



Editors' Column

This issue of the MSA News is dedicated to caregivers, those individuals who have found themselves in the position of taking care of a loved one. While I was researching this topic, I ran across the following article which seems to summarize the fears that caregivers have when faced with a role that no one has prepared them for. JC

What are we afraid of?

Caregiver fears...rational or otherwise.

When you become a caregiver, your life changes forever. You cannot recapture the past, and in facing an unknown future, you may be overcome by fear. My own experience proved I was so busy trying to be the best caregiver possible that I didn't take the time to deal properly with all the fears that were accumulating at the back of my mind. I wasn't admitting to them or talking about them.

As a result, these fears become magnified; we can spend too much time facing them alone, feeling that there is no one else out there who could really understand what it's like. It doesn't have to be like this.

What are some of the fears we know too well?

- **FEAR** of financial problems related to caring for a loved one—that the money will run out while at home or that there

isn't enough money to even consider institutionalization, no matter how desperately needed.

- **FEAR** that you'll fail as a caregiver—that you won't be able to keep up the pace physically. How many times have you asked yourself: "How long can I go on doing this? How many more days, years, before I fall apart?" For how long have you tried against all odds to smile and say, "We're managing, thank you"?

- **FEAR** of the inability to handle the emotional stress. You finally start to understand what the stress is doing to you; you're afraid you'll never regain your original self: that person filled with energy, curiosity and optimism.

- **FEAR** of having to watch a loved one's pain and suffering. Feeling helpless to stop or even control it.

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Advocacy

Putting a face on stroke

You are invited to become a member of the American Heart Association/American Stroke Association's (AHA/ASA's) *You're the Cure* (YTC) network, a diverse team of almost 200,000 individuals from across the country who feel passionately about the need to put into place policy changes that would improve the health of all Americans.

YTC members include survivors, caretakers, researchers, healthcare professionals, families and individuals, all of whom understand the power they have to influence lawmakers at both the federal and state levels to make change happen.

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Living with a stroke

Anne Sterlock

Don was 62 years old and retired when he had a stroke on April 8, 2009. Don had been in reasonably good health prior to the stroke—he walked the dog three times a day, had not smoked for more than 30 years, and had lost some weight.

When the stroke occurred, I was at home with Don and called 911 immediately. We got to the ER in less than 45 minutes from the occurrence. When it was determined that a clot

had caused the stroke, he was given TPA. Initially, he had no movement on his right side and could not respond. After several days of just rest in the ICU, he was started on brief PT, OT, and SLP, and later at a nursing home for sub-acute rehab. He worked very hard at his therapies while there. He had several health issues from the stroke—

urinary tract infections, excessive bleeding following a prostate procedure, and seizures that sent him back to the hospital during the first months after the stroke. Each time he received therapy when he first returned home. Later he was able to attend outpatient therapy 3-4 days per week for one year. The center was for clients who had had a stroke or brain injury. I drove him each day and watched as he continued to improve from hard work and determination both at therapy sessions and at home.

One of the special parts of this therapy unit was weekly group sessions with a neuropsychologist. Meeting with the doctor allowed Don and me to see that he was not alone in what he was going through. As Don's primary caregiver, I also had the support and comfort of his parents, four sisters and their families, and several sets of very good friends. Our three daughters are scattered across the country and could not be present on a regular basis. We kept in touch via phone and email and visits whenever possible.



Anne and Don Sterlock
Calaway Gardens, GA

How do you not lose the ability to care for yourself, becoming so involved in caring for another?

At first when my husband was home, I had to do quite a bit for him or to help him. As OT and PT progressed, he was able to do more. I was then able to take some time for myself. I would watch a different TV show by myself in the bedroom. I would walk the dog. I kept my doctor's appointments. I got my hair cut.

As Don improved, I was able to leave him by himself in the house. I always ASKED if it would be okay with him if I went out to wherever I was planning to go. I would give him an approximate time I would return and would call if I was going to be later than expected. My errand time lengthened as he improved. I left things nearby that he might need while I was away. I was not away at medicine time. If my stay away from the house was extensive, I asked someone to stay and visit with him. I would call back to see if everything was still okay. When I was visiting my husband in the hospital or nursing home, I had numerous puzzle books (crossword, Sudoku, etc.) in my case. This gave me something to do NOT related to his care that I could start/stop easily during the day. I continue to carry these paperback puzzle books with me for his therapy and doctor's appointments. Also, when he was in the hospital and rehab, I would "walk the halls" periodically, rather than just sitting for hours. Never far away from his room but just enough to get out some of the cobwebs and kinks in the joints.

