Caregivers and Diabetes
Doing double duty

You Don’t Have to Be a Hero Every Day
A caregiver’s tale

Shoulder Subluxation
Answers from a PT

Life at the Curb
No Limits Dogg

Between a Rock and a Hard Place
When is long-term care the right decision?

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A Life-Changing Article

Your September/October 2008 issue made an incredible difference in the lives of my wife Peggy and me. We read the article “Coming Back from a Bleeding Stroke” about Lori and Dainis Vober. Lori had had a hemorrhagic stroke in January 2003. Dainis discovered an intensive neurotherapy program. With Lori’s perseverance and the expertise of the professionals she worked with, she recovered significantly.

This article brought hope to us. Peggy had a bleeding stroke in October 2000. After the operation, she was in a coma for 10 days. Her entire right side was affected, and she could not speak, eat or walk by herself. Neither one of us knew how long this would last. After many years of therapy and numerous rehabilitation centers, Peggy learned how to eat, talk and finally walk with a cane or walker.

After reading the article, I went online and checked the Web site of Southwest Advanced Neurological Rehab. Then we planned the 1,300 mile trip. Peggy started therapy and within 10 weeks she was walking without any aids. It was wonderful watching her progress week by week. We had the opportunity to meet Lori at therapy, and I told her that without her article, Peggy would not be walking by herself. Lori was so pleased. And Peggy continues to get stronger by walking every day. We cannot thank Stroke Connection, Lori Vober and all the people at SWAN Rehabilitation enough for making our lives a lot better.

Nine years with a positive attitude, hard work, therapy and your magazine, Peggy is living a much better life. This is a miracle.

John C. Wilds Sr., Caregiver
Imperial, Missouri

FOOT DROP


WalkAide is the biggest name in the treatment of foot drop. WalkAide can help you step up your mobility significantly and live life on your terms again. With its compact, single-unit design, WalkAide leverages functional electrical stimulation to improve brain reaction and restore mobility. Many health insurers are now covering the Walkaide. Now is the time to take the big step forward by taking advantage of a free WalkAide trial. For more information or to request a free patient kit, call 866-909-WALK (9255) or visit walkaide.com.
Even when patients recover most functional ability in the first months after a blood clot-related stroke, they gradually become more dependent over the next five years — especially those with Medicaid or no private insurance — according to a large study reported in Stroke: Journal of the American Heart Association.

Based on their recovery level after the first six months, the odds of patients having a full recovery (living independently or needing very little assistance) fell as much as 9 percent per year over five years, depending on which factors were included.

“We usually speak of stroke as an episode from which one hopefully recovers, but this new data suggests that, in terms of function, it could be considered a chronic condition showing a steady decline over time,” said Mandip S. Dhamoon, M.D., M.P.H., a fourth-year neurology resident at the Columbia University...
Learning to Pay Attention

Improving impaired attention may help patients recover from stroke

It may be possible to improve impaired attention after stroke — which could aid recovery — according to research in Stroke: Journal of the American Heart Association.

Impaired attention is the most prominent stroke-related neuropsychological change and is reported in at least 46 percent and as many as 92 percent of stroke survivors, said Suzanne L. Barker-Collo, Ph.D., a senior lecturer and neuropsychologist at the University of Auckland in New Zealand.

Impaired attention can reduce cognitive productivity and the ability to focus on tasks. It’s key to relearning motor skills.

In the first full-scale single-blinded, randomized clinical trial using Attention Process Training (APT), 78 stroke survivors (average 18 days post-stroke) were randomized to receive APT or standard rehabilitation care. APT is designed to improve the ability to maintain attention, as well as to shift attention (such as when having a conversation with more than one person) and to attend to more than one thing at a time. It’s been used successfully in people after traumatic brain injuries but hasn’t been tested in stroke patients.

Researchers tested participants in four aspects of attention — sustained, selective, divided and alternating — as well as visual and auditory aspects of attention. Patients receiving APT had up to 30 hours of individual training, in one-hour sessions for four weeks. They received on average 14 hours of training.

Researchers said people who underwent APT had a significantly greater improvement on a test of attention than those who received standard care. At six months, those who had APT had an average improvement of 2.49 standard deviations higher than standard care patients on “full-scale attention scores.”

The improvement in attention didn’t correlate with significant improvements in outcomes, but researchers said six months may not be enough time to gauge the impact of improved attention. Differences on other measures of attention and broader outcomes were not significant.

Early identification and rehabilitation of attention should be part of stroke rehabilitation because APT is a viable and effective way to improve attention deficits after stroke, said the researchers, who recommend more research on the issue.

College of Physicians and Surgeons in New York.

Patients’ insurance status had a significant impact on this. Uninsured patients and those covered by Medicaid had a significant decline in function over five years, while those covered by Medicare or private insurance did not. Researchers speculated this was because the Medicaid and uninsured patients got less therapy and were less able to manage their blood pressure and other risk factors.

