



ALS Support Group of NW WI

**A Gathering of Individuals Touched by ALS
Share Joy, Sorrow, Laughter, Tears, and Hope.**

**Receiving a diagnosis of ALS is challenging and can be very overwhelming.
The ALS support group provides a safe place where patients, families, friends, and caregivers
Gather to share information, support, and resources with others who understand.**

*Second Thursday of each month, 1:00pm – 3:00pm At Chippewa Valley
Bible Church in Chippewa Falls*

November 14, 2014 Support Group Meeting Notes:

In honor of caregivers this month we viewed three short videos – focusing on caregivers, gratitude & humor. Thank God for good caregivers. Some attendees had attended the Smokey Express & Community Choir Christmas Show in Amherst, WI. This talented extended family after 22 Christmas shows have given away \$166,000! This family donates to several causes & our local ALS Support Group right here in the Chippewa Valley has been fortunate to be a faithful recipient for years. The dinner & show were excellent & family friendly & fun. Think about going next November. If interested call Janet Glodowski at 715 824 2525. They also have a summer fun event to raise funds for great causes.

Our December meeting will have two lovely ladies demonstrating with their food processors some foods & drinks to sample. We have an interest in our group right now on eating & swallowing & not choking for people who are experiencing difficulty in this area & require soft foods.

By Barbara Bronson Gray, RN, MN



Nancy Sterling with
her caregiver, Rachel
Volavola.

Nancy Sterling was living a busy life – she was a competitive swimmer, physical therapist and quartet singer -- when she noticed a slight foot drop and weakness in her left foot. Nancy suspected she had ALS and was diagnosed with the disease about a year later in 2007.

After working for 30 years as a physical therapist, Nancy, 58, now types with her eyes and drives her wheelchair with her head, the only part of her body she can move. She cannot speak.

Nancy, who lost her husband unexpectedly two years ago, lives in Salisbury, Md., between the Atlantic Ocean and the Chesapeake Bay.

She understands caregiving from two different perspectives now. Before she developed ALS, she helped start Interfaith Volunteer Caregivers in two Maryland counties. There, the art of caregiving and receiving was simply explained: for anyone to be blessed by giving, someone must bless the giver by receiving. “Most of us have enjoyed the good feelings that come from being able to help another person,” she said. “Imagine if that person had refused your help?”

Care receivers have an opportunity to gratefully accept help and let others experience the same good feelings they may have felt when they were able to give of themselves to others, Nancy noted. “I remember when I was a teenager I used to help to exercise a neighbor who had ALS, and she always made me feel better for having helped her.”

Now Nancy relies on two caregivers who together are with her around the clock. The transition from independence to dependence was challenging for her. “It was hard for me to admit that I needed help. I didn’t want to need help!” she said. She resisted receiving assistance until the point when she couldn’t get her legs into bed and was unable to fix her own food. “It was either accept help or starve,” she explained.

Caregiving is Extremely Challenging

Nancy understands that caregiving can be extremely difficult. She said caregivers often feel exhausted; overwhelmed by the changes that ALS progression brings; challenged by having to deal with equipment that often signals alarms and requires adjustments; worried about their own health; and deeply concerned about the future, and whether they will have the financial ability to pay for the care and resources that may be needed.

People with ALS can do a lot to support their caregivers, whether they are family members or are paid to provide assistance, Nancy said. “Allow friends to be with you so your caregiver can get away for lunch with a friend, do shopping, or just to stay home

and take a nap. A simple ‘please’ and ‘thank you’ goes a long way. I need help for everything, so my requests come often and can get tedious for my caregiver.”

She also encourages others with ALS to recognize that while a lot of things are out of their control, they can take charge of their attitude. “ALS comes with many losses and much frustration, but none of that is the caregiver's fault. Avoid taking those frustrations out on those closest to you,” she suggests.



Nancy also advises others to make sure their caregivers get the support, information and respite they need. Participating in support groups helps both the caregiver and the person with ALS know they are not alone in the challenges they face, she said.

Both the person with ALS and the caregiver need to help maintain their relationship by doing things they enjoy together. “Watching a movie can help you maintain your sense of humor and keep your relationship intact,” said Nancy. She noted that it’s also important to have open discussion about how to meet new challenges together, take time to go to religious services, and be sure to hash out any disagreements as soon as possible.

Nancy also suggests that people with ALS make it a point to talk about their advance directives and other legal matters so their caregivers know what they want. “There is real comfort and peace in having everything taken care of.”

Learning to Accept Help outside the Family

Some people find it especially difficult to adjust to a caregiver outside the family, Nancy said. “Sometimes we are not confident that someone other than our regular caregiver will know what to do, and sometimes the caregiver has the same concern. I find that people want to help, they just don't know our needs.”

Nancy recommends making a list of the people who say, "Call if there is anything I can do," and another list of things you need people to do. For example, you may benefit from having someone bring dinner, shop for groceries, visit with you while your caregiver takes a nap or goes out for a while, mow the grass, water house plants – and much more, she said.

Nancy has friends who come on regular days. “The Friday friend takes care of my African Violets, the Sunday friend refills the bird feeders, the Wednesday friend takes care of my aquarium after she stretches me out to help make me limber, and the Tuesday friend takes care of the outdoor flowers,” she explained.

