Finding help when you feel helpless

Patient advocates shine a light on solutions

Aphasia Therapy
When Insurance Runs Out
Continuing speech recovery on a budget

Tips for Keeping on Track
Expert advice for managing diabetes

Life at the Curb
Setting up is hard to do

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

sanofi aventis

Bristol-Myers Squibb Company
Cover Story

12 A Light Through the Fog
Need help negotiating the healthcare morass? A patient advocate may be your answer.

Features

10 Tips for Keeping on Track
Diabetes requires constant monitoring. We’ve got expert advice on how to manage medications and lifestyle prescriptions.

16 Aphasia Therapy When Insurance Runs Out
Here are eight ways survivors with aphasia can continue their recovery after their coverage runs out.
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 1-800-905-1921.

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?
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.

OVER Dosage
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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Robot-assisted therapy may help stroke patients make gains in their physical abilities long after the stroke, according to research presented at the American Stroke Association’s International Stroke Conference 2009 in San Diego, Calif.

“Because most stroke survivors are left with significant disability, there is a huge need for new therapies to make the best of the brain that survives,” said Steven C. Cramer, M.D., senior author of the study, associate professor of neurology and anatomy and neurobiology, and director of the Stroke Center at the University of California, Irvine.

Researchers studied 15 patients, average age 61, with partial paralysis on the right side of the body. Their strokes had occurred an average 2.6 years before this therapy, ranging from four months to 10 years.

Seven patients received a robotic technique termed “motor therapy,” which consists of computer-aided grasping and releasing, alternating with rest. Eight others received a more complex robotic approach called “premotor therapy,” which requires grasping, releasing and resting depending on details of a timed visual cue. Dealing with this more complex activity requires additional engagement of a higher level of the brain, the premotor cortex. Only when the patient incompletely squeezed or relaxed their hand did the computer complete the movement for them so the brain could experience the signals of a completed correct movement.

Researchers assessed patients after two weeks of therapy, which included 24 hours of hand-wrist exercises and virtual-reality video-game playing, and again one month later.

Among the study’s findings:

• Patients had significant gains one month after treatment.

• Among all 15 patients, both forms of therapy produced similar gains.

• However, the six patients with less disability and less motor system damage showed significantly more gain with premotor than with motor therapy at one month. Nine patients with higher levels of disability showed no difference in gains between the two therapies.

“The status of a patient’s motor system at the beginning of therapy is very much related to how treatment will affect them,” Cramer said. “Robotic therapy may be useful in its own right. But it could also help rewire, or reshape, the brain in conjunction with other stroke therapies. The way we use robots to help people recover function might differ according to how severe their stroke was.”

The risk of stroke increases with the number of fast-food restaurants in a neighborhood, according to research presented at the American Stroke Association’s International Stroke Conference 2009 in San Diego, Calif.

After statistically controlling for demographic and socioeconomic factors, researchers found:

• Residents of neighborhoods with the highest number of fast-food restaurants had a 13 percent higher relative risk of suffering ischemic strokes than those living in areas with the lowest numbers of restaurants.
The Golden Hour
Patients who reach hospitals within one hour are twice as likely to get tPA

Patients who arrived at specific hospitals within one hour of experiencing stroke symptoms received a powerful clot-busting drug twice as often as those who arrived later in the approved time window for treatment, according to a new study presented at the American Stroke Association’s International Stroke Conference 2009 in San Diego, Calif.

Among more than 100,000 patients treated at hospitals participating in the American Heart Association’s Get With The Guidelines–Stroke (GWTG–Stroke) quality improvement program, 27.1 percent who arrived within the “golden hour” (within one hour of symptom onset) were treated with the clot-busting drug tPA. Of those who arrived within one to three hours of symptom onset, 12.9 percent received the drug. The drug is only approved for use within three hours of symptom onset.

Researchers reviewed records of 106,924 ischemic stroke patients treated in a four-plus year period at 905 GWTG–Stroke hospitals.

The analysis found that:
• 28.3 percent of the patients arrived within 60 minutes;
• 31.7 percent arrived one to three hours after symptoms started; and
• 40.1 percent arrived more than three hours after symptoms started.

“That more than one quarter of ischemic stroke patients presenting to GWTG–Stroke emergency departments arrived within the ‘golden hour’ is a very encouraging finding because in stroke, time lost is brain lost,” said Jeffrey L. Saver, M.D., lead author of the study and professor of neurology and director of the Stroke Center at the University of California, Los Angeles.