Patients also were significantly more likely to be disabled within five years if they:

• were older at the time of the stroke.
• had diabetes.
• were unmarried.
• had a more severe stroke.
• had a right-hemisphere stroke.
• had urinary incontinence within a week of the stroke.

Gender and ethnicity were not significant predictors of functional decline in the study.

Researchers assessed patients’ function using the Barthel index, a 100-point scale that rates the ability to carry out 10 life activities with and without assistance. Ratings were made six months after the stroke and annually for five years.

“The longer after the initial stroke, the greater the likelihood that people were more dependent, with the greatest declines beginning three years after the stroke,” Dhamoon said.
I am an X-ray technologist, and on Jan. 21, 2004 I was working the night shift. I had gone to the ER to do a chest X-ray when I felt weak and strange, like the bottom had fallen out of me. Unable to function, I asked my partner tech to take over for me. I took my blood pressure and ran a three-lead EKG and took those results to an ER physician. He suggested we do a five-lead EKG. They put me in an ER bed, ran some labs, did another EKG and gave me a barf bag, since by this time I was vomiting. A few hours later, after another blood test, I was moved to a medical floor where I continued to vomit the night away. The next morning, my cardiologist had me transferred to ICU, and within 30 minutes I was in the catheter lab where they placed three stents in my totally occluded right coronary artery. I was 61 years old. That was the beginning of 2004 and my life of fear. Over the next nine months I had many visits to the ER for chest pain and four more heart catheters. During the first three of these I talked so much the cardiologist finally told me I talked too much. So during the fourth procedure I didn’t talk. If I had, he probably would have noticed something and given me medicine to stop the stroke.

After the procedure I was kept in PCU (post-operative care unit) for about an hour and then was allowed to leave. I went to the parking garage to get my motorcycle. I had a little difficulty uprighting it but attributed that to the fact I had just had a heart cath. I started the bike and rode home on the freeway at 70 m.p.h. Once home, I had some difficulty parking, but then went in and went to bed. Since I was off work the following two days, I just rested.

I noticed a slight weakness on my right side and began lifting weights and exercising, something I never do because I figure I get enough exercise moving patients all day. I also noticed some changes in my memory and difficulty completing my sentences or doing computer programs. All of my symptoms were annoying, but none made me cry for help.

When I returned to work I took my boss aside and asked if she noticed any difference, but she said no. Fortunately, I did not believe her and stopped my cardiologist in the hall and told him something was wrong. He reluctantly ordered a CT scan. Since I work in radiology, I registered myself and had a brain scan done. When I went to look at the images, the tech said they’d already been sent to the radiologist, but her door was closed. When I came back, she was talking to another radiologist about my scans. There was a bleed on the left side about the size of a half dollar. Fortunately it had stopped, but it had been almost two months since it had started. I took my cardiologist to see my radiologist; she told him the bleed was caused by plaque dislodged during my fourth heart cath.

Now I’m 66 and have only minor residual complications from my stroke. I guess you can recover from a stroke without anyone ever knowing you had one.

Sharron Sammon, Survivor
Oxnard, California
At 39 years old, I am a stroke survivor — never thought I’d say that! My stroke happened in December 2007 and turned my life upside down. I was very fit, exercised, ate right, no high blood pressure or high cholesterol. After the stroke, I had blind spots in my left eye and numbness in my right hand and arm. I also lost my speech and a bit of my memory.

I have two children, ages 13 and 14, and they were devastated to see their mom in that state. It still cuts to my heart to remember their faces, but their responses made me determined to get my life back. I told them that it was only temporary, that I would get better. I put my heart and soul into my recovery, and I can say today that I am a 41-year-old survivor.

My message to other survivors is never give up, stay focused and determined and don’t feel sorry for yourself. Take that negative energy and make it positive. You can do anything you set your heart and mind to.

Ligia (Lee) Paiva, Survivor
Fall River, Massachusetts

You Never Know Who’s Watching

Just before Christmas 2007, I was at the beauty shop, where I met Pat, a staff person at my gym. We were both finished with our appointments and took our conversation to the waiting area.

As we chatted, a woman came in and sat down. I noticed that she seemed to be observing me, but as a stroke survivor, you get used to the looks and stares. I continued flapping my jaws for a few more minutes, telling Pat about my trip to Pennsylvania. When I was finished, my husband helped me on with my coat, and the woman who had been observing me said, “Zenta, do you know who I am?”

“You’ll have to come closer, my eyes are impaired.”

“I’m Ellen, from Sinai,” she said, and we reached out and embraced. Then she took a step back. “Look at you, no wheelchair, no cane, speaking clearly. What a Christmas gift you are. You are a blessing to me.”

I thought, ‘Blessing to you? You are a blessing to me!’

