

ALS Support Bulletin

Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,
FAMILIES AND CAREGIVERS

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www.alsa.org
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[www.georgiahealth.edu/
neurology/specialties/
neuromusc](http://www.georgiahealth.edu/neurology/specialties/neuromusc)

Join Our List

ALS Upcoming Events

November 14th 2013

Chelsey Park Health and
Rehabilitation Fundraiser

Time: 6:00 pm-8:00pm.

Location: Vino Venue
4478 Chamblee
Dunwoody Rd.
Atlanta, GA 30338

Got Feedback?

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Did you find the information
in this newsletter helpful?

Issue: # 10

November 2013

Welcome to the November 2013 issue of the ALS Support Bulletin. This 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. The goal is to Advise, Learn and Share information with patients and caregivers of the disease.

Karen Kelly - FREEDOM!

By Karen Duffy

I met Karen Kelly early in 2007; we had been communicating via email for a few months and finally got together for lunch at Atlanta Country Club. It was instant friendship and our lunch lasted nearly three hours. Karen found me through the War on ALS; I was the person who received all of the emails from people interested in supporting Team Blazeman, a team of multisport athletes competing for the purpose of raising awareness and funding for ALS. Team Blazeman was founded by Jon Blais, who was the only person with ALS to complete an Ironman triathlon. Jon's story, shared in the 2005 NBC broadcast of the Ironman World Championship from Kona, touched the hearts of hundreds of people; my friendship with Karen was one of many formed because of Jon Blais.

During our long lunch, Karen told me her mother and grandfather had died from ALS and she was on a mission to qualify for the Ironman World Championship and use that race as a platform for ALS awareness; she also said she was determined to raise \$50,000 for research. She was 57 years old and had just started competing in triathlon. A few months later, Karen did earn her slot at Ironman Brazil.

From May to October Karen trained for the big race, became actively involved in the Blazeman Foundation for ALS and met her goal of raising \$50,000. Our friendship grew during these months - we worked closely as members of the Board of Directors for the Blazeman Foundation and Karen was the board President. At the Ironman World Championship in October 2007, Karen wore bib #179, the number Jon Blais wore in 2005 and competed with guts and determination - she did it as a personal goal, but more for the memory of her mother, grandfather, Jon Blais, and the cause of ALS Awareness.

Are there specific topics that you are interested in?
Would you like to contribute to an upcoming issue?
The Editorial Team wants to hear from you. Click [here](#) to contact us.

Resource Group Meetings

Athens - Oconee Veterans Park. 3500A Hog Mountain Rd, Watkinsville, GA 30677

Fayetteville - Senior Services Center. 4 Center Drive, Fayetteville, GA 30214

Marietta - First United Methodist Church. 56 Whitlock Avenue, Marietta, GA 30064

New Patient - ALS Association of GA. 1955 Cliff Valley Way, #116, Atlanta, GA 30329

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.

Karen and I continued to be passionate participants in fundraising and awareness for ALS, and lifelong friends. She would eventually move from Atlanta to Kona, the place that brought her the most joy and peace in life. On May 3, 2012 Karen posted this on Facebook, "My first day as an official resident of Hawaii. Dreams do come true!"

Two months later I got a text from Karen that read, "Hi KD. I've had very ALS-like symptoms for quite awhile. Not sure if I'm just tired and working too much or..." I called immediately and during our conversation encouraged her to find a neurologist. August 7, 2012 was the day that Karen Kelly was diagnosed with ALS. Family and friends rallied around Karen with phone calls, visits, encouraging words on Facebook, and several of us created special fundraising campaigns in her honor. Our goal was to support our dear friend, keep her spirits up and raise money for research.

One friend who instantly went into action was April Hartsook. April had met Karen in 2007 on the race course at Ironman Brazil. As April encouraged Karen to keep moving, Karen shared why she was there - that she had to earn a slot to Kona to tell her ALS story. April completely understood as she had lost her mentor and friend to ALS. She also knew of and was inspired by Jon Blais. The chance meeting in the middle of an Ironman race evolved into a strong bond of friendship.

Karen Kelly died on September 13, 2013. Those of us lucky enough to call her our friend were crushed; we thought we had more time. Karen's influence and "never give up" mantra will be with all of us forever. She faced ALS with a positive attitude, determined spirit, and peaceful resolve.

On October 12, 2013, athletes from all over the world gathered in Kona for the 2013 Ironman World Championship. Also present that weekend was Karen's family and April Hartsook. They met to scatter Karen's ashes at the bay at Kailua; she will rest forever in her favorite spot. April has been fundraising all year in Karen's honor; now in her memory.

I invite you to read her story and make a donation if you are able [here](#).