Researchers said “golden hour” patients showed significantly more stroke deficits than later arrivals, suggesting that more intense symptoms propelled them to seek medical attention early. Early and late arrivals were about the same age and were split almost evenly among men and women in each category. However, blacks were less often early arrivals, of which only 11.8 percent arrived within one hour and 11.9 percent arrived within three hours.

Before stroke treatment with tPA can begin, patients must undergo numerous tests, including a brain scan to ensure the stroke’s cause is a blocked artery and not a hemorrhaging blood vessel.

“There are a huge number of reasons for waiting, but they are all trumped by the fact that the longer you wait, the more brain dies,” Saver said.

The relative risk of stroke increased 1 percent for each fast-food restaurant in a neighborhood.

However, the researchers said the discovery of increased risk only demonstrates an association; it does not prove that fast-food restaurants raise stroke risk.

“The data show a true association,” said Lewis B. Morgenstern, M.D., lead author of the study and director of the University of Michigan’s stroke program and professor of neurology and epidemiology in Ann Arbor. “What we don’t know is whether fast food actually increased the risk because of its contents, or whether fast-food restaurants are a marker of unhealthy neighborhoods.”

Neighborhoods with large numbers of the restaurants are prime areas for stroke prevention programs, Morgenstern said. “We need to consider targeting communities that have a lot of fast-food restaurants as places where we can improve health.”

This study supports previous research that suggested a link between fast food and cardiovascular disease — to which some fast-food chains have responded by including more nutritious options on their menus.

“We need to start unraveling why these particular communities have higher stroke risks,” Morgenstern said. “Is it direct consumption of fast food? Is it the lack of more healthy options? Is there something completely different in these neighborhoods that is associated with poor health?”

What’s in YOUR Neighborhood?

The Golden Hour
Patients who reach hospitals within one hour are twice as likely to get tPA
Rehab University

Transfer class is fun. I always thought a transfer was something you used to go from one bus or train to another, not getting from your wheelchair to your car.

I had a hemorrhagic stroke at age 56. After six years, I still have no use of my left arm and cannot walk without my AFO. At first, I wanted to toss that in the air out of frustration, thereby making it a “UFO” (unidentified flying object) on the rehab radar.

Every weekday we had to do an accounting by the half hour of each rehab exercise we had done. Sometimes I did not remember what I had done the hour before! I would also lose my way to the cafeteria, which was only two turns from my hospital room. I kept my notes to remind me that I have made progress since my early days post-stroke. Here is what I wrote at that time:

Since there are no official classes on the weekend, I thought I would write a comprehensive accounting of a typical day at “Rehab University.” We are not patients here; we are students. Every day we learn something new, like how to speak without slurring words, or how to dress, which is a task that you may be unsure about even though you have done it your whole life. Just finding your hand/ arm can be a challenge — is it under the covers or on top? I think they call that “proprio” something — proprioception?

Transfer class is fun. I always thought a transfer was something you used to go from one bus or train to another, not getting from your wheelchair to your car.

Meal time is another learning experience. How do you open the cereal box? I gave a special demonstration to the new patients one Saturday: Puncture the box at a 90-degree angle with your fork, then pull the cardboard flap with your teeth. Danger!! Watch out for opening those little individual mayonnaise containers with your teeth. I squirted mayo across the table at another patient, who was very understanding. We all laughed, which everyone needed.

Now for my grades:

“Milk containers” is a graduate class as liquids are not easy to deal with when you have use of only one hand. I got a B, even though I did spill a little. In “dressing yourself” class, socks are a two-credit course — positioning is everything. “T-shirts 101” can be a three-credit course, depending on the size of the T shirt — the larger the easier, with fewer credits earned. “Pantyhose” was hard even before the stroke. Bras are not part of the Rehab University curriculum. So far my GPA is 3.5. Can I add that to my resume?

As far as extracurricular activities, I organized the one and only (according to my physical therapist) Hemi Olympics. This involved wheelchair races down the longest hall in the hospital, not easy with one leg and one hand. I won the bronze medal.

In my philosophy of life, you have to extract humor out of horror.

Carolyn Ryan, Survivor
Greenville, South Carolina
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INNOVATIONS IN STROKE RECOVERY RESEARCH

Do you or someone you know have arm or leg weakness, or muscle tightness from a stroke?

The NewYork-Presbyterian Center for Stroke Rehabilitation is seeking participants for studies of innovative treatments to improve movement after stroke. Participants must reside in the New York metropolitan area.