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SCALE's Family & Caregiver Education & Support Program

A dynamic and interactive 8-week series providing:

- education about stroke & aphasia community resources
- information about the latest technologies for aphasia
- educational resources (DVDs, websites)
- counseling to promote independence & family adjustment
- strategies to develop coping & caregiving skills
- training about how to support communication with your family member with aphasia
- training about how to support & advocate for your family member with aphasia in every stage of recovery

This program is open to all families, caregivers & friends of people with aphasia, regardless of when the stroke occurred. Membership in other SCALE programs is not required. Our goal is to meet the needs of those who care for individuals with aphasia throughout the ENTIRE rehabilitation continuum. Professional counselors serve as guest speakers throughout the program and speech/language pathologists provide training in techniques to facilitate communication at home and in the community. Peer support and information about aphasia and community resources are also available. The program will be offered on Thursdays from 1:00-3:00 beginning April 28th, 2011 through June 16th, 2011. For more information, please contact Denise McCall, Program Director, at 410.323.1777 or info@scalebaltimore.org

SCALE (the Snyder Center for Aphasia Life Enhancement) is a 501(c)3 organization dedicated to improving the quality of life for people living with aphasia and their families.

Caregivers' fears

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- *FEAR* of making the wrong care decision, leading to an unexpected outcome and the possible wrath of other family members.
- *FEAR* of dealing with a loved one's incontinence. Can I change an adult's diapers? How does he feel when I have to do this?
- *FEAR* of dementia: that your loved one will no longer be able to recognize you.
- *FEAR* of aggression caused by illness: how will you deal with a loved one's violence towards you?
- *FEAR* that your loved one's needs will be sacrificed to those of the system.
- *FEAR* of seeing your own future in a loved one who is deteriorating.

- *FEAR* of losing your "self"—of becoming so involved in caring for another that your identity is lost, your needs remain neglected and unfulfilled.
- *FEAR* of facing the future alone, of losing the comfort of an embrace, the assurance of unconditional love.
- Finally, the tremendous *FEAR* of admitting to emotions you are "not supposed to feel"—frustration, anger, a momentary desire to strike out or to flee.

All caregiver fears are real, for no other reason than they exist. Are they rational? Each of us has to decide this for ourself; we may need help to do this. If you have trouble talking with the person you care for, talk to someone who has been there or talk to a professional.

Communicate how you are feeling; learn how someone has dealt with their fears. It's not wrong to be afraid; it goes with the territory. It is wrong to suffer alone and in silence.

No one can perform the act of caring without help. Remember that we are, after all, only human; caregivers aren't perfect although we can kill ourselves trying to be so.

Please accept support. Remember the joy you bring to those you love and thank yourself every day that you care.

*This article was reprinted with permission from Karen Henderson, Founder/CEO, Long Term Care Planning Network
www.ltcplanningnetwork.com*

Support Group of the Quarter

There are many excellent support groups throughout the state and we focus on one group in each of our newsletters. If you would like to see your group highlighted, contact Judy Crane at jcrane@oneiq.com; we'd love to hear from you!

Talbot County Stroke Support Group

The Talbot County Stroke Support Group began several years ago when Christina Ball got her picture in the paper. She was celebrating the designation of The Memorial Hospital at Easton as a regional stroke center.

Melissa Malcolm saw Christina's picture that day and something clicked. Ever since suffering her own stroke in 2004, she wanted a support group of other survivors. She contacted Christina and they agreed to get together for a preliminary meeting. However, Christina knew of someone else who was interested in a group. Ruth Arnouts also wanted a team to discuss ideas and situations. The three women met and our Support Group was formed.

Our first meeting was in April 2008. We remember one meeting, in the beginning, when only three or four people attended. A lot of time was



spent in those early days, trying to figure ways to increase the attendance.

A monthly newsletter was born in April 2009. Attendance began to rise as the word spread. The average monthly meeting now numbers around 30 people. But we weren't content with resting on our laurels. Interest in a Peer Mentorship Program developed as our group remembered their feelings when they were first diagnosed with a stroke.

