

ALS Support Bulletin

Advising, Learning & Sharing

Diagnosed, now what?

By Ted Harada

If you are reading this newsletter, then I assume that you or a loved one are in the same situation as me. You have been diagnosed with ALS, aka Lou Gehrig's disease. I received my preliminary diagnosis in May 2010 and my final diagnosis which was my second opinion from Dr. Glass in August 2010. I heard those three letters that no one wants or deserves to hear associated with their name—ALS. I remember sitting with Dr. Glass, Nicole and other members of the wonderful Emory staff along with my wife and best friend, Michelle. It all seemed so surreal. After examining me and then leaving with his staff, Dr. Glass and Nicole, returned and confirmed what I did not want to hear, but by that point knew was inevitable. I will never forget what Dr. Glass said, "I unfortunately have to confirm your diagnosis, I'm sorry, you did not do anything to cause this, it's not fair and I'm sorry I do not have a cure yet." Everyone from Emory and the ALS association were so warm and comforting and then I went home.

So now you have a diagnosis, what do you do, how do you react? There is no book on the right or wrong way to deal with a terminal diagnosis. I imagine everyone copes differently. Certainly crying is healthy and therapeutic. My wife and I did that together. The next day, I realized the sun still rose and so did I. I also knew I had a choice. I could sit in a corner and suffer in self pity and stop living life, of course then the disease would have already won; or I could love and live my life! I chose the latter and it has been the best choice I ever made. I would never wish this diagnosis on anyone and pray every day that they find a cure, but none of us are promised tomorrow. All of a sudden, I had a new appreciation for life, family friends,

love, and hugs. It seemed much more important to me. The little things I had taken for granted, I now value. I realized that when I tell my kids I am too busy to play, I may not have a chance to play with them in the future, so make time and do it now! I now tell my friends regularly that I love them and I have learned to embrace hugs because they are emotional boosts! I decided that if you are my friend, I am going to hug you and tell you how much you mean to me.

So I think, "Why did I have to be diagnosed with ALS before I learned how to do this?"

There is one other important lesson I learned. You see I was always the "fixer". I never asked for, needed or wanted help. I had pride in being independent, was proud that besides my wife and kids I did not need anything from anyone. Well, I learned that not only was I not alone, but all of a sudden, it was ok to ask for and accept help from others! There is no shame in it. When you surround yourself with people you love and care about and who feel the same way about you. They want to help. Accept the help. It is okay,

"I also knew I had a choice, I could sit in a corner and suffer in self pity and stop living life, or I could love and live my life. I chose the latter ."

they want to help and they are enriching and getting joy in their lives by being there for you, someone they truly care about. It is a lesson that I am proud and lucky to have learned!

So for me, I certainly wish ALS did not exist, let alone be diagnosed with it, but I also realized that I had life yet to live. I did not just owe it to myself, but to my family, friends and loved ones to live my life to its fullest everyday! Ultimately, the unfortunate fact is that ALS will most likely win in my battle against it, but I am not going to let it win prematurely. I have a lot of life left to live and I am going to do that one day at a time, surrounded by people I love and care about. I hope you do the same!

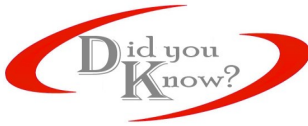
Ted, 39 years old, is married to his best friend Michelle for almost 17 years and they have three children, Ted (13), Jordan (11) and Ashleigh (7). They are active members of St. James Catholic Church, McDonough and Ted also serves on the Board of Directors for the Georgia ALS Association.

SUPPORT GROUPS

Athens Oconee Veterans Park, 3500A Hog Mountain Rd, Watkinsville, GA 30677	Alpharetta Mount Pisgah UMC, South Campus, 9820 Nesbit Ferry Rd, Room A006, Alpharetta, GA 30022	Fayetteville Senior Services Senior Center 4 Center Drive, Fayetteville, GA 30214	New Patient ALS Association of GA 1955 Cliff Valley Way, #116, Atlanta, GA 30329
Macon Central Georgia Rehab 3351 Northside Drive, Macon, GA 31210	Marietta First United Methodist Church. 56 Whitlock Avenue, Marietta, GA 30064	Norcross Norcross First United Methodist Church. 2500 Beaver Run Road, Norcross, GA 30071	FOR ADDITIONAL INFORMATION ABOUT THE SUPPORT GROUPS INCLUDING DATES AND TIME OF MEETINGS, PLEASE CONTACT THE ALS ASSOCIATION OF GA at 404-636-9909 OR VISIT THE WEBSITE www.alsaga.org
Columbus My Party Place. 1019 Broadway, Columbus, GA 31901	Cleveland The Bridge Church. 976 Kytile Street, Cleveland, GA 30528	Rome Rome First Methodist Church. 202 East 3 rd Avenue, Rome, GA 30161	

**Information and Treatment
Links**

www.als-mds.org
www.als-link.org
www.neurology.emory.edu/ALS
www.clinicaltrials.gov
www.alscenter.org



... that a piece of 2X4 or 4X4 can be put under a favorite chair to aid in getting up? This can also be used under a couch or bed.