For more information, contact Grace Kim, Research Occupational Therapist
212-746-1356 or email grk9006@nyp.org

NewYork-Presbyterian
The University Hospital of Columbia and Cornell

May | June 2009 STROKECOMMUNICATION 7
A Mother’s Day Tribute

I miss the mother from my childhood who was always there, so loving and supportive of my sister and myself.

wheelchair literally became a part of my mother, Gilda Romanolo, for the rest of her life after she had a severe stroke on Jan. 23, 2000. She had just turned 71 in November and had been retired less than six years. For the next eight and a half years the wheelchair was an appendage to her.

Before her stroke, Mom was vivacious, a full-of-life person who would selflessly help anyone. After her stroke, she was paralyzed on her left side and could no longer walk or use her left hand. She had to depend on my sister, Lillian Graniero, and me as well as our families. She also had to depend upon various live-in aides as she needed 24-hour care. Some of the aides were like family while others were horrible; I can’t imagine how hard it must have been for her.

After her stroke, few friends and family kept in touch; my sister and I are so grateful to the ones who did. Her life became very lonely, especially after her mother died in 2000. It was heart wrenching to hear Mom call out for her when she was most depressed and frustrated with her situation. For years she hoped and prayed she would fully recover. My sister and I knew that she would not because of her age and the surgery she had undergone. Eventually she developed dementia, and near the end she hallucinated much of the time. It was very hard to see the mom we had known slowly disappearing.

Mom passed away on Oct. 1, 2008. There are many parts of her that I miss. There is the mother I remember from childhood who was always there, so loving and supportive of my sister and myself. There is the mother who became a widow at age 49 and had to go back to work full-time and support herself as my dad died too young for her to receive any of his pension. There is the mother who took care of my grandmother after my grandfather died, visiting every day to keep her company. There is the mother who returned home from the rehabilitation center, her life turned upside down. She would become so frustrated and angry at her fate that she would lash out at God, my sister and me as well as her aides. There is the mother who still had hope that she would fully recover from her stroke until the day she realized she would not. There is the mother who became a victim of dementia and would lose control of her mind more and more frequently. There is the mother who started to live in her own world and made no sense at times. There is the mother who left this world and went to the next as the result of another severe stroke.

Through all these years there was the mother who still loved her family selflessly, with all her heart and wanted only the best for her children and their families. We all miss her so.

Donna Cain, Family Member
Staten Island, New York
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Know where you stand. The odds are African Americans are twice as likely to suffer a stroke as white Americans.

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Diabetes requires constant monitoring, especially for those who use insulin. In addition to medication, there are lifestyle prescriptions that must be adhered to. We talked about the importance of medical adherence with Dr. Sherita Hill-Golden, chair of the Glucose Management Committee and director of the Diabetes Management Center at Johns Hopkins University School of Medicine.

“Medication and behavioral treatments are essential to proper diabetes self-management and prevention of complications,” said Dr. Golden, who is also an associate professor of medicine and epidemiology at Johns Hopkins. “Adherence to taking medications, consuming a proper diet and maintaining an exercise routine result in improved glucose control and ultimately, a lower risk of diabetic complications.”

Good glucose control is important for preventing complications of diabetes, particularly small vessel complications — eye disease (retinopathy), kidney disease (nephropathy) and nerve damage (neuropathy).

Dr. Golden shared five tips that can improve adherence to medication and lifestyle prescriptions:

1. **Using a medication organizer** helps people remember to take their pills. Some dispensers even have compartments for medications that are taken twice a day so that morning and evening medications can be grouped.

2. **People with active lifestyles** who take insulin may benefit from an insulin pen because it is more easily transportable and less cumbersome than carrying an insulin syringe and vial. This can enhance compliance with insulin administration at lunchtime, during work hours or when eating at restaurants. For similar reasons of convenience, insulin pumps (subcutaneous devices that are an alternative to multiple daily insulin injections) can increase adherence.

3. **Meal planning is essential** to adhering to the proper food choices. For those who work, bringing lunch allows them to control their portion sizes and carbohydrate consumption. This is more difficult to do when you eat out. Planning and cooking meals on the weekend for the upcoming week can also reduce the likelihood of eating out or overeating.

4. **People are more likely to adhere** to a physical activity regimen that they enjoy. Picking enjoyable activities and scheduling time each week increases the likelihood of maintaining an exercise routine. Some find that group exercise activities increase their adherence by providing motivation as well as accountability and support.

