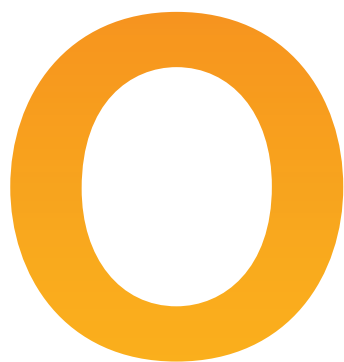


How **Not** to be Overwhelmed by the Overwhelming

By Jon Caswell



Over the two decades of *Stroke Connection*, many stroke families have shared stories like this: In the beginning, there was fear, and the fear was overwhelming. After the fear came courage. Then we learned about stroke, rehabilitation and recovery, which is individual and unique. And then, finally, came perseverance.

“Stroke is often a shot out of the blue, and that makes it hard to prepare for,” said Dr. Barry Jacobs, director of behavioral sciences at Crozier-Keystone Family Medicine Residency Program in Springfield, Penn., and the author of *The Emotional Survival Guide for Caregivers*.

People who haven’t had any experience with stroke don’t really know what it is, and when it’s happening they are inevitably confused. Those who recognize stroke is happening understand it is life threatening, and that causes a lot of fear. “People often respond to fear with denial or minimization: ‘You’re fine. That tingling will go away soon,’” Dr. Jacobs said. “Some people are in denial and won’t take action to get their spouse medical help.”

Knowledge conquers fear, Dr. Jacobs said, but when we are overwhelmed with fear we’re not good listeners or critical thinkers. At the moment of shock, the spouse can’t take in much. As the shock dissipates, spouses are able to understand more of what’s happened and where the road ahead goes. “When spouses can have that path laid out for them, their feelings of being overwhelmed go away,” Dr. Jacobs said. “They know that there is a prescribed path and there are people who are knowledgeable to guide them. That provides a lot of reassurance.”

Stabilizing the survivor reduces fear and begins recovery. At first, there is often a lot of hope because recovery is variable, and one can always hope for complete recovery. “Since there are a minority of stroke survivors who do recover fully, that hope is not

unwarranted,” Dr. Jacobs said. However, there is also no exact science to know how fully someone will recover, and that uncertainty is stressful. So in order to maximize recovery, survivors need to take full advantage of the medical resources and rehabilitation possibilities as early as possible. “There is a window of opportunity that we want to take full advantage of,” Dr. Jacobs said. “To maximize that opportunity, the caregiver has to be supportive. They’ve got to gain some skills, especially in regard to rehab.” One way that the spouse can deal with the uncertainty is by becoming part of the treatment team and taking on a role that is really essential in improving the survivor’s recovery.