.... that you can use sheets of sticky rubber to open bottles or jars.

Respiration - How to deal with the upcoming cold months

By Rob Kelley

With the winter months and cold and flu season ahead of us, here are some very important tips to help prevent some of the issues that could make us sick.

This sounds simple, but hand washing is definitely one of the most valuable tools during this season. Caregivers must always wash their hands and keep them clean and free of germs before assisting loved ones and patients.

Wear your BiPap regularly to help rest the crucial organs in your body. This will certainly make you stronger and better able to resist those nasty bugs going around.

How about the favorite machine in our arsenal of

machines? Everyone's friend (I hope) - the Cough Assist! If used correctly, this could be one of the best tools to help PREVENT the ever dreaded pneumonia.

Perform the full treatment at least two if not three times per day. By doing these treatments, you are moving the mucous around that is down in your lungs. This is key to avoiding infection. Even if you do not feel like performing the cough cycle, you may use the Cough Assist machine to exercise your lungs. Keep your lungs good and open by taking in big deep breaths.

Keeping your equipment clean is crucial during this

season. As you crank up your heat to stay warm, know that heat and moisture make a perfect breeding ground for bacteria. Clean it regularly to keep it free of bacteria.

Please practice these simple tips to avoid catching infections during the cold months. Remember, if you having difficulty with your BiPap or Cough Assist, do not hesitate to call your Health Care company and ask for help. Have your respiratory therapist go over the process again. Practice certainly makes perfect. Do not leave your equipment unused and collecting dust.

Rob is with Home Medical Professionals, a company that specializes in providing the very best of patient care and medical equipment for the home.

Air Travel During the Holidays

As we quickly approach the holiday season, and air travel is likely for many families, here are some good tips to help you carefully plan your journeys.

- Always travel with your living will, for emergencies.
- Take the phone number of your ALS clinic doctor.
- Choose flights that use jet ways to avoid steps to the airplane. If there won't be a jet way, ensure there will be a forklift with a platform and a forklift operator to raise you in your chair up to the plane door.
- Arrange for an aisle seat near the front. If you can't get a seat toward the front, airline employees are trained to take passengers down the aisle in a straight back wheelchair or aisle chair.
- Never take your power chair when traveling by air, to avoid damaging it. Check your manual wheelchair at the gate instead of curbside or sending it through with the luggage. It will be brought right to the front of the plane when it's time to exit the aircraft.
- Allow at least an hour between connecting flights for gate changes.

Wheelchair users are the last passengers off the plane.

- Call ahead to the rental car company to make sure the shuttle is wheelchair accessible.
- Always reserve your hotel room in advance. Specify your exact requirements. Bathrooms have to be large enough and have a raised toilet seat and grab bars. You may also specify that you want a roll-in shower. Before leaving home, double-check that your needs will be met.
- Carry travel insurance at all times.
- Organization is key. Make a supply list for all equipment needed for your care. Remember to include everything from portable lifts to eye-tracking communication devices.
- Most importantly, don't put it off. Travel where you want to go when you can. Go to the distant places before your needs increase.

Equipment Educator

The **Transfer Board** is used with a transfer or gait belt to move patients from a bed or chair into the wheelchair.

- Position the wheelchair and lock it parallel to or at a slight angle to the bed. Patient should lean slightly and the sliding board should be placed well under the buttocks, with the other end of the board over the wheelchair seat.
- Grasp the belt at the back and perform the transfer by a series of leaning and sliding movements until the patient is moved down the board into the chair. Once on the chair, remove the board and release the patient when sitting in a good position.

Ask your doctor if a Home Health Physical Therapist visit can be ordered to teach safe and proper transfer techniques.



The **ALS Support Bulletin** is a quarterly publication from HisGrip Home Care in close collaboration with professionals, patients and caregivers of Amyotrophic lateral sclerosis (ALS, Lou Gehrig's disease) to **Advise, Learn and Share** information to patients and caregivers of the disease. To request copies of this publication or to be added to the distribution list, please contact the Editor, Nike Aremu at nike.aremu@hisgriphomecare.com.

Portions of this publication have been adapted from the MDA-ALS website. <http://www.alsaga.org>