5. **Managing depression is extremely important.** A recent study of patients with both diabetes and depression found that adherence to medications, diet, exercise and glucose monitoring was reduced in those who were depressed. Speak with your healthcare provider if you are experiencing significant depression, as appropriate treatment may ultimately improve your ability to stay on track and improve your condition.

“Following a proper diet — low in saturated fat and sodium and high in fiber and nonfat or low-fat dairy products — can help to reduce cholesterol and blood pressure, both of which are strong risk factors for development of heart disease and stroke,” Dr. Golden said.

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**The Heart of Diabetes**

The American Heart Association created *The Heart of Diabetes* campaign to raise awareness of the connection between type 2 diabetes and cardiovascular disease. The program encourages patients living with type 2 diabetes to get regular physical activity, eat healthy foods and work with a healthcare provider to develop a comprehensive treatment plan. By reaching these goals, people can better manage their type 2 diabetes and reduce or delay associated risks, including heart attack or stroke. Visit IKnowDiabetes.org to enroll.
Living with type 2 diabetes can be a challenge, but managing it doesn’t have to be. By enrolling in The Heart of Diabetes™ program, you can access tools to help you get one step closer to setting and reaching your treatment goals. Enroll today by visiting www.IKnowDiabetes.org and learn how you can better manage your type 2 diabetes.

Some things can be a challenge.

Managing your type 2 diabetes doesn’t have to be.

American Heart Association
Learn and Live

The average person spends 80,000 hours building up assets during their lifetime, yet fewer than 4 hours planning what their heirs will receive. Now, in less than one hour you can begin creating a plan that will protect your hard-earned assets and ensure your wishes are known and followed. Our will and estate planning kit, Matters of the Heart, can help you save time, money and hassle. To get your free copy, simply complete and mail the attached card today, or call 888-227-5242. You can also e-mail us at plannedgiving@heart.org or visit us at americanheart.org/plannedgiving.

Take five minutes to learn how one hour can make a lifetime of difference.

Please send to: American Heart Association, Planned Giving Department, 7272 Greenville Avenue, Dallas, TX 75231-4596.

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☐ I am considering a gift to the American Heart Association through my estate plan. (QBC)
☐ I have already included the American Heart Association in my will/estate plan. (QBB)
A Light Through the Fog
by Jon Caswell

When Tim Giles left the hospital in 2007 after two strokes and a heart attack, he couldn’t walk, talk or swallow and, at 46, had to move back in with his parents, both in their 70s. A self-employed single father, Tim was uninsured, and his nine days in the hospital left him with $55,000 in medical bills. His mother, Betty Giles, remembers how the family felt: devastated.

Kay Anderson, 51, had similar feelings when a local rehab hospital sent her husband Mark Sullivan home after his 180 days of insurance coverage had run out. Mark, also 51, required a trach and a feeding tube with special formula; he was released with $600 worth of prescriptions to be filled. Though he couldn’t walk, his stroke left him with a lack of awareness of this limitation, and he kept falling when he would get out of bed. His release form listed 50 items of concern.

Kay, who lives in Piedmont, S.C., works full time as a county appraiser. She had to hire her mother to take care of Mark during the day after three home health agencies refused to accept him because he needed skilled nursing care. “I worked all day and then came home and took the night shift,” she said. “If he didn’t sleep, I didn’t sleep. I wasn’t eating or drinking, and I lost 55 lbs. The same thing happened with my mother; I just watched her shrink. At the hospital he had had 24-hour care, but when he came home, it was just us.” A social worker who visited said Kay was suicidal. “The truth is I had thought of suicide because I knew without me, the hospital would have to take him. I felt like I was in quicksand.”

Many hospitals and insurance companies have created positions designed to help patients and their families. These positions may be labeled “patient advocate,” “customer advocate,” “patient representative” or “patient liaison.” The Center for Medicare and Medicaid Services requires every hospital, care facility and home health agency that gets federal money to have a process and a person to handle complaints, and they are required to follow up. This is the person to call when there is a question about medical records, personnel concerns or the loss of personal belongings. Typically, they are trained by the health system and are well connected to different departments throughout the organization. Their job is to help patients at no charge.

Another avenue

As helpful as these patient liaisons can be, sometimes there are situations like Tim Giles’ or Kay Anderson’s that are more complicated and require solutions that are outside a hospital liaison’s ability or scope of work. And there are situations where the care facility’s final response to the patient’s family is unsatisfactory.

