like an uncontrollable spasm. Words started coming out of my mouth that I had never uttered before or after the stroke. “I CAN MAKE DINNER … I CAN VACUUM … I CAN DUST … I CAN MAKE THE BED!” I sounded like I was interviewing for a position at Merry Maids. The next thing you know I’d be shopping for a frilly little French maid’s outfit. (Naw, the ruffled apron would have made me look fat.)

It was like I never spoke. Apparently there was no end to Mister Uni-hand’s feats. She raved about how he opened jars by securing them in his armpit. “Ahhh, The Pit Squeeze,” I interjected like an old pro. I didn’t like that move for three reasons:

1) My left arm was too weak to do it.
2) If you’re opening something like a jar of pickles you better get into a limbo position or you’ll be wearing Eau De Gherkin cologne, and small vermin will follow you around for a week.
3) I own the handy-dandy “Spill-Not Jar Opener.”

I figured it was time for the Hail Mary pass so I asked, “Yeah, but can he tie his shoe one-handed?” Now, I can tie a shoelace with one hand, but I never do because my sneakers have those elastic laces that Marilyn pre-tied so I can just slip them on. She didn’t call me on it, but it did halt the barrage of her bro’s endless achievements.

OK. Perfect time to open a bottle of Two Buck Chuck.

Love those twist caps! 🍷
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.

**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.

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 1-888-352-7531.

Plavix.
(clopidogrel bisulfate) 75mg tablets.

Blood platelets can stick together and form clots.

PLAVIX helps keep blood platelets from sticking together.

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

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