Nancy also gratefully accepts the help of local high school students and scouts who are required to perform community service. “A friend's son gets his service hours cutting my grass, and the scouts rake leaves in the yard.”

The bottom line? Caregivers need caregiving too, said Nancy. “Just as you create a plan

to get your own critical needs met, put some thought into ensuring the energy and happiness of the people who care for you.”

Travel Tips: Speeding through the Long Lines

By Barbara Bronson Gray, RN, MN

With the holidays approaching, the prospect of crowded airports and long delays can be daunting for anyone. But for people with ALS and their caregivers, the challenges can be particularly stressful and exhausting.

Experts say there are some good ways to avoid long waits when you're traveling. Here are some tips:

- **Send your luggage straight to your destination.** No more lugging your belongings, packages, or any equipment that you won't need during your journey. Consider using the U.S. Postal Service. A Priority Mail large flat rate box costs \$16.85, up to 70 pounds. United Parcel Service (UPS) and FedEx also offer attractive rates, especially if you don't need the package to arrive the next day.

- **Use PreCheck security.** Available at 92 U.S. airports, PreCheck allows U.S. citizens who have been “pre-cleared” to go through the security screening process more quickly. TSA PreCheck allows participants to keep their shoes, belts and lightweight jackets on. It also allows those pre-cleared to go through just a metal detector, rather than a body-scanner. Expect the program to be available in 350 airports by mid-2014. Apply for PreCheck online, and then verify your identity and get fingerprinted at a TSA PreCheck enrollment center. The application costs \$85 and is good for five years. Learn more at tsa.gov/tsa-precheck.



- **If you're flying out of the country, consider using a government program called “Global Entry.”** It's a U.S. Customs and Border Protection program that allows expedited clearance for pre-approved, low-risk travelers upon arrival in the United States. There are self-service kiosks at more than 40 airports. Once in the program, your passport and fingerprints can be scanned, and you can sail through immigration and customs. To join the program, you need a background check and an in-person interview. The fee is \$100, and the membership is good for five years. Learn more at <http://globalentry.gov/>.



- **Check into your hotel more quickly.** Some hotels allow you to check in at lobby kiosks by just swiping your credit card. All you have to do is approve the reservation, and the kiosk gives you your receipt, room assignment and keys. Some hotels have expedited check-in using your mobile phone, and others even allow you to check in at airport kiosks, allowing you to skip the hotel lobby experience entirely. Ask about such features when you're making your hotel reservation or check with your travel agent.

Learning to Put Worry Aside

By Barbara Bronson Gray, RN, MN

We all worry from time to time. It's easy to find yourself focused on all the many "what ifs" in life. But worrying can be exhausting, self-defeating, discouraging and depressing.

What is worry? It's allowing your mind to dwell on difficulty or troubles, creating anxiety or unease.

Martin Rossman, author of *The Worry Solution*, explained that learning to stop worrying won't remove tragedy or hardship from our lives. "But it can eliminate a great deal of tragedy and hardship that never actually happens," he noted. The key is to separate things into those you can do something about from those you can't and learn how to deal better with both, he added.

"It doesn't mean life is easy, but it can help us avoid making life harder than it needs to be," Rossman said. Rossman and other experts say there are several things we can do to minimize the time and energy we put into worrying, freeing ourselves for happier and more productive pursuits:

- **Accept uncertainty.** Worrying sometimes occurs when we are frustrated with the uncertainty of a situation. We automatically fill in the gap with worst case scenarios. Remind yourself that uncertainty is really neutral. The situation could turn out all sorts of ways. And to embrace uncertainty, you have to accept your own limitations. Try to release your natural desire to be in control of things



- **Note what issues are troubling you the most.** Write them down. Address each one logically. For example, if you're worried about a health issue, can you phone your physician? Do you need more information to make a decision? Write down the action you are going to take and follow through for each worry listed.

- **Enlist the help of your family and friends in your "anti-worrying" campaign.** Tell them you're trying to quit the annoying habit of worrying and ask them to help you regularly turn your attention away from the infinite realm of possibilities to the here-and-now. They, too, may realize that they need to tackle their own tendency to worry if they are to effectively support you.

- **Catch yourself in the act of worrying.** At first you'll probably notice you're worrying about quite a wide range of things, from issues related to ALS to economic

problems to all sorts of other things. You may not have realized that worrying has become a habit and an attitude. Evaluate whether your tendency to worry may be lowering your spirits and exhausting you.

- **Don't allow yourself to focus on issues that might not materialize.** Remind yourself that if and when something becomes a problem, then you'll create a plan of action.
- **Actively deflect worries.** Identify your most pressing issues and create an "action plan" for each. Think "I've addressed that" or "I have a plan for that." Don't dwell on the concern. Turn your attention to something else interesting or compelling.
- **Understand that learning to give up worrying may take some time.** Like any habit, it will most likely take a while to overcome. Remind yourself that if you can't plan action for dealing with something, you're going to have to let the thought go.
- **Focus on the moment.** Practice dealing with each day as it happens, enjoying all you can and appreciating the simple pleasures.

Take Good Care
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