For instance, in Tim’s case, he was screened by the hospital for Medicaid and told he was not eligible, though the hospital did give his mother a Medicaid application. (Medicaid is a federally funded, state-operated health insurance program for low-income families and individuals.) Filling out complex forms was not first on Betty Giles’ priority list with an incapacitated son and 12-year-old grandson moving in. She received no training in his care, which included a feeding tube and suctioning his saliva. At the time, Tim could neither talk nor walk.

A friend’s visit to a medical equipment company to pick up a suction device proved fateful. Across the street were the offices of the Patient Advocate Foundation (PAF), which is headquartered in Tim’s hometown of Newport News, Va. The friend told them of Tim’s predicament, and they contacted

Hospital liaisons

The Giles and Anderson families’ stories are not unique. Stroke and other diseases leave countless families to negotiate a challenging healthcare system at a time when their lives have been turned upside down and their finances devastated.
In the medical storm of stroke, advocates can often guide you to a safe harbor.
him by phone and opened a case file on him. As it turned out, his case manager, Margie Griffin, was a member of his parents’ church.

In Margie’s estimation, Tim was eligible for Medicaid, and she worked with Betty to understand and complete both Social Security Disability (SSDI) and Medicaid applications. Because there is a six-month waiting period for SSDI and a three-month recheck by Medicaid for stroke patients, she understood the importance of getting the paperwork started as soon as possible. Margie then contacted all of Tim’s doctors and made interim payment arrangements on the family’s behalf until his Medicaid application was approved. She also provided the doctors with Medicaid and Social Security contact information for medical record requests to expedite the Medicaid and SSDI application process. Then she followed up with them to make sure all records had been sent to the state Medicaid and disability offices. She also contacted the state’s disability determination offices to ensure they had received all the records they needed, and re-contacted doctors where notes were still pending. The result was a timely review and approval of Tim’s applications for both Medicaid and SSDI. Margie then notified all the doctors and pharmacy and instructed them to bill Medicaid.

Another story
At the end of her rope, Kay Anderson also found PAF.
“People kept telling me God wouldn’t put more on me than I could handle, and after Thanksgiving last year, I told God, ‘I can’t keep going,’” Kay said. “That night I found PAF on the Internet. Gayle Patrick e-mailed me the next day and became our case manager.”

Kay had been told that she made too much money to qualify for Medicaid, but she didn’t make enough to pay for the care and drugs Mark required. Gayle called her the following day and began the process of finding long-term, skilled nursing care through the Medicaid system. There are only 44 such beds in South Carolina’s Medicaid system, which means a two-year wait. However, one of Kay’s friends found out that one of these beds would be opening up and contacted Kay, who called PAF. They succeeded in securing the bed for Mark the week before Christmas last year. Gayle assured her there were many programs that they would eventually qualify for.

Once Mark was safe, PAF began working on debt relief for Kay and negotiating with her employer over all the time she’d taken off. Kay has two mortgages to pay and four credit cards that are maxed out from paying for medications. Gayle contacted all of these creditors and negotiated payment modifications and relief. “Gayle treated this case like it was her own family,” Kay said. “She calmed my fears about the misinformation I’d gotten. She kept me updated on what was going on and what was coming up. PAF worked like I was paying them.”

And that’s where the really good news comes — PAF does not charge patients or their families for any services. (See “Patient Advocate Foundation” at right.)

How things have worked out
Tim Giles has returned to his home with his son, but he is a long way from recovered. He still cannot work and lives on SSDI. He can’t afford therapy and his meds alone are $200 a month. “Mainly I just take care of my son,” he said. “That’s a full-time job in my condition. When I was in the hospital, I thought I’d be up and about in a couple of weeks. Nobody told me what to expect. It’s been 16 months, and I’m a long way from where I was.” Still, he knows it could be so much worse, with $55,000 of medical debt, no job, no SSDI and no Medicaid.

For Kay and Mark, life remains difficult. He is still a long way from coming home to live. He still has a trach and a feeding tube and can only walk with a walker. Even so, “there is freedom in knowing that he is being well taken care of,” she said. “Those six weeks he was home, it was like being in prison — that walls-closing-in-on-you feeling. I was always afraid that I would do something wrong and he would die. Having him where he needs to be gives me peace of mind. I can sleep now and spend time with my grandkids, which is important to me. Now it’s a pleasure to go to work knowing that I don’t have to go to work again when I come home.”