I hadn’t seen Ellen in four years. She had been my speech therapist for six weeks. Every morning she entered my room with a big “Good morning!” and a smile from ear to ear. She rolled up her sleeves, washed her hands and proceeded to put her hands in my mouth and pull and stretch because I couldn’t speak and the left side of my face drooped to my chest due to my stroke. With Ellen watching over me, I wanted for nothing. She took good care of me, and her therapy worked because my face is restored and I can speak clearly.

I was a gift and blessing to Ellen because she was able to see the product of her hard work. And she was a blessing to me because her dedication gave me quality of life. I think this is the true meaning of Christmas.

Zenta Sheehan, Survivor
Taunton, Massachusetts

With Ellen watching over me, I wanted for nothing. She took good care of me, and her therapy worked.

Zenta Sheehan in her home

November | December 2009 STROKE CONNECTION 7
Caring for a family member in the aftermath of stroke presents many challenges. Things are further complicated when the survivor has diabetes. We talked to Dr. Mikhail Kosiborod, a cardiologist practicing in Kansas City, Mo., about the caregiver’s role in managing diabetes following stroke.

“Special attention needs to be paid to blood sugar monitoring, administration of diabetes medications, and the nutritional content of the meals,” Dr. Kosiborod said.

**Hypoglycemia** (defined as blood sugar below 70 mg/dL) as well as severe hyperglycemia (very high blood sugar) are major concerns in diabetes care. Hypoglycemia may occur as a result of not eating snacks or eating too few calories at meal time. Some of the symptoms are hunger, shakiness, confusion, irritation and thirst. If you suspect your survivor has low blood sugar, check their level with a blood sugar monitor. If it is below 70 mg/dL, give them a half cup of fruit juice or a regular (not diet) soft drink or several pieces of hard candy.

**Hyperglycemia** (defined as blood sugar over 180 mg/dL after a meal or 130 mg/dL after fasting) may occur as a result of eating too many grams of carbohydrates or not taking diabetes medication. Symptoms may include headaches, blurred vision, increased thirst and frequent urination. You’ll need to work with your doctor to find the safest way to lower blood glucose levels.

Caregivers may be unprepared for the investment of time and attention required to frequently monitor blood sugar and administer diabetes medication, which may include frequent injections of insulin. “Constant adjustments in doses of medications can be difficult to cope with,” Dr. Kosiborod said. “The time-consuming nature and complexity of diabetes management can be overwhelming.”

But there are ways to make things easier. For example, make a diabetes travel kit with all the supplies (including glucose tablets or hard candy) and take it with you whenever you leave home with your survivor. Use a datebook, Palm Pilot or other scheduling system to help you track care tasks, like checking blood sugar, giving medications, staying on track with exercise and doctor’s appointments. Keep all diabetes supplies in one place so you don’t waste time looking for them.

Meal planning is critical to successful treatment and may require the assistance of a dietitian to take away some of the anxiety. There are Web-based resources to help you. A good place to start is at the American Diabetes Association Web site, www.diabetes.org. Click on “Nutrition” at the top of the home page.

Finally, it is critical for patients to be certain that their caregiver will be there for them. “A caregiver’s knowledge about diabetes management as well as patience and a calm demeanor are very important,” Dr. Kosiborod said. “In addition, a caregiver’s ability to allow patients to express their concerns, anger and frustration, while maintaining an upbeat, can-do attitude, can be very therapeutic to patients.”

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**AT THE HEART OF THE HEART OF DIABETES**

The American Heart Association created The Heart of Diabetes program to raise awareness about 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 HeartofDiabetes.org to enroll.
Some things can be a challenge.

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

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.
Between a Rock and a Hard Place
Choosing long-term care can be difficult. How do you know you’re making the right decision?

by Jon Caswell

Joseph Magliulo misses his wife, Maria. She moved to a long-term care (LTC) facility near their home in Staten Island, N.Y after she had three strokes between 2002 and 2005. Joseph, a retired police sergeant, can’t take Maria home because of physical and cognitive deficits. He is 74; she is 72 and requires a Hoya lift to get out of bed.

Joseph arrives at the facility every day between 9 and 10 a.m. He feeds Maria, participates in her care and wheels her around the grounds. Once a week he schedules handi-rides, and they visit a mall or restaurant. Each day he stays until she falls asleep, if he’s lucky, otherwise she cries when he has to leave at 10 p.m., asking over and over why they can’t live together. He returns to their home, which he shares with their daughter, eats a little, takes a shower and goes to bed. Tomorrow will be exactly like today. This is not a burden for Joseph; it is his duty and his honor: “It is the way I express my love for this angel God put on this earth,” he said.

Making the long-term care decision

Joseph’s situation isn’t unique or unusual. Stroke often causes changes that require care a spouse or adult child simply can’t provide. One of the biggest questions caregivers must ask themselves is when to bring in additional assistance—and how much is needed. Is this a long-term situation or is regaining a degree of independence promising? There are many unknowns in the chronic phase of stroke.

