

PM&R ASSISTIVE TECHNOLOGY PROGRAM

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SPECIAL
POINTS OF
INTEREST:

INSIDE
THIS ISSUE:

Veteran's Story 3

Parkinson's Disease Education Community 4

Meet McGuire's AT Staff 5

Nuts & Bolts 6

Management of Communication Needs in ALS...Beau Bedore, MA, CCC-SLP Minneapolis VAMC

Amyotrophic lateral sclerosis (ALS) is a progressive neuromuscular disease whose cause remains unknown and for which no cure has been identified [1]. Generally, ALS is classified according to three types: bulbar, in which symptoms are first observed in the cranial nerves; spinal, in which symptoms are first observed in the limbs; and mixed, in which symptoms are observed in both brainstem and spinal motor neurons [3]. The best approach to clinical decision making in ALS is to consider not just speech decline, but also decline in upper- and lower-extremity functioning [4]. Yorkston, Miller, and Strand (2004) described a typical progression of the speech course in individuals with ALS:

Stage 1: No Detectable Speech Disorder

Stage 2: Obvious Speech Disorder with Intelligible Speech

Stage 3: Reduction in Speech Intelligibility

Stage 4: Natural Speech Supplemented with Augmentative Communication

Stage 5: No Useful Speech

(Readers are encouraged to visit www.aac-rerc.com for more information on a clinical pathway model for communication changes with ALS.)

Approximately 95% of persons with ALS are severely dysarthric or unable to speak at some point prior to their death [2]. Because of the high percentage of severe speech impairment in ALS, most individuals will benefit from using augmentative and alternative communication (AAC). AAC assessment and acquisition should be based on observed decline in speaking rate. It is recommended that when speaking rate (calculated from sentence reading tasks on the *Sentence Intelligibility Test*) reaches 125 words per minute, with 190 words per minute considered typical for adult speakers, an AAC evaluation should be initiated [3].

Selection of appropriate augmentative communication systems depends on a variety of factors.

Among the most important of these factors in the ALS population is the user's level of mobility and hand function. Six groups, each reflecting different AAC needs, have been identified [5]:

Group 1: Adequate Speech and Adequate Hand Function

Group 2: Adequate Speech and Poor Hand Function

Group 3: Poor Speech, Adequate Hand Functioning, and Adequate Mobility

Group 4: Poor Speech, Adequate Hand Functioning, and Poor Mobility

Group 5: Poor Speech, Poor Hand Functioning, and Good Mobility

Group 6: Poor Speech, Poor Hand Functioning, and Poor Mobility

This classification of groups is one way of providing an overview of augmentative communication needs in the ALS population based on these critical factors; however, one should always consider the progressive nature of ALS, that capabilities change over time, and that people will move from group to group as their speech, hand function, or mobility changes. Therefore, it is necessary to consider projected changes in capability in addition to the person's current status.

Assessment of current and anticipated capabilities (see Table 1.1) will determine the range of AAC strategies that might be considered for an individual with ALS with regard to speech, hand function, mobility, vision, hearing, cognition, and social support. The AAC matching phase of the assessment involves the identification of low-tech and high-tech AAC options that meet current and expected communication needs while being consistent with current and expected capabilities.

(continue on Page 2)

Management of Communication Needs in ALS, cont.