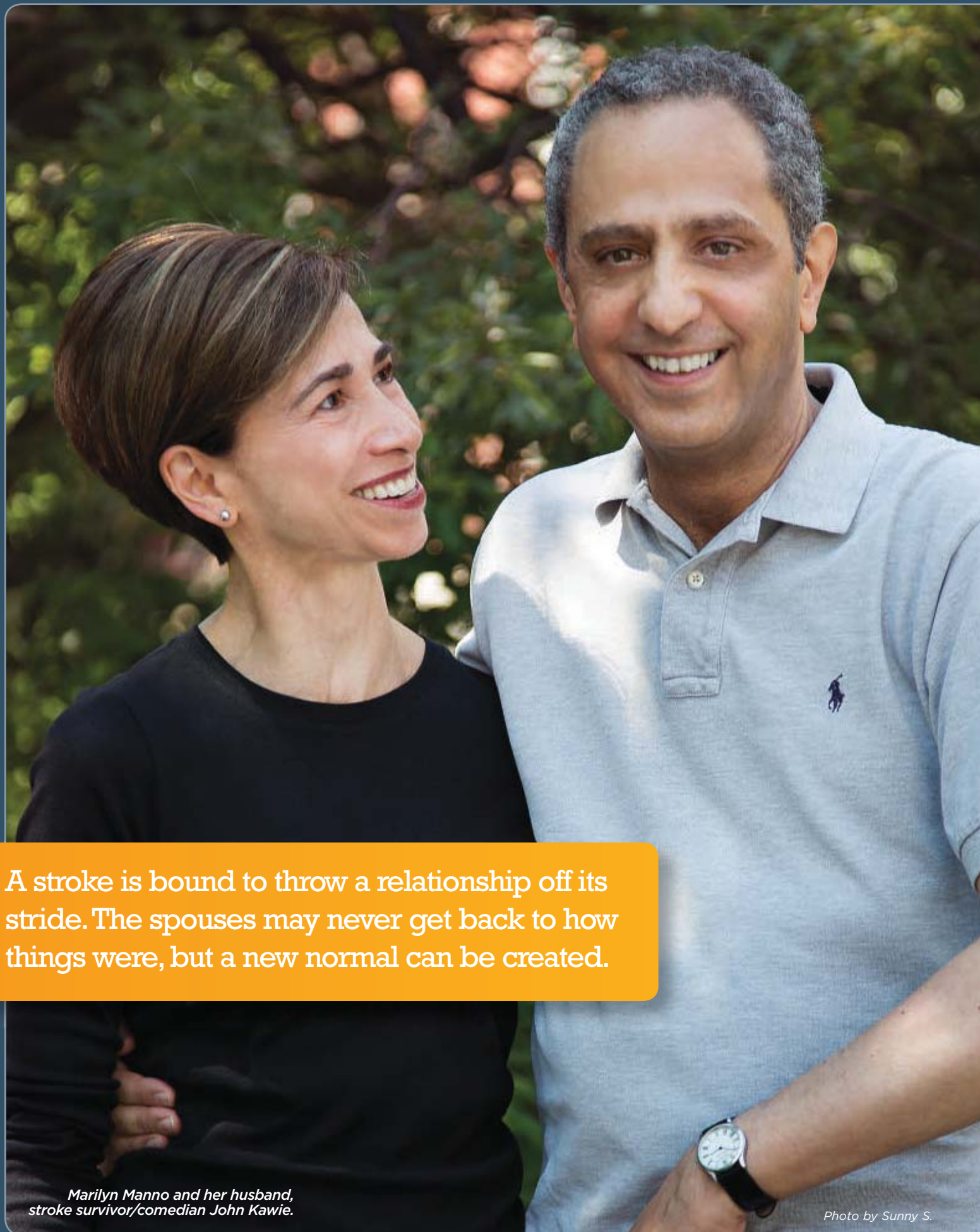
Dr. Barry Jacobs

Negotiating the cul-de-sac

It is common for caregivers to feel anger and guilt. If the survivor didn’t handle his or her health risk factors, the spouse may be angry about that. But it’s also important to realize that it is not always possible to know the reasons for a stroke. “Whatever the cause, anger is not actually going to facilitate the recovery process,” Dr. Jacobs said. “The pertinent question is, ‘How I do I engage my loved one in rehab so they can maximize their recovery?’ If caregivers direct their anger at their loved ones, they might impede their survivor’s ability to engage in rehab. I do think caregivers are justified in feeling anger at times, but that anger needs to be addressed elsewhere. Lambasting the survivor can actually be detrimental.”

Caregivers may also feel guilt that they did not do enough to prevent the stroke. “Guilt is a cul-de-sac,” Dr. Jacobs said. “It doesn’t lead anywhere. It doesn’t lead people to become better problem-solvers, it doesn’t lead them to take effective action.”

Bottom line, anger and guilt need to be ventilated elsewhere. In the beginning the main effort needs to be put into engaging the survivor in rehabilitation and making a big effort there. That push is one that will make a difference in the future.



A stroke is bound to throw a relationship off its stride. The spouses may never get back to how things were, but a new normal can be created.

*Marilyn Manno and her husband,
stroke survivor/comedian John Kawie.*

Photo by Sunny S.

A whole new job

Caregivers have months of uncertainty ahead of them. Dr. Jacobs counsels them to recognize this, and to adopt the mindset that they have started down a path that has no immediate end in sight. “They have to put themselves in a frame of mind that they have embarked on a new journey and this journey is going last for a while,” he said. The hardest part is at the beginning, when the person they love is in their worst functioning state. The survivor is more than likely going to recover to some degree. The caregiver is empowered when they acknowledge they have a new and important role: “They have to play cheerleader; they have to play rehab assistant; they have to apply the things they learn from therapists,” Dr. Jacobs said. “They are taking on a whole new job.”

Regaining control

A stroke is bound to throw a relationship off its stride. The spouses may never get back to how things were, but a new normal can be created. For the caregiver spouse, that means increasing his or her knowledge and embracing the new role. They should work with the healthcare team as closely as possible, but they must also remain firmly on the side of the survivor, always advocating for more rehab.

Caregivers also need to talk to others who understand, such as other stroke caregivers, if possible. They need social support in general. They need to talk to whoever they talked with and vented to in the past. “New caregivers feel like they have plunged into an alien world and they need to give themselves time to acclimate,” Dr. Jacobs said. “They have to be patient with themselves and others.”