“When a family member becomes disabled, roles change,” said Robin Straight, a social worker in West Virginia and a volunteer with the National Family Caregivers Association. “It is critical to remain as realistic as possible about what is needed and what the family caregiver can provide both financially and physically. One of the biggest pitfalls is for the caregiver to try to do everything alone and not allow an external care team to help.”

There are many issues involved in evaluating this change. Maria responded well to therapy after the first two strokes and only had brief stays in the LTC facility for rehab. But the third stroke left her unable to get out of bed on her own, and the cognitive impairment was much greater. She needed more care than Joseph could provide.

Robin Straight suggests asking these questions before deciding whether to place a family member in LTC:

• What degree of assistance does the survivor need with medications, food preparation, toileting and other activities of daily living? Will they be safe and can they thrive with an in-home aide, or do they require skilled nursing care?
• How many hours a day does the survivor require assistance? Is care needed only while family caregivers are at work, or 24 hours a day?
• Are there cognitive issues, such as memory loss, awareness or communication challenges that may make it unsafe for them to be unsupervised for extended periods of time? For example, can they remember that they can’t move safely around the house by themselves? If they can’t take care of themselves or call for help, they might need to go into a LTC facility.

• Is the kind of care they require available? While finding professional caregivers may be easy in a large metropolitan area, they may not be readily available in rural areas.

• Can the family home be modified so it’s safe and accessible?

• What will it cost? Twenty-four-hour-a-day care is very expensive (not to mention home modifications). Neither is covered by Medicare or Medicaid.

• Is there a family member who is willing to provide the necessary care? Do they have physical limitations or time constraints?

“The No. 1 concern for the family is what is best for the patient,” Robin said. “Spousal caregiving is one of the biggest triggers for going into a LTC facility because a spouse simply may not be capable of providing the care needed.”

Dealing with the emotions

Few families can place a loved one in a LTC facility without feeling guilty. This is especially true of spousal caregivers. In their minds, no one can take care of their loved one as well as they can. “In coming to terms with this decision, the thing I stress is, ‘are you emotionally and physically capable of handling the work?’ Often caregivers think they are, but they’re not. Another concern is ‘how comfortable are you with receiving the help you will need to bring into your home?’”

How can caregivers best accept making the LTC decision? “It’s almost impossible not to second-guess yourself, especially if it’s a spousal caregiver,” Robin said. “But try to look at it as a long-term process. You’re making the best decisions you can with the information at your disposal at the time. You are making the decision out of love and because it’s best for the survivor.”

Unfortunately, cognitive and emotional changes caused by the stroke may prevent the survivor from understanding that this is the best decision, as with Maria Magluilo. There is no easy and satisfactory way to handle this situation. “Caregivers must keep focused on the fact that they are providing the best level of care that is available and affordable. Remember, you aren’t abandoning the survivor, you are transitioning them to better care.”

In addition to feeling guilty about placing a spouse in a LTC facility, caregivers often feel a sense of failure when they have to shift care responsibilities. But, of course, they have not failed. At the very least, moving a survivor to a LTC facility means that the family is facing a more critical level of illness. It may be the first time the spouse has realized the survivor may not improve enough to live at home. This can be emotionally overwhelming.

Family and spousal caregivers are still caregivers when a LTC facility is doing the heavy lifting. “You are functioning in a caregiving role if you are visiting in a LTC facility like Mr. Magluilo, attending therapy sessions or simply sitting with the person,” Robin said. “Your caregiving duties change, but they do not stop. Keeping this in mind will assist in dealing with the feeling that you have ‘abandoned’ your loved one. Family caregivers remain a critical part of the care team.”

Quality of life and long-term care

As part of the caregiving team, it is important to learn the routines of your survivor’s LTC facility and to whom to direct questions.

This starts with the admissions process. “Start by meeting both the director and assistant director of nursing,” Robin said. “Learn the routines of the CNAs, LPNs (licensed practical nurses) as well as the RN providing supervision. Everybody in the place may be wearing medical garb, so be sure you know who’s who.”
Social worker Robin Straight reminds caregivers to “keep in mind that the decisions you make are centered in love and respect for the person you are providing care for.”

At admission, find out who is providing medical care—your doctor or a staff physician? To whom on the nursing staff should you direct questions? “Have all the legal documents ready that say you are the responsible party and that give you permission to ask questions and get information. Otherwise you will not get the information you need because of health information privacy laws. Find out who works when. What are the physician’s hours? What is the schedule of therapy? For insurance purposes, who is going to decide progress in therapy? Is there a rehab goal or are you anticipating the survivor will always be there? Today survivors may be admitted to a LTC facility for a short term of rehab. This must be clarified at the beginning.”