Reinventing Health Care

EIGHTY MILLION AMERICANS suffer from cardiovascular diseases, including stroke, and too many of them cannot afford the health care they need. Lack of health insurance and barriers to accessing quality care pose tremendous problems for patients who have difficulty affording essential treatments. Insurance policies with high premiums and practices that penalize those with preexisting conditions create a challenging and expensive reality for heart disease and stroke survivors. That is why the American Heart Association is working to achieve a meaningful reform that serves the best interests of patients.

No family should ever have to choose between an empty pantry and an empty medicine cabinet. Yet, this is a reality for many people with heart disease and stroke. Join the American Heart Association in calling on lawmakers to achieve meaningful healthcare reform. Become a You’re the Cure advocate for affordable, accessible, quality health care today by visiting heartsforhealthcare.org
The Patient Advocate Foundation provides a ray of hope in the storm of stroke.

The Patient Advocate Foundation (PAF) began in 1996 after CEO Nancy Davenport-Ennis and her husband spent three years helping a cancer patient negotiate the healthcare system. “We learned from that experience that you have to have help when dealing with these issues,” Nancy said. “After her funeral I wrote the business plan that is PAF. Last year we opened more than 48,000 cases, and 9.8 million people contacted us for quick information or a live chat on our Web site.”

Based in Newport News, Va., PAF has offices in California, Iowa, Nevada, New York and Tennessee; however, they handle cases in all 50 states. PAF has a professional staff of case managers, social workers, certified medical coders and billers, debt managers and people experienced in job retention. “We give direct advocacy services on behalf of patients,” Nancy said. “We’re trying to solve medical debt issues that prevent patients from being in the healthcare cycle. For instance, we have clinical personnel that try to get pre-authorization approved. They write a lot of appeal letters and work with many out-of-network issues.”

PAF intervenes directly on behalf of the patient. If the patient is uninsured, PAF negotiates for charity care. “Any hospital that gets federal funds must allocate a certain percentage of care to uninsured and at-risk patients,” Nancy said. “If the patient is insured, then our staff of coders and billers goes over the records to see what can be worked out.”

PAF works with patients at all points in the healthcare cycle. “We try to get services for people left in life-threatening situations, like Kay Anderson’s, for patients like Tim Giles where there was no discharge planning.”

PAF also works with rehab organizations. “We work tirelessly to keep people in therapeutic rehab as long as their doctors say they need it, not just the 30 days most get.” There is also a “co-pay” fund for people who are insured but don’t have the means to make their co-payments. And though they won’t directly pay a mortgage, they will negotiate with the mortgage company.

As far as Stroke Connection could ascertain, PAF is unique. In fact, they have written chapters in the textbooks for new masters-level programs in patient advocacy at three universities. “Most hospitals and insurers have staff called ‘patient advocates,’” Nancy said, “but we are the only organization in the United States that does this independently.”

The Web site, patientadvocate.org, provides free, downloadable information on many subjects pertinent to stroke families. The site also has an online chat where patients and their families can ask questions and get answers that day. There are also PAF videos on YouTube.

Patients are never charged. PAF is funded by a combination of corporate grants as well as state and federal funds and other nonprofit organizations. Large hospital systems as well as pharmaceutical companies and individual philanthropists also contribute.

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patientadvocate.org
Options for Aphasia Therapy When Insurance Runs Out

By Rosalea Cameron, MS, MCISc, CCC-SLP
and Sandra Wright, MA, CCC-SLP
American Speech-Language-Hearing Association

Recovery from aphasia is a process that may continue for many years. Unfortunately, most people with aphasia find that their insurance coverage runs out before they are done with therapy. It is often frustrating for the patient and their family as they try to continue the recovery process with very limited professional support. Some insurance plans allow you to renew services periodically (e.g., 20 therapy sessions per calendar year) while other programs will cover an assessment and/or therapy following a change (positive or negative) in communication skills. Given that insurance companies may change their policies, you should stay in contact with your insurance company after you stop direct speech-language pathology intervention. Review your written policy and contact the company directly for clarification. Ask about what needs to happen for you to qualify for additional therapy (e.g., improvement or decline in communication skills, new medical diagnosis and time since therapy) and what specific written information you need to provide.

Even with insurance policies that allow for a lot of therapy, it is almost inevitable that at some point you will spend time without direct treatment. Although your communication needs are unique, the following list of low-cost options may help you continue your progress.

1. Ask your speech-language pathologist (SLP) for information about low-cost or free therapy services in your community. Universities offering speech-language pathology training programs may have clinics that provide individual or group therapy performed by graduate students supervised by SLPs who are certified by the American Speech-Language-Hearing Association (ASHA). The quality of treatment is typically excellent, but cost is generally low given that services are provided in an educational setting.