After months of research and development, we are now trained to visit patients who are still in the hospital unit after their stroke. Our goal is

to mentor any interested stroke patient who may want to see us. We have a weekly rotation schedule that started in May 2010 and continues every Sunday afternoon.

Our group has volunteer drivers who offer rides to and from meetings. We have pet parents who will visit anyone whose spirits need a lift. A Guest Speaker Committee invites speakers to discuss various health issues each month.

We distribute flyers to medical offices and therapy centers to spread the word about our group. And, we're now affiliated with the Maryland Stroke Alliance.

In short, we're a vibrant community of individuals who have suffered a stroke. We don't allow stroke to identify us; we are learning to accept our new lives and embrace the renewed opportunity that has been given to us.

Stroke Awareness Fair in May

The Stroke Awareness Team at Good Samaritan Hospital is holding a Stroke Fair on Friday, May 20, 11 am-1 pm for stroke survivors and caregivers/friends. The free event celebrates Stroke Awareness Month, and promotes education, prevention, and community resources.

Information booths and activities such as Wii and Tai-

Chi will be available as well as networking opportunities for stroke survivors, and refreshments.

The fair will take place in the Parker Conference Room, located on the first floor of the hospital. Parking is free.

For more information, call Kate Gerber at 443-444-4618 or kate.gerber@medstar.net.

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Maryland launches a new MAP website

On December 1, 2010, Governor Martin O'Malley announced the unveiling of the Maryland Access Point (MAP) website, www.marylandaccesspoint.info, a one-stop resource that gives Marylanders information on long term supports available in Maryland.

"We are proud to offer our Maryland citizens, especially our older adults and persons with disabilities, this powerful MAP website that will give them useful information on long term services and a single point of entry for access to publicly funded programs and benefits," said Governor O'Malley. "The MAP website responds to the urgent need to simplify the way in which older adults, persons with disabilities, and caregivers access information about services."

The MAP website helps individuals assess their needs; explains care options such as in-home care, caregiver resources and community health and social services; provides links to services; and gives information on financial support available.

During the unveiling, Secretary of Disabilities Catherine A. Raggio and Secretary of Aging Gloria Lawlah participated in an interactive presentation of the website. They were joined at the event by more than 125 representatives of the various partners who participated in the development of the MAP website, including the Department of Health and Mental Hygiene, the Maryland Department of Veteran Affairs and the Maryland Department of Human Resources "Access to information about supports and services is vital for people with disabilities of all ages," said Secretary Raggio. "This new website will help people identify resources in every area of the State and empower them to make choices to live and flourish in our communities."

"The passage of the Americans with Disabilities Act (ADA) has changed the expectations of people with needs for long term services in our country and State," said Secretary Lawlah. "We believe the MAP website will enable them to more easily find the supports they need to remain in their own homes and community."

The Maryland Access Point website is part of the National Aging and Disability Resource Center (ADRC) initiative from the U. S. Administration on Aging and Centers for Medicare and Medicaid Services operating in 54 states and territories with the purpose of providing streamlined access to information on long term supports and services. For more information, visit the MAP website at www.marylandaccesspoint.info.

Putting a face on stroke

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YTC members use the *power of constituency*; they understand that lawmakers listen to and want to please the people who voted them INTO office initially ...and have the power to vote them OUT of office in the next election. YTC members use the power of constituency to let their elected officials know the facts about heart disease and stroke and how these conditions affect the lives and the finances of the communities they serve. And they ask their

elected officials to support specific policies or bills that, if passed and signed into law, would improve cardiovascular health and ultimately reduce healthcare costs. As a member of the Maryland Stroke Alliance, you also have the *power of survivorship*. You can "put a face on stroke" by telling your personal story and helping the legislator connect your experience with the action you are asking him to take.

You're the Cure members can influence policy in many ways, including sending

e-mails, writing personal letters, making phone calls, making personal visits either to the legislator's home or Capital (state or federal) office, providing and/ presenting testimony at a public hearing or writing (or signing) a letter to the editor. AHA/ASA provides ongoing support by keeping you updated on the issues and pending legislation. However you choose to communicate, **Become an advocate for advancing the mission of the Maryland Stroke Alliance... TODAY!!**

How-to...

