

ALS Support Bulletin

Advising, Learning & Sharing

A PUBLICATION FOR ALS PATIENTS,
FAMILIES AND CAREGIVERS

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Information and Treatment links

www.alsa.org

www.alscenter.org

www.als.emory.edu

www.als.mda.org

www.clinicaltrials.gov

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

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ALS Upcoming Events

March 23 to Aug 28

A Hike of Hope on the
Appalachian Trail
Georgia to Maine

www.donsbrother.com

September 9

Terance Mathis Celebrity
Golf Outing for ALS.
Alpharetta Athletic Club

www.cureforals.com

September 21

Walk to Defeat ALS

Issue: # 8

June 2013

Welcome to the June 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.

A Hike of Hope on the Appalachian Trail

By Karen Duffy

There are times when the worst circumstances bring out the best in people. An ALS diagnosis not only impacts the person but also the entire family. I have seen relationships mended, bonds strengthened, and amazing actions from people who will take leaps of faith to honor and support a pALS whom they love. Mike Stephens is one of those people.

Mike's brother, Don loved the woods, fishing, baseball, and the Andy Griffith show. He enjoyed all of those throughout his life, even during his short time living with ALS. Don was diagnosed in May, 2011 and died in August, 2012.



Mike and Don

I received this note from Mike last fall: "While my brother was still alive, I discussed with him my desire to do something substantial in his memory regarding raising funds for ALS research. I am currently in the planning phase of preparing for a thru hike of the Appalachian Trail,

which I hope to begin on March 23, 2013. Since 2002, I have hiked over 1000 miles of the approximately 2180 mile trail in sections. For years I have thought about trying a through hike, a continuous hike of the entire trail from Springer Mountain in north Georgia to Mt. Katahdin in Maine. Every year between two and three thousand hikers begin the trek in late winter or early spring. Fewer than 25 percent reach their goal. I am

GA World Congress
Centre

www.alsaga.org

October 5, 2013
4th Annual ALS Run for
Jeremy 5k, Hamilton GA

www.runforjeremy.com

October 26
3rd Annual Skydive for
ALS Guardian Angels

Thomaston GA

Click [here](#) for more
information



Did you find the
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newsletter helpful?

Are there any 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

determined to be one of those who make it."

I met Mike last November and was impressed at how detailed his plans already were for a quest that wasn't to begin for another four months. He was very specific about what his plans were, how he wanted to share, not only his journey on the trail but share Don's life story and raise awareness and funds for ALS research in the process. People doing long hikes either give themselves a trail name or are given one by someone else. Long before Mike Stephens set foot on the Appalachian Trail he knew what his trail name was - Don's Brother.

Don's Brother did begin his journey on March 23, 2013. He has chronicled every day, sharing stories and amazing photos, on his website: www.donsbrother.com. He has had ups and downs, physically and emotionally - enduring rain, cold, and an injury, but also sunshine, warmth, and fellowship with other hikers. I have already told him that he has the makings of a great book - but that's a project for the future. The goal now is to get to the finish line in Maine.

On June 4, 2013, Don's Brother crossed the bridge over the Shenandoah River to what many consider the half-way point. He'd hiked 1,016 miles. From his journal entry of the day he shares, "I must admit that I got a little emotional thinking about my brother as I crossed the Shenandoah River and realized that I was at what many consider the (first) half way point. I could just see Don standing by the river, fishing rod in hand. There will be other rivers and ponds and lakes along the way. I know he'll like them all as we start the second half of the adventure on the Appalachian Trail."

Mike has told Don's story countless times on the trail and has met many others who have been affected by ALS, as well as some pALS who are doing section hikes. He asks everyone he meets to visit his website and consider making a donation. All funds collected will benefit ALS research, either via the ALS Association's global research or to the ALS research laboratory at the Emory ALS Center. Donors can choose the direction of their gift from the donation page on his website.

Don's Brother is an example of inspiration, perseverance, determination, and boundless love. I hope you will take the time to visit his website, read through the journal entries, and share it with others. Make sure to take the time to also visit each of the pages, listed at the top of the homepage. I won't be surprised if you sign up to get the daily posts, as I have done, so you can follow Don's Brother on his Hike of Hope along the Appalachian Trail.