At the time of admission, find out if you can bring in photos, if the person can wear their own clothes, if pets can visit and if you can bring food that they enjoy. Do these have to be cleared? With whom? Who is the responsible person on each shift? What is the facility’s policy on calling you if there’s a problem? Don’t be shy or intimidated about asking questions when you don’t get the information you need.

“Know what time therapy is, when meals are and when the doctor’s rounds are,” Robin said. “Can you take your loved one out? Ask these questions prior to admission. If they are willing to discuss these things with you, you’re going to feel better about the facility.”

Robin suggests integrating as much family life into the LTC environment as reasonable. “Hold family dinners at the facility,” Robin said. “If the family gathered at a parent’s house on Sunday for dinner, gather at the facility dining room. Attend religious services, anything that would have been part of the routine when the person was at home. Provide your family member with personal comforts, like family photos, a favorite blanket, a special lotion, books, music or magazines they like. This will allow your loved one to maintain their connection to the family, and it extends the family to the facility setting. This adds to their quality of life.”

Advice for the long run

Caregivers are routinely asked to make very hard decisions about their loved ones. “Keep in mind that the decisions you make are centered in love and respect for the person you are providing care for,” Robin said. “If you can stay focused on that single thought, it can serve as your guide for all the decisions you have to make. Arm yourself with all the information you can find to make an informed decision. Ask questions, ask for time, and above all, ask for and accept help. This is the greatest gift you can give your loved one. Trust that your life experiences will provide you with the strength and wisdom you need. You will remain the center of their care team.

“Caregivers often come to what I call a ‘reachable moment.’ It is a point when all your emotions come together and you ‘reach out’ to others for assistance. Each individual comes to this moment in their time. The guilt fades, peace and grace settle in, and as a caregiver, you value the gift of time you have with your loved one at this stage in their life.”

Joseph Magluilo has bought a lift so he can bring Maria home for a few hours at some time in the future if doctors say she is ready. Until then, he continues his daily 12-hour ritual of devotion. He feels it is the least he can do for his angel.

Editor’s Note: For more information on Maintaining Physical and Psychological Health and Dealing with Stress and Depression related to long-term care, visit www.strokeassociation.org/strokeconnection.
Despite my own chronic illness (myasthenia gravis), I dashed into emergency mode when my husband Ted, age 86, woke me up before dawn making strange grunts, then fell to the floor. After his severe left-brain stroke, the visits to the ER, hospital room and subsequent nursing home became dreaded vigils. At age 71, I needed every ounce of energy to be positive and cheerful in his presence. It was shattering to see my intelligent spouse struggling to say the word “pajamas.”

Tending to his needs took priority, but then someone asked, “What about you? How are you?” The polite answer was “Fine. And he’s improving.” The honest answer was “I can barely keep going, and we don’t know what the outcome will be. I feel like it’s the end of the day — in the morning.”

I know it’s true that to be a caregiver you need to take care of yourself. But it’s not easy when your spouse doesn’t want strangers in the house, or when family doesn’t live nearby, or when you’re reluctant to impose on friends, colleagues and neighbors.

In the house of illness, stress is no stranger. As tension increased and stamina decreased, I felt waves of irritation, anger and frustration followed by guilt that I, who could walk and talk, did not have more charity. The pounds I’d valiantly been trying to shed suddenly slipped away despite generous servings of comfort food delivered by compassionate friends. Projects waited on my desk, but it was impossible to focus.

When I returned each day from the nursing facility, I’d collapse, barely able to read the paper or answer solicitous calls. When someone asked what I’d like, I answered, “A half-hour on a beach in Hawaii.” As I said it, I almost felt the warm sand on my aching bones and visualized the turquoise sea lapping the shoreline. The reality was that I had to cancel our planned vacation, and instead I escorted my husband with his walker to the barren courtyard of a nursing facility.

When he returned home after a month, thrilled to “get out of prison,” there were significant improvements—and frustrations. Against his wishes, I hired someone so I could go for a swim or attend a meeting, but even with my cell phone on, I worried. The “what if’s” jangled my nerves. Telling your agitated self not to worry is like telling an insomniac to go to sleep.

So, what do you do if you’re trying to protect your own health and equilibrium while functioning as prime caregiver? Here are some suggestions:
Make a list of what only you can do, and what someone else could do. (Be honest!) Delegate the burdens you can.