Criterion-Based Assessment of Visual Acuity	
Vision	Determine whether the individual can perceive the visual information associated with the AAC options being considered: Font type and size, color contrasts, display precision, and zoom features are assessed with and without corrective lenses. Typically, a formal eye examination is not required.
Criterion-Based Hearing Assessment	
Hearing	Determine whether the person with ALS and (most important) frequent listeners understand the voice output of the preferred AAC devices. This can be accomplished by creating questions using the device that require a response from various communication partners. Women frequently choose to use male voices if hearing is an issue because of the greater ease of understanding male synthesized speech. Increasing loudness levels of voice output can also facilitate understanding. A trial period of device use is advised to ensure that important communication partners can understand the voice output when hearing may be an issue.
Criterion-Based Cognitive Assessment	
Cognition	Determine whether an individual can operate AAC options and use them functionally to communicate. The person must have access to specific AAC options before a determination of cognition or cognitive function can be finalized. This is especially important if the person is no longer able to produce intelligible speech or dementia is suspected. It is typically not necessary to complete a formal <i>language assessment</i> because it is uncommon for people to experience language impairments as a result of ALS; a screening of overall language skills will usually provide necessary information to determine whether the person will be able to read and spell messages. <i>Literacy skills</i> can be evaluated by determining what the person enjoys reading: If the person indicates that he or she never reads, magazines or newspapers can be used to screen literacy ability.
Assessment of Social Support	
Social Support	This assessment identifies the availability of people to interact with the individual with ALS. It assesses the available technical, instructional, and emotional support for the individual on a regular basis. It attempts to identify whether an individual has the technology support necessary to operate a technically complex AAC system involving communication interaction, computer access, Internet access, and environmental controls. Without ongoing technical support, the complexity of the AAC option might need to be reduced. This assessment will also identify the availability of an AAC facilitator who will coach the individual who relies on AAC, train new communication partners, interact with the AAC specialist and the manufacturer, and troubleshoot problems. AAC facilitators tend to be family members—spouses, adult children, or grandchildren. Friends or clinicians may also serve as facilitators. Finally, this assessment attempts to determine the support of family members regarding the individual's decision to use AAC technology.
Matching Phase → AAC Trials	
Matching Phase	In matching a person with ALS to the available devices, it is important to consider a combination of low-tech and high-tech AAC solutions that allow for communication in multiple environments. The majority of people with ALS are literate and will require a device that allows them to create novel utterances using text-to-speech options.



Figure 1.1. Individual with bulbar ALS utilizing an iPad with an augmentative communication app (Proloquo2go). This individual has impaired speech, adequate hand functioning, and adequate mobility and is classified in Group 3.



Figure 1.2. Individual with spinal ALS utilizing a speech-generating device with eye gaze (Tobii C12 with Ceye). This individual has impaired speech, impaired hand functioning, and impaired mobility and is classified in Group 6.

Antonio Council's Story

Mr. Council is a 41 year old Veteran who is currently an inpatient in the Spinal Cord Injury Service. He was a Master Sergeant in the Navy and the Chief Cook and Steward on the USS Dwight D. Eisenhower Aircraft Carrier.

In June 2012, Mr. Council was involved in a motorcycle accident resulting in C4 tetraplegia. This injury has imposed significant limitations on Mr. Council's independence. He was referred to the AT Program in August for Rehabilitation Engineering services related to computer access and electronic aids to daily living evaluation. In his own words, this is what he had to say about the AT program.

Tell us about your experience with the AT Program.

It has been a great time.

What challenges were you having that resulted in your referral to the AT program?

I couldn't use my laptop. I wanted to check my bank account and use social networking websites.

Who did you see?

Jenna, Brian, and Ben

What devices did you receive?

The Jouse 2, Permobil Bluetooth mouse, and an Origin Sip-n-Puff.

How has this device changed your life?

A great deal; It has given me the freedom to do what I want to do and connect with the world.

What activities are you doing now that you were not able to do before?

Use the Internet, Online banking, social networking.

Would you say your quality of life has improved?

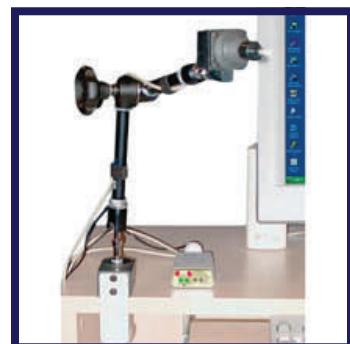
Absolutely, working with everyone has been uplifting.

Is there anything we have not covered that you would like to include?

The VA Hospital has been a great help!



Origin Sip-n-Puff



Jouse 2

Parkinson's Disease Community Education Day

In October the Assistive Technology (AT) Program participated in the Annual

Parkinson's Community Education Day in Richmond, VA. This event, sponsored by the Metro Richmond chapter of the American Parkinson's Disease Association and the McGuire VAMC

Parkinson's Disease Research Education and Clinical Center (PADRECC), is intended to provide a community based forum to help educate and connect people and families living with this disease. The AT Program was invited to participate in order to help raise awareness about AT services within the VA for Veteran's living with Parkinson's as well as to educate the community on the

current state of the art in assistive technology devices and software.