What does it mean to be a happy person when you are a family caregiver?

from the National Family Caregivers Association

These are heady questions, and ones that have been discussed often at the National Family Caregivers Association. We have looked for answers in our own experiences, in books, from professionals, and from other family caregivers. We've thought long and hard about these issues because they are at the core of our search for meaning and our need to have principles to live by as family caregivers.

We call our approach to caregiving, Four Messages to Live By. They are the fundamental tenets of our philosophy. They have helped thousands of caregivers to date and we hope you will use them as guideposts in your own personal search for a sense of direction and inner peace.

How can you find a balance between your own needs and those of your loved ones?

1. Believe in Yourself—and Take Charge of Your Life

Trust your instincts. Let your inner voice guide your decision making for your loved one and yourself. Believing in “You” is the first step toward building confidence, an essential tool in coping with being a family caregiver.

2. Protect Your Health

Taking care of yourself is not a luxury...it's a necessity! If your health is compromised, it's hard for you to be an effective caregiver. Your life is hard enough. For your own sake, and your loved one's, take good care.

3. Reach Out for Help

Family caregiving is not a one-person job. Asking for help is a sign of strength, NOT a sign of weakness. Help comes in various forms, from others

How can you gain a feeling of confidence in your abilities and have a sense of pride in your achievements?

pitching in to having more information about your loved one's condition to sympathetic understanding from your boss.

4. Speak Up for Your Rights

In your daily life, speak up for respect and more support for yourself and your loved one. Speak up for the rights of all family caregivers by talking about the need for education, financial support and better chronic illness care.

About NFCA

The NFCA educates, supports, empowers and speaks up for the more than 65 million Americans who care for loved ones with a chronic illness, disability or the frailties of old age. NFCA reaches across the boundaries of diagnoses, relationships and life stages to help transform family caregivers' lives by removing barriers to health and well being.

10 Tips for Family Caregivers

1. Caregiving is a job and respite is your earned right. Reward yourself with respite breaks often.
2. Watch out for signs of depression; don't delay in getting professional help when you need it.
3. When people offer to help, accept the offer and suggest specific things that they can do.
4. Educate yourself about your loved one's condition and how to communicate effectively with doctors.
5. There's a difference between caring and doing. Be open to technologies and ideas that promote our loved one's independence.
6. Trust your instincts. Most of the time they'll lead you in the right direction.
7. Caregivers often do a lot of lifting, pushing and pulling. Be good to your back.
8. Grieve for your losses, and then allow yourself to dream new dreams.
9. Seek support from other caregivers. There is great strength in knowing you are not alone.
10. Stand up for your rights as a caregiver and as a citizen.

Caregiver's Story

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As a caregiver, where have you found guidance and support, both physical and emotionally?

Before my husband had a stroke, I had an occasion to visit a therapist. Several months post-stroke, I started going back to her. I was able to talk about my concerns, and feeling of anxiety and shortcomings. One of the best things she told me, when I recalled my daily activities, was that things didn't HAVE to be done. I also talked extensively with our new primary care physician. He was able to give me a low-dose daily anti-anxiety pill. This has helped me remain calmer with the extra demands on my time. I also kept in touch by phone with several really good girlfriends. They listened while I talked. The fact that Don's four sisters and husbands visited also gave me support that we were not alone.

What advice would you give someone who has recently become a caregiver?

- Even though your life has been turned upside down, keep some semblance of normalcy. Just coming home from the hospital or nursing home and walking our dog helped my stress at the end of the day.
- Because visiting hours are usually not early in the day, sleep in if you can or just stay in bed a little bit longer to rest. Not every day, of course, but once in awhile. Other mornings can be for errands

or at-home needs.

- Be sure to eat several times a day. Don't skip meals. Go to the hospital cafeteria just to get a break from the medical "stuff." Eat your main meal at the middle of the day. This makes coming home easier if you don't have to fix a big meal. Have some type of packaged bar/snack with you at all times—you never know when you will need it.
- Always have OTC meds such as Tylenol with you for aches, pains, or headaches that occur.
- Use email to notify several people at the same time of updates so all get the same information. Special people can be notified by phone but use a type of phone-tree to cut down on YOUR calls.
- Even though it takes time initially, take notes of the daily happenings, doctor's information, etc. This "journal" comes in very handy later during doctor's appointments or insurance discussions.
- Be an advocate for your spouse, especially if he/she is unable to communicate. Make sure you AND your spouse understand what is happening.
- Keep as positive an attitude as possible about your loved one's recovery. Realize that there is no timetable following a stroke. Each person's case is different. See any amount of change as growth. Your loved one will not be the same person as before the stroke but will reach what one doctor

called the "new normal."