- Make a list of the patient’s medications (name and dosage); how to order same and the credit card to use; any identifying medical number as with an HMO; and the doctor’s names and how to reach them (telephone and e-mail).
- Keep a file of all hospital expenses, medical appointments, bills and payments (bank check or credit card number and date) in case there’s any question.
- Go through your insurance policies carefully, preferably with a consultant, to make sure you understand what is and isn’t applicable. (I found out that our long-term care insurance didn’t kick in for 45 days.)
- Make sure you have a notarized Advance Health Directive regarding health issues for one another. (You can find information and free forms on the Internet. Type “advance directive” into your search engine.) File it with your primary physician, but store a duplicate copy in a safe deposit box, and keep a third copy at home in a secure, accessible place. In our case, both the Emergency Room and the nursing home wanted the same information. Since there may be no communication with your primary doctor’s office, it’s insufficient to file the document only there.
- Welcome and accept offers from family, friends, colleagues and neighbors. But recognize that some people, even good friends, can’t stomach illness and may disappear from your life.
- Make a list of what only you can do, and what someone else could do. (Be honest!) Delegate the burdens you can.
- As soon as the patient is able to receive visitors, encourage friends to visit. This can cheer the patient and give you a reprieve.
- Invest in a supply of thank-you notes. When the flowers, plants, magazines, charitable contributions, casseroles and chocolates start arriving, let people know that you appreciate their thoughtfulness.
- If family lives nearby, try to arrange weekly visits. You may need to attend initial medical appointments with primary physicians, physical therapists, etc., but perhaps someone else could drive the patient for blood tests, x-rays, etc. (Our son obtained family leave from work so he could help us one or two days a week.)
- Applaud each success. As soon as it’s realistic, encourage the patient to bathe, dress, exercise, make the coffee and do whatever will hasten independence. Keep reminding the patient of all he or she can do and of the progress that’s being made daily.
- If you don’t already have cell phones, get them and program a quick dial, so that you can reach each other easily.
- Know and respect your own limits. Cut corners. Sometimes it’s better to buy than bake.
- Illness alters your lives, either temporarily or permanently. But in time both you and your loved one will be able to reclaim your lives—if not totally, then in part. Remember, “And this, too, shall pass.”
- Until the survivor can be left alone, hire someone you trust for a few hours each week, so you can do the marketing, attend a meeting, etc.
- Take time every day to do something for yourself: a walk, a swim, a chapter of a good book, lunch or coffee with a friend, a 15-minute chair massage.
- Keep a journal so that you can pour your heart out and spare the clerk or waitress who innocently asks, “How are you today?”
- Find one or two people to whom you can speak candidly. Prepare a pat answer for casual inquiries from everyone else, e.g. “He’s improving. Thank you.” Remember if you are reckless enough to give an “organ recital,” the inquirer may respond with details of her own catastrophic medical experience and that means more stress.
- REST—as much as your body demands.
- Eat nutritious meals to give you energy.
- Get some exercise every day to relieve stress, e.g., walking, swimming, yoga.
- If you feel sad or depressed, select novels or films that will lighten the spirits. Humor is a healer.
- If one is available, attend a support group for caregivers, where you can talk frankly with those who are facing similar issues.
- Suppose the patient doesn’t make a full recovery. Then, treasure the time when you are both able to enjoy a moment together. Nothing takes the place of listening — and loving.
- Finally, remember you are a legal spouse not a licensed nurse. You don’t have to be a hero every day.

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National Family Caregivers Month is organized each November by the National Family Caregivers Association to thank, support, educate and empower family caregivers. NFCA is hosting “Safe & Sound: How to Prevent Medication Mishaps,” a national TeleClass/Webinar for family caregivers, on Nov. 12 at 2 p.m. ET. For information and to register, visit thefamilycaregiver.org or call (800) 896-3650.
“He’s got two choices...”

either he wears Life Alert around his neck, or he has a healthcare attendant shadow his every move,” demanded the head honcho at my hospital discharge meeting. First, I’m always a little defensive when someone’s talking about me in the third person when I’m sitting right there. Second, I didn’t know what her problem was. After all, I was a model patient. Never used the nurse call-button (busted), never complained about the meals (mystery meat), and I took all my meds including the LMDs (laxatives of mass destruction). OK...
I did steal clean pajama bottoms from the laundry cart at night. Nobody’s perfect. Pants in a hospital are like cigarettes in Alcatraz: “Hey man, I’ll trade you 10 Ativans for a pair of those bottoms.”

He pushed my wheelchair as fast as he could, then hopped on like I was a dogsled in the tundra... the brakes were smokin’.

Anyway, back in 1997, the year I “escaped,” Life Alert was running that cheesy commercial where grandma is lying on the floor screaming, “I’ve fallen and I can’t get up!” It was torturous to watch. My comedian buddies had a field day, and if word got out that I was wearing one of those things, there would have been talk of commitment proceedings.