Survivors may be physically different, but they are also emotionally different; their personalities have changed. “The crucial question for most caregivers is, ‘How do I find a way to have a relationship with this person?’” Dr. Jacobs said. “There is a lot of grief in that process, really grieving, not just who the person was but grieving what the relationship was. It’s pretty certain that the relationship will change – the caregiver is going to be doing more of the hands-on tasks, maybe doing the family finances, making decisions they’ve never had to make before. That’s very stressful, but it is also very sad because one of the partners is no longer able to take their part of the marital responsibilities.”

Dr. Jacobs suggested that caregivers get counseling to help them adjust. “Whether the spouse gets professional or pastoral counseling, these are people who can offer support and guidance and can commiserate that life has changed permanently,” Dr. Jacobs said. “That new life entails a change of perspective and making more sacrifices than the caregiver has ever had to make. Those kinds of adjustments are facilitated by having a guide working with you.”

The immediate aftermath of a stroke is one of the most difficult times anyone will ever go through. In talking with caregivers, it’s clear that it is a period that they don’t recall very well later. They remember where the loved one was when the stroke occurred but recollections of what happened afterward are blurry because the caregiver was so emotionally overwhelmed. “My advice to spouses is just hang in there and be patient with yourself and accept that this process will unfold slowly,” Dr. Jacobs said. **SC**

Living Through a Spouse’s Stroke

By Marilyn Manno

Editor’s Note: Marilyn is married to our own John Kawie.

Initially, I was annoyed with John’s behavior.

We were at breakfast with friends, and he was drooling food and not keeping up with the conversation. When I realized it was more than bad manners, my annoyance quickly turned to fear, especially when I saw the frightened look in his eyes.

At that point, all I cared about was getting John to a hospital so they could fix whatever was happening. It was there that we first heard the word “stroke.” I was naive and clueless about what a stroke entailed. Stroke was something my old relatives had – not the 47-year-old man I married just a week before.

I wasn’t really scared, at first, because I didn’t grasp the gravity of the situation. But every day John was in the hospital and his left side wasn’t functioning the way it used to, I became more alarmed. This wasn’t going to be like a heart attack where they fix you up, give you some pills and you walk out unaided. When the enormity of the situation settled in, I wondered what the future would hold. Would there even be a future? It was then I first realized that life as we knew it was gone.

There’s no planning for this kind of thing. You’re thrust into this new universe of terminology that you didn’t know existed and were never prepared to enter. You have to be a quick study; I was not. Overnight I went from newlywed to “caregiver,” a term I had never heard before. Then came the foreign world of rehab filled with wheelchairs, canes and braces, a world where you’re not only a caregiver but also a patient advocate, trying to get the best healthcare possible.

When John didn’t recover the use of his left arm and leg during that first week, I remember thinking, “He might never recover.” I had no idea of what to expect. He kept repeating the same phrases. His timing — something he valued as a comedian — was

off. When I realized that John was affected both physically *and* cognitively, I knew we had a long haul ahead of us. I had to prepare myself before every hospital visit to make sure I didn't show John how upset I was at this new person he'd become. I tried to be the positive energy in the room so that he would work harder at his therapy.

I was surprised at how insensitive doctors could be. After one examination, a well-known neurologist blurted out to John that he would never regain the use of his arm. John was so upset that he broke down in his office. I called the doctor the next day and reamed him out for his bedside manner. He apologized, but told me he was just being honest. I told him that he took away the one thing that John clung to – hope – and that no one knew for sure how the brain could rewire itself. By then I was becoming more knowledgeable about stroke and more of an advocate for John.

John was a stand-up comedian with no health insurance. The week we were married I signed him up for my company's plan; the coverage kicked in three days before the stroke, which turned out to be a godsend. When John was first admitted to the ICU, my company's health department assigned me a "case manager" – yet another term that was foreign to me. Salley turned out to be John's guardian angel and I don't know what I would have done without her. She helped us navigate the complex and overwhelming world of healthcare, fought for more therapy than most received, explained endlessly and patiently what I was ignorant about, to the point that we became a team fighting for John.

John was released from the hospital after two months. After that, I remember not wanting to be home much. Work was a safe haven. I would arrive early and just chill, enjoying my coffee and alone time, and in the evening I'd find things to delay my return home, just to have a few extra minutes of peace and normalcy. Work was structured, orderly – a total contrast to what our apartment had become. My work space became a home away from home with friends stopping by to gossip and share news. John was not handling conversation well and I was feeling lonely. I also felt extremely guilty. If I found myself having a good time at work I would suddenly tear up realizing it had been months since I was able to experience some sense of fun and laughter with my new husband. I had given John so much of my energy the first few months that I wanted some me-time. I now realize caregivers need this, but at the time I felt very selfish about it.