- Have someone help you with many of the new activities in which you will become involved: doctor's appointments, getting and giving meds, handling new procedures. I had to deal with my husband's catheter, administer antibiotic via a pic line, and give Lovinox shots in his belly. Ask for help, either to be there with you or handle some of them for you.
- Keep all of the papers from doctors, hospitals, rehab, insurance together. Organize by topic and date.
- Be patient and help your loved one to not expect too much too soon.
- When your loved one is in therapy, encourage him/her to do the activities as much as possible.
- Last, but not the least of my advice, is to laugh as much as possible. Laugh together, even at the silliest of things.

What is your husband involved in? Does he have interest/hobbies?

Don liked photography before his stroke and this is one activity that has carried over. He even ASKED for a digital camera for his birthday last year. His ability to read has returned and he is able to read library books. His newest interest is jigsaw puzzles—his father has always done them. He now gets them (larger piece puzzles) from his dad and we work on them together.

Don enjoys going out to eat and spending time with

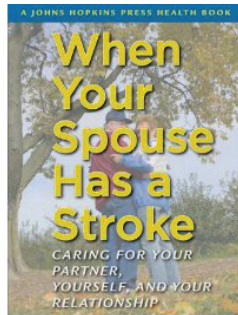
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When your spouse has a stroke

Sean Mackey

A stroke can forever alter the life of not just one person but two in an instant. For the person who has had a stroke, simple tasks suddenly become difficult or impossible. For that person's partner, life seems to revolve mostly around the stroke survivor's needs. Such a drastic change naturally requires making a series of sometimes taxing adjustments. In this book, two experts in stroke recovery help couples deal with the impact of stroke on their lives and relationship.

Sara Palmer, Ph.D., is a psychologist and assistant professor in the Department of Physical Medicine and Rehabilitation at the Johns Hopkins University.



Jeffrey B. Palmer, M.D., is a professor and Director of Physical Medicine and Rehabilitation at Johns Hopkins University. Drs. Sara and Jeffrey Palmer explain how to successfully confront three major challenges after your spouse or partner has a stroke: providing quality care for your partner; maintaining or rebuilding your relationship; caring for yourself as an individual.

I met Sara at the Towson Stroke Group in 2006. She interviewed my wife and me together and separately in our home, and she left two surveys. One was for the survivor and the other for the spouse/caregiver. Both surveys were

confidential and were very personal. Many couples won't discuss sex, loneliness, burden and money themselves, but Sara did it seriously and sensitively.

Through the experiences of the couples interviewed in the book, readers will learn strategies for improving essential aspects of their relationship, including communication, accepting roles and responsibilities, and sexuality. A list of practical tips summarizes the main points of each chapter, providing a handy reference for dealing with each day's challenges.

This book focuses on the psychological and social consequences of stroke and the deeply personal side of caregiving. *When Your Spouse Has a Stroke* will relieve some of the couples' burdens and help reinforce a healthy partnership.

Caregiver's Story

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has been able to expand his activities by attending SCALE (Snyder Center for Aphasia Life Enhancement). This innovative approach to speech therapy involves interactive classes for SCALE members, based on their interests. Don has especially enjoyed classes in Travel, Photo Talk, Cards & Games, and a new interest in Yoga. By being with others who have aphasia, his confidence to communicate in whatever way he can has increased.

How long did it take before you started facing your fears about your new life with a stroke survivor? What are those particular fears you are dealing with?

My husband's stroke was completely unexpected. In the back of my mind, I fear that he will have another one, even though he is currently getting a good deal of close medical follow-up. It was only when I had to answer this question that I actually expressed my fear to my husband. My other major fear deals with my caregiving

skills. Our three daughters live out-of-state (DE, MA, and OR). Once they went back home after the first weekend, I had to be their eyes, ears, and voice. I needed to ask the questions THEY had and relay the answers back to them. I was taking care of their father and I had the sole responsibility of that. It was very stressful to question if I were doing an adequate job and conveying the information back to them correctly.