So healthcare attendant it was. The term evokes an angel of mercy, and I figured I’d be spending the day with the healing spirit of Mother Teresa. But when I opened my door there stood Patrice. I did a double take. Apparently, while I wasn’t looking, the rapper Snoop Dogg switched careers. The bling around Patrice’s neck blinded me like a flashbulb. Once my sight was regained, I got a perfect shot of his Calvin Klein briefs because his jeans were down around his knees. Call me old-fashioned, but I like to be introduced before I know what brand of underwear someone is wearing. His T-shirt said “No Limits Dogg,” which I thought was a motivational rehab slogan. Actually it was Snoop’s latest hit. Patrice immediately found the kitchen, opened the fridge, and asked if I had anything to eat. My Hip Hop-to-English dictionary wasn’t handy, but I figured that’s what “Food in the box, Pappi?” meant. While I was trying to figure out who Pappi was, he came out gnawing on a drumstick and proceeded to wipe his hands on the sofa.

Watching must be one of the requirements for this profession, and here Patrice excelled. He watched “The Peoples Court,” “Maury Povich,” “Montel,” “Ricki Lake,” “Jenny Jones,” “Jerry Springer,” and me, taking a shower. Which was fine, but did he have to pull up a chair? I contemplated wearing pasties and a thong just to make it more interesting for him.

I was still in a wheelchair, so wherever I went, he went. Simply pushing my chair was “too A-A-R-P man!” Instead, he pushed as fast as he could, then hopped on like I was a dogsled in the tundra. His bling jingle-jangled like a runaway Mister Softie truck warning unsuspecting pedestrians as we barreled down the street. The brakes were smokin’.

As I braced myself for stroke number two I came to a realization. I was having … fun. In a way, Patrice was a human Life Alert alarm. “You out’ the hospital Pappi — time to live!” Not that speeding down the streets of Manhattan in an out-of-control wheelchair is living. But it was a start.
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As a physical therapist, I help stroke survivors achieve the best possible recovery for their affected arms and hands. Weakness and stiffness in the arm muscles as well as shoulder pain are common effects of stroke. Shoulder subluxation may also be an issue for many survivors.

**What is shoulder subluxation and what causes it?**

Shoulder subluxation is a partial dislocation of the shoulder joint. For people with stroke, it is usually caused by weak rotator cuff muscles, which connect the upper arm bone (humerus) to the shoulder blade. These muscles are responsible for maintaining shoulder joint alignment during arm movement. When the rotator cuff is weak, gravity pulls the humerus down and away from the shoulder blade, causing shoulder subluxation. Slumped posture caused by weak back muscles can increase shoulder subluxation. Occasionally, muscle stiffness causes subluxation by placing uneven stresses on the shoulder joint, pulling the joint out of alignment. In these cases, most commonly, the arm bone has pulled forward and away from the shoulder blade.

**Do I have shoulder subluxation?**

As many as 37 percent of stroke survivors develop shoulder subluxation. A physical therapist or physician can diagnose the condition by feeling the space between the arm bone and the shoulder blade. The space should be less than one-finger width. A separation of one-finger width is considered a mild subluxation. The more finger widths of separation, the more severe the subluxation.
Does shoulder subluxation cause pain?

The shoulder is the most common source of pain among people with stroke. Research is not definitive as to whether or not subluxation increases risk for shoulder pain. Other conditions such as stiffness (hypertonicity) and decreased range of motion, particularly in turning the arm away from the body (external rotation), are known to contribute to shoulder pain. It is important for stroke survivors to work with their physical therapist or physician to determine the extent to which subluxation might be contributing to shoulder pain.

What can I do to manage or prevent shoulder subluxation?

A physical therapist will apply his or her expertise and understanding of research to work with you to develop an appropriate treatment plan. The following are prevention and management strategies I recommend.

Activities to improve arm function and strength may be used as specific interventions to address shoulder subluxation. These activities may include:

• constraint-induced movement therapy (forcing the use of the affected arm by restraining the unaffected arm with a sling);
• mental practice with motor imagery (rehearsing a physical activity by memory without body movement); and
• task-specific training (relearning a given task by training specifically for that task).

With improved function and strength, the risk for shoulder subluxation decreases. Work closely with your physical therapist to ensure that the shoulder joint is protected during all exercise and training activities.

Neuromuscular electrical stimulation uses electrical currents to activate weak shoulder muscles by placing electrodes on the skin. This is often effective for reducing subluxation, but it can be painful and irritating to the skin, so it may only be practical for short-term relief right after a stroke has occurred, when the arm is most likely to regain strength rapidly. For some survivors, neuromuscular stimulation can be used at home. A physical therapist can help you learn to use it safely.

Shoulder slings of many different styles and designs have been developed to reduce subluxation. Slings that support the weight of the arm while allowing the elbow to straighten (such as the GivMohr™ Sling and Rolyan® Hemi Arm Sling) are the best option for reducing subluxation while promoting use of the arm, which is vital to recovery.

Slings that hold the elbow bent and the forearm close to the body (such as the triangular sling) promote stiffness that can lead to shoulder pain and should not be used for long periods of time. Because slings vary significantly in style, it is best to work with a physical therapist to choose the most appropriate style and learn how to wear it correctly. An incorrectly fitted sling can do more harm than good.