2. Some communities have research programs that provide free or low-cost therapy for individuals with aphasia who qualify for participation in treatment studies. Universities, private clinics and government agencies such as the Department of Veterans Affairs and the National Institutes of Health can be great sources for these types of programs. The Web site for the National Aphasia Association (aphasia.org) has links for several research programs that may currently be looking for participants. You may also find studies recruiting participants by visiting clinicaltrials.gov.
3. You may benefit from continued speech-language practice with a friend or family member. Before you stop therapy, ask your SLP if this may be an appropriate option for you. If so, your therapist may be able to develop a home therapy program for you and help one or more assistants learn to work effectively to help you improve your communication skills. If you have already been discharged from direct intervention, your insurance company may pay for the development of a home therapy program.

4. Because working on speech and language can be emotional and sometimes frustrating, not everyone can work with family members at home. It is sometimes helpful for a volunteer who is new to you and your family to help you practice. Your community may have volunteer organizations, churches, colleges or senior centers that could assist you in finding a volunteer who may be interested in helping you improve your communication skills.

5. Some people find computer-based software programs helpful for ongoing, independent speech-language practice. Ask your SLP to help you explore programs that may be appropriate for your individual needs. Many companies offer free trial software with no obligation to purchase materials. If you have already been discharged from therapy, try a variety of free computer programs to find one that is challenging but not too frustrating. If you find one that fits your needs you may want to consider purchasing the software and/or equipment.

6. Being read aloud to may help improve communication skills. Also, depending on how much your reading skills are affected, you may benefit from reading single words out loud or may find it most helpful to read newspapers or books. Ask your SLP if this might help you. If so, have your SLP direct you to reading materials that might be appropriate given your particular strengths and challenges.

7. The use of books paired with matching audiotapes, CDs, DVDs, etc., may help some people. You can read along (silently or out loud) while listening to the words, poems or stories. It may be helpful to start with simple books, moving to more complicated poems or stories as your reading and/or understanding skills improve.

8. Aphasia or stroke support groups are another resource. See if there is a support group in your area and get involved (go to aphasia.org for a list of aphasia groups in your state or province, or visit strokeassociation.org/strokegroup). If there is not a support group in your area, consider starting one. Support groups are a great resource for sharing practical strategies with one another.

**Editor’s Note:** To find an ASHA-certified speech-language pathologist near you, go to asha.org and click on “Find a Professional” or call (800) 638-8255.
I answered the intercom Monday morning and immediately recognized the Brooklyn accent of Peter, our doorman. “Yo, John-ny, ya gotta box down here.” He sent it up in the elevator, and when I saw what it was I said to myself out loud, “Man, that was faster than Chinese take-out!” It was our new HP Photosmart Wireless C6300 Zippity-doo-da All-In-One printer to be exact. There’s an unwritten rule that says when you want something to show up fast, it takes forever. Like those Kellogg’s Frogmen I sent away for when I was a kid. I bet I consumed a thousand bowls of Sugar Pops just to reach the number of box tops they demanded as legal tender. I had such a sugar high I could have jogged to Battle Creek, Mich., and picked them up personally.

Conversely, when you don’t want something right away, “shazam!” it magically appears. Like our new wireless printer. I’ll admit I wasn’t ready to tackle the installation of anything with the word “wireless” in it. I still hadn’t fully recovered from setting up our wifi. (For those of you who are as digitally disabled as yours truly, “wifi” is short for wireless fidelity.) So Marilyn and I decided to wait until Saturday because the weekends are better for yelling. Here’s a snapshot of our Internet installation with me relegated to reading the brochure, because of the stroke, while she does the heavy lifting:

“That doesn’t go there.”
“That’s where you said to put it.”
“No, I said over there.”
“Where’s there?”
“Here!”
“Here where?”

We ruled out seeing a marriage counselor because we needed the money to pay for the printer. I remember being a cool, cutting-edge 15-year-old with the latest B&O diamond stylus equipped turntable, megawatt amp, and speakers like those Marshall 100 watt stacks with the super 100 JH head that Hendrix used in concert. The whole thing was crammed into my bedroom like Mr. Peabody’s WABAC machine from “Rocky & Bullwinkle.” And man, did it have wires! It looked like one of those prehistoric pterodactyls swooped in and built a huge nest. But I could set that baby up in 20 minutes and in no time I’d be kicking back listening to “Are You Experienced?”