One thing I learned is that rehabilitation is the key to recovery. I can't emphasize that enough. PT, OT, cognitive, speech – they all help the survivor to



Dancing at our wedding in October, 1997

heal. We were lucky that our case manager fought to get us more than most. Try to get as much from your insurance company as possible. When the insurance runs out, try to get involved in studies where therapy is included. In addition to the obvious benefits, therapy allowed John to socialize and rebuild his self-confidence. It sure beat staying at home all day, which can be an invitation for depression to sneak in.

A second thing I learned is that you have to be your healthcare advocate. Translation: Be pushy. When the stroke happened, I didn't know what to ask the doctors, and I accepted most of what they said. Eventually, I learned to speak up. As the weeks went by, I became John's voice. I asked questions and if I wasn't satisfied with the answers I'd probe until I was. I found the younger doctors were more willing to share information, whereas the older doctors weren't used to being questioned.

My advice to new caregivers is to hang in there. The person you love is still there, just a little lost and frightened. You might both get angry and frustrated along the road to recovery, but that's natural and will hopefully bring you to a better place. Also, try to get a support system to give you some relief. You don't realize how much energy you put into your spouse's recovery, and if you get sick then you're no good to anyone.

Approach recovery as a journey. It may not be the path you had planned, but once you've gone through it, you might discover strengths you never knew you had. I know we did. We've also become closer. I made up signs of support for John's hospital room to help him get through the day. One said, "We're in this together," and 16 years later we still are; we make a great team.

Never give up hope. Neither of you. Nothing is impossible.

Spouse as Cheerleader

Dr. Jacobs recommends not dwelling on the future early on. Caregivers should instead focus on helping their survivor get mobilized and nurturing a sense of hope. "It's the spouse's job to come in and say, 'Let's go, we're going to do this. I'm going to work with you to overcome this.'"

Spousal encouragement and cheer leading play a crucial role in getting survivors motivated. Survivors who feel demoralized and depressed are not the ones working hard in physical therapy and strengthening themselves. They are not getting the most neurological recovery because they are not using their brains as intensively as someone who is fully engaged. "The spouse who is helping as a coach and cheerleader is likely to develop an even stronger bond with his or her survivor because the two of them are bonding against the common enemy of stroke," Dr. Jacobs said.

Tips from a Caregiving Pro

By Janet Scott

When my husband, Thomas, had his stroke in 1997, I was numb at first, in shock. I felt helpless. I was afraid that he would not make it, and if he did, what kind of quality of life would he have? I was concerned that I would not be able to assist him. It scared me when the doctor told me that Thomas would probably not be able to communicate, walk or work. I was told that there was little hope he would have any type of normal life. The doctor said that he might have to go into a nursing home.

My family was very supportive. We had been through this with my mother when she had a stroke.

Thomas did not make a complete recovery, but he has proved the initial prognosis wrong. He is able to walk and communicate. And he has worked full-time for years. He has aphasia, which affects the way the brain processes information, so it can be challenging to communicate with him at times. But I have learned how to communicate with him, so that neither of us gets frustrated.

I have been a caregiver for 16 years and have had the opportunity to interact with caregivers on the American Stroke Association's Stroke Family Warmline since 2012. Here's what I can tell you from my experience:

- Take it a day at a time.
- Be patient. Notice and celebrate any improvement.
- Stay encouraging and hopeful.
- Take time to take care of yourself. If you don't, you will not be of service to the survivor. You will feel overwhelmed and frustrated.
- Get involved with a stroke support group. You will gain a lot of useful information, and you will also discover you are not alone.
- Remember that your loved one does not want pity, just encouragement.
- You may lose friends and family members, because they feel uncomfortable and aren't sure how to respond. They fear they may say something wrong, so they just stop coming around. They may have a hard time understanding the survivor, due to aphasia. (For more on coping with other's reactions, see Expanding Comfort Zones, Fall 2012.)
- Prayer has helped me through the rough times.
- Realize that the survivor may not be the same person they were before the stroke. Some survivors' personalities change as well as their behavior. The survivor often does not realize these changes.
- If you are able to access the Internet, go to strokeassociation.org. There is a lot of valuable information to help you understand the effects of stroke and what treatments are available.
- Accept the changes and move forward. Don't look back; it will only hinder you in accepting and coping with the changes.



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