With improved arm function and strength, the risk for shoulder subluxation decreases.

Shoulder strapping involves the use of athletic tape on the shoulder to reduce subluxation. Studies of strapping have shown limited benefit; however, it may be helpful for short-term treatment. With training from a professional, a caregiver can learn to apply strapping. Like neuromuscular electrical stimulation, skin irritation is a common side effect of shoulder strapping.

Other positioning devices may be used to support the shoulder while in a wheelchair or bed. Wheelchair devices such as lap trays and arm troughs may be effective for reducing shoulder subluxation. It is important to position the device and the arm correctly to prevent over-correction of the condition.

Proper positioning in bed may be accomplished with pillows. For lying on the back, pillows should be placed under the forearm. This allows the upper arm to rest on the mattress. Ask a physical therapist to teach you proper positioning for each lying position.

When caring for someone with stroke, follow careful patient handling procedures. It is important to protect the survivor’s weak arm when helping to transfer from bed to a chair, for example, or when walking. Never pull on the affected arm when helping the person move. Likewise, during activities such as dressing and bathing, it is important to monitor the position of the arm. For example, when putting on a shirt, always put the affected arm into its sleeve first. Range of motion exercises must also be done properly to prevent shoulder subluxation and pain. Overhead exercises without appropriate support of the shoulder blade have been shown to substantially increase the risk of shoulder pain after stroke.

Shoulder subluxation is common following a stroke. Proper support for the shoulder is the key to prevention and treatment. By working closely with your physical therapist and physician, you can find the treatment plan that is right for you. Learn more about conditions physical therapists can treat and find a physical therapist in your area at moveforwardpt.com.

About the author...

Dr. Julie Tilson is a physical therapist and assistant professor in the Division of Biokinesiology and Physical Therapy at the University of Southern California in Los Angeles. She has specialized in stroke rehabilitation since 1998 and has been involved in research to improve stroke recovery since 2005.
Books about Stroke

Take Brave Steps for Stroke Survivors and Families
By Ron Gardner  |  Infinity Publishing

This book is a roadmap that leads survivors and loved ones through the mental, emotional and social maze of stroke recovery, taking them from bitter to better. With personal stories of motivation and hope, the author, a survivor, guides readers through the fears, adversities and challenges that stroke families often must navigate. In this book he outlines his 10 Brave Steps process. The objective of this process is to gain insights and wisdom to help survivors progress from life-shattering illness to recovery and health.

Rewire Your Brain, Rewire Your Life
By Bob Guns, Ph.D.  |  Self-published

Stroke Connection readers will recognize Bob Guns as the author of funny stories about post-stroke life. His handbook for survivors and caregivers outlines the RAISE program Bob developed after his stroke. RAISE stands for Reflect, Analyze, Identify, Start and Evaluate, and it supports improvement by assisting survivors in identifying and then using their strengths. Bob interviewed survivors and caregivers and about half the book is devoted to their experience and the wisdom it gave them.

The Caregiver Helpbook: Powerful Tools for Caregivers
Compiled by Legacy Caregiver Services
Legacy Health Systems
ISBN 0-9785448-0-3

This book originally accompanied a six-week educational program to provide family caregivers tools to increase their self-care and confidence. While not specifically for stroke caregivers, the book is organized around tools and strategies that empower them to take care of themselves while dealing with the many requirements of a stroke survivor. The first half of the book covers basic self-care and communication tools and strategies, such as reducing stress and making tough caregiver decisions. The second half addresses specific caregiver issues, like problems in the workplace, hiring in-home help, tips for long-distance caregiving and caring for memory-impaired survivors.

Stronger after Stroke: Your Roadmap to Recovery
By Peter Levine  |  Demos Medical Publishing
ISBN 1-932603-74-3

Peter Levine is the co-director of the Neuromotor Recovery and Rehabilitation Laboratory and a researcher with the Department of Rehabilitation Sciences at the University of Cincinnati Academic Medical Center. This book presents a new and potentially more effective treatment philosophy. In chapters dedicated to different aspects of therapy, Levine brings to life the idea that “the mind can change the brain.” There are chapters on safeguarding the investment in recovery, exercise elements essential to recovery, recovery strategies, spasticity control and elimination as well as “cool” treatment options.

My Stroke: 450 Days from Severe Aphasia to Speaking, Reading and Writing
By Donald F. Weinstein, Ph.D.

Stroke Connection published an article (“Reclaiming My Dignity”) by Donald Weinstein in January/February 2008 about his experience as a survivor with aphasia. He has now expanded that article into a book about getting back his language. The book chronicles the first 15 months after his stroke, including monthly activities, feelings and thoughts after his stroke and the assistance he received from professionals, loved ones and supporters. It is available through the National Aphasia Association, www.aphasia.org.

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