The AT Rehabilitation Team was represented by Brian Burkhardt and Ben Salatin. They were present throughout the day offering AT Program information and product demonstrations. Technology on display included medication reminder systems, large button adapted key-

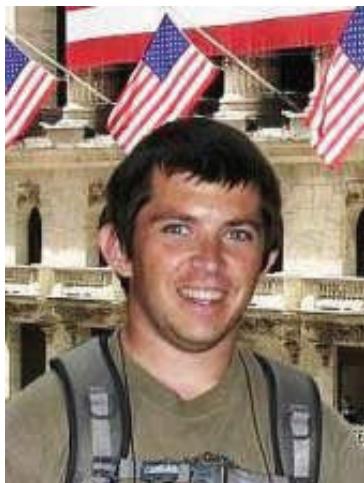
boards, alternative access mouse pointers, speech recognition software, and electronic cognitive devices (including the iPad). The day was a great success, with many informative lectures on topics ranging from genetics to spiritual growth and a variety of exhibits from local organizations. The AT Program's presence during the day's events helped educate many Veterans about AT services at the McGuire VA. The AT Program's exhibit also provided all conference attendees the opportunity to experiment with a variety of



AT devices related to Parkinson's Disease.

Meet McGuire's AT Team

...Ben Salatin, MS



Ben Salatin grew up on the west coast of Borneo, Indonesia for 15 years where his father was a bush pilot for a mission organization. After his family returned to the US, he attended Old Dominion University for a BS in mechanical engineering. During this time, he discovered the field of rehab engineering and decided that he wanted to pursue it as a career. Having grown up with childhood arthritis, Ben had used and designed his own AT from a young age and was interested to learn there was a field of engineering dedicated to this area.

So in 2007 he began an MS in Rehabilitation Science & Technology at the University of Pittsburgh where he worked at the Human Engineering Research Labs, a VA affiliated research lab. His research focused on robotic power wheelchair control systems and wheelchair user driving training.

Since joining the AT program at the McGuire VAMC in spring 2011, Ben has worked hard with his coworkers to build the new AT program into an integral part of the McGuire healthcare system, serving patients in multiple service areas throughout the entire hospital. He enjoys working directly with the patients as part of the clinical rehab team and has learned a lot from the patients and other therapists.

He considers it a blessing that he is able to provide his patients with such a wide range of AT devices and services, not as commonly seen in the private sector. "Applying my engineering skills to AT has been much more fulfilling than the other areas of engineering I've worked in." Ben said. He enjoys working with all areas of AT but has a particular interest in mobility technology and augmentative & alternative communication systems. And as patient needs dictate, he enjoys developing customized or new AT solutions.

In his free time, he enjoys sampling local restaurants, movies at the historic Byrd theatre, and volunteering around Richmond with his church. He also loves to travel and host other travelers as they pass through Richmond, getting to know people from around the world.



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Assistive Technology Program Mission

To enhance the ability of Veterans and Active Duty members with disabilities to fulfill life goals through the coordination and provision of appropriate interdisciplinary assistive technology services.

To serve as an expert resource to support the application of assistive technology within the VA health care system.

Nuts & Bolts of Rehab Engineering...

What is 3D Printing and How Can It Serve AT?

- Ben Salatin, MS

Additive manufacturing, commonly referred to as 3 Dimensional (3D) Printing is an advanced manufacturing process which allows a 3D solid object to be created directly from a 3D digital computer model. This technology which was developed in the 1980s has become much cheaper and more robust in the last decade allowing this high tech process to be used in everything from the fashion industry to the medical field. There are several different methods for performing 3D printing based on the precision requirements of the part you are creating but all the methods create parts in the same general way. They print out a very thin layer of material one on top of the other like a layer cake until after several hundred layers in

most cases, the 3D part is created. The material being printed is most commonly a type of plastic but can even be a metal like titanium in some cases.

The