Now? I’m a 21st-century Rip Van Winkle and I’ve woken up to this gadget-driven, techno, Bluetooth, ethernet world. The wifi experience put such fear in my heart that the printer stayed in the box for a week doubling as a plant stand. But the work was piling up, so we summoned our courage, ripped off the tape, and while I held the box, Marilyn carefully delivered our new baby. I nervously grabbed the instruction manual and started reading the “Network Set Up” section out loud, half cringing like each step was a stick of dynamite. Marilyn followed along, pushing this and plugging that. Then she asked, “And…?” Surprised I said, “That’s it.” The next thing we knew it was slippin’, slidin’, and shakin’ and in no time, a page popped out. I was beyond myself. I felt like Archimedes, only I yelled, “It works! It works!” It was as exhilarating as walking without a cane for the first time.

So this cool, cutting-edge, 59-year-old digital survivor dude downloaded a little Jimi, kicked back, and let the C6300 do its thing.
The average person spends 80,000 hours building assets during their lifetime, yet less than 4 hours planning what their heirs will receive. Even more unsettling is the fact that 7 out of 10 Americans die without a will — leaving the distribution of all they have worked for to chance or to the state’s discretion. The number one reason people fail to make a will is the belief that it is a complex and expensive process. Not true. Now, in less than one hour, you can begin creating a plan that will protect your hard-earned assets and ensure your wishes are known and followed. Our will and estate planning kit, Matters of the Heart, can help you save time, money and hassle with forms that quickly organize everything you own into an inventory.

To get your free copy, simply complete and submit our electronic form, or call 888-227-5242. You can also e-mail us at plannedgiving@heart.org or visit us at americanheart.org/plannedgiving.

We advise you to seek your own legal and tax advice in connection with gift and planning matters. The American Heart Association does not provide legal or tax advice.
How Many Calories Can I Save?

If you’re like two-thirds of Americans today, you could stand to shed a few pounds. Part of that means eating fewer calories, and one way to do that is to find lower-calorie alternatives to favorite foods. Here are 30 trade-offs that cut about 100 or 150 calories.

**TO SAVE ABOUT 100 CALORIES:**
- Eat 1 cup of breakfast cereal instead of 2 cups.
- Drink 1 less glass of wine per day.
- Have 1 dinner roll or tortilla instead of 2.
- Switch from whole milk to 1% milk (save 100 calories when you drink 2 cups of milk).
- Switch from 2% milk to nonfat milk (save 100 calories when you drink 3 cups of milk).
- Eat a small handful of unsalted nuts (1/8 cup) instead of a large handful (¼ cup).
- Have broiled fish instead of beef.
- Leave the cream cheese off your bagel (2 Tbsp. is 100 calories).
- Leave the margarine or butter off your bread (1 Tbsp. is 100 calories).
- Skip the second helping of pasta (1 cup of pasta is 100 calories).
- Skip the second helping of potatoes or rice (½ cup is 100 calories).
- Eat 1 cookie instead of 3 (2 cookies is 100 calories on average).
- Have fruit instead of French fries.
- Eat half an order of French fries instead of a whole order.
- Eat half a donut and give the other half away.

**TO SAVE ABOUT 150 CALORIES:**
- Eat half a sandwich instead of a whole one.
- Drink 1 less beer or cocktail per day.
- Drink water or diet soda instead of regular soda (one 12-oz. can of soda is 150 calories).
- Drink black coffee or use low-fat (1%) or nonfat milk with your coffee instead of sugar and cream/creamer (save 150 calories in 2 cups of coffee).
- Switch from whole milk to nonfat milk (save about 150 calories when you drink 2 cups of milk).
- Have a 3 oz. serving of lean meat or chicken instead of a larger (6 oz.) serving.
- Have one taco instead of two.
- Use seasoned vinegar or lemon juice instead of salad dressing (2 Tbsp. salad dressing is 150 calories).
- Skip the snack crackers (about 8 crackers is 150 calories).
- Have 1 less piece of pizza than usual.
- Order a regular burger instead of a quarter-pound or double burger.
- Have air-popped popcorn (no butter) instead of microwave popcorn.
- Skip the chips (1 cup of chips is 150 calories).
- Eat 1 less scoop of ice cream (150 calories per scoop).
- Pass up the candy bar.

Source: *An Active Partnership for the Health of Your Heart*
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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Bridgewater, NJ 08807
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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.

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.

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

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.