Communication Strategies for pALS

By Kathleen H. Kaminski, MA, CCC-SLP

Communication is defined as an exchange of information and a means for connection between people and places. For people with ALS (pALS), the timing, rate of change, or severity of a communication impairment cannot be predicted and typically vary by type. pALS with bulbar-onset ALS face early communication changes because their speech and swallowing muscles are affected first. pALS with respiratory-onset may see a decrease in their volume as well as in the length of the phrases that are produced with one breath. pALS with limb-onset may or may not see communication changes during their journey with the disease.

No matter the type or time of onset, communication changes frequently lead to frustration for pALS and their communication partners. Assessment of speech and language skills (modes of communication currently being used and their effectiveness) and identifying communication needs (with whom, where, about what, and by what means), by a Speech-Language Pathologist (SLP), helps determine which communication strategies or tools may increase communication effectiveness. These may include "no-tech", "low-tech", and/or "high-tech."

No-tech strategies include direct eye contact, gestures, facial expressions, and verbal communication. Modification of one's environment may increase opportunities for energy conservation and thus, effective communication. Eliminating external distractions (TV volume or radio on in the car) to reduce the need for pALS to compete with background noise when speaking is one example. Using direct eye contact allows for communication partners to read nonverbal communication as well as hear the speech being produced. Avoiding communication between family members while in different rooms within the home is also a good habit to keep. Additionally, schedule modification may also assist in allowing pALS to communicate at their "best" when they have the most energy during the day. For example, if pALS have the most energy in the morning (and therefore their speech may be easier to produce and for others to understand), consider conducting phone calls, scheduling appointments, and sharing visits with friends and family during those hours. Instead of celebrating a birthday with an evening gathering of family, reschedule the celebration for earlier in the day!

Low-tech strategies or tools, to supplement spoken language, may also reduce the likelihood of frustration during interactions. Using pen and paper is a quick solution for literate pALS who have functional hand movement and have literate communication partners. Additionally, pre-printed phrases written within a notebook may also facilitate communication with unfamiliar listeners, especially for typical events such as ordering your favorite cup of coffee. Communication boards (alphabet or phrase/word based) can also supplement spoken language that may be difficult for others to understand.

High-tech strategies such as speech generating devices may be used when no-tech and low-tech strategies do not meet the communication needs of pALS. Selecting the device that will meet a pALS needs is best conducted during evaluation with an SLP who has experience in assistive technology and augmentative communication.

Frequently, using a multi-modality approach within various environments yields the greatest opportunity for effective communication. Discussing communication challenges and goals with an SLP is highly recommended to help assess effectiveness of strategies currently used and trialing new strategies.

Kathleen is a Speech-Language Pathologist at the Atlanta VA Medical Center. The views in this article do not reflect the views of the Department of Veterans Affairs.

What's On Your Mind?

By Nicole Yarab

Question: What are some good suggestions on how to keep my weight up?



Answer: When someone is living with ALS, it is essential to maintain adequate nutrition. People living with ALS typically require more calories just to maintain their weight. When respiratory muscles become weaker, the work of breathing uses a lot of energy (calories). When limbs become weaker, it takes more effort and energy to complete activities of daily living. Changes in swallowing can occur and consuming enough calories to maintain

your weight can become a challenge. Additionally, some people have special dietary needs (e.g. - gluten-free, diabetic, etc.) or food and lifestyle preferences (e.g. - organic, vegetarian, etc.). Therefore, it is important to consult with your ALS neurologist and registered dietician so they can assess your specific dietary needs. These professionals are best able to partner with you to create an individualized plan for maintaining weight and good nutrition.

Here are some general tips that you might find helpful for consideration and discussion with your health care provider:

- Weigh yourself weekly. If you are losing weight, even a few pounds, consult your physician and registered dietician. They may recommend that you increase your caloric intake.
- If you find it difficult to maintain your weight and to consume enough calories, you may consider eating smaller, more frequent meals.
- When engaging in more vigorous activities, even more calories are required to maintain your weight.

- A simple way to increase calories is to make a milkshake or drink instant breakfast mix or liquid nutrition supplements like Ensure Plus or Boost Plus (or store-brand equivalents). You can even add ice cream for additional calories.
- You can increase your caloric intake by:
 - Add powdered milk or egg whites to your food
 - Add oil, butter or other healthy fats like nut butters or avocado
 - Add condiments, gravies, syrups

These are general tips for increasing calories and maintaining weight. This is not a substitute for medical advice and each individual should consult with their personal physician.

You may also find valuable information in The ALS Association brochure entitled "Maintaining Good Nutrition":

<http://web.alsa.org/site/DocServer/nutrition.pdf?docID=67921>

Nicole Yarab, RN, is Manager, Certified Center Programs, The ALS Association National Office. She previously served in several nursing capacities at Emory University, including Nurse Director of the Emory ALS Clinic.