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.



Mike on the Trail

iPad and ALS: A good relationship or not?

By Nike Aremu

The iPad has been hailed lately as an augmentative, alternative communication (AAC) device since its birth in April 2010. For people with speech disabilities, the portability, varied functionality, large touch screen and relatively cheap price made it an attractive alternative to more traditional communication devices.

So how well does the iPad work for a person who has ALS?

Portability: The iPad is lighter than a laptop, net book or traditional AAC device, but users with diminished hand strength may find that, at 1.5 pounds (1.75 with a speaker); it's still too heavy to lift. One man with ALS had the iPad mounted on his power chair so he could access it easily and not have to worry about it falling out of his lap while he was driving. The iPad can also be placed on a table, pillow, holder or lap desk.

Functionality: Text-to-speech applications (apps) for the iPhone are available for the iPad. This works well for patients who still have the use of their arms and hands but cannot speak clearly. Its relative ease to use and the word prediction feature makes it even more attractive to these users. It may require the use of an external speaker in some settings or the user may simply type in large font and turn the iPad so the person can read the words.

In addition to serving as an AAC device, the iPad also can be used to access the Internet, watch movies, read books, play games, send and receive photos and e-mail, listen to music, and do other functions performed by computers. If you plan on downloading movies, TV shows, or have a large music library, you need the extra memory. Movies and TV shows especially take up a lot of memory. Users have access to a plethora of free apps such as Speakpad, iSpeech, Locabulary, Talk Assist, MyVoice, NeoPaul & NeoKate.

Touch screen: The iPad's large touch screen (as compared to a phone) and virtual keyboard are great for people who have trouble manipulating their fingers. Big letters on the keyboard is another attractive factor. However, some users with ALS say the dexterity and finger-strength needed to tune on the virtual keyboard is still a problem. Some people

find it easier to type on a manual keyboard that plugs into the iPad.

Ranging in price from \$500 for a basic model to \$830 for a model offering greater storage capacity and faster Internet connectivity, the iPad is much cheaper than traditional AAC devices, which run upward of \$3,000.

The iPad is not covered by insurance or Medicare, whereas traditional communication devices may be at least partly covered. But even without insurance reimbursement, generally an iPad with some applications still costs much less than a traditional AAC device.



Text and images can be viewed either horizontally or vertically.

Social perception: Patients with ALS admit that there is definitely a 'cool' factor with the iPad that makes it fun to carry and use in public. According to one patient, "When I use it in restaurants to place an order, the sense I get is that waiters assume I am doing it to show off the iPad rather than because I cannot speak." "The comparison between using an iPad in public versus using an earlier stage type-to-talk device would basically be night and day."

Downside: The main drawback of the iPad as a communication device for people with ALS is that it requires the use of the hands. Patients who require alternative access may not be able to use the iPad effectively. As a user's needs and abilities change over time, the iPad may not offer the versatility of a traditional AAC device in terms of multiple alternatives in accessing it, such as through eye gaze, a switch or head mouse.

The verdict: For patients with ALS who only have their speech affected but not so much their hands, the iPad offers a relatively inexpensive, easy-to-use and attractive means of communicating. Even those with even more limited hand function still may be able to use some of the apps such as Proloquo2Go, since it can be preprogrammed and offers one-touch communication. However, the iPad can't "voice bank" - a handy feature on many traditional AACs that allows you to record yourself saying phrases for playback later. Invest in a good case - You've made an investment in an iPad, protect it with a quality case. NO INSURANCE plan will cover a cracked screen on an iPad. You will need to replace the entire device

If possible, try out both the iPad and more traditional AAC devices before buying. While the iPad may be a better deal in the short run, if you ultimately end up having to buy a more expensive AAC device as well, it may not be worth it.

Parts of this article were adapted from

- *MDA/ALS Magazine VOI.15, No. 6*
- *'iPads for Communication, Fun, and Improving Quality of Life' - presented by Alisa Brownlee, an Assisted Technology Specialist at the ALS Association. Check out her blog which is dedicated to assistive technology issues, disability issues, and ALS here:<http://alsassistivetechology.blogspot.com>.*

Air Travel and ALS

As we quickly embrace the summer months, 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 wheel-chair 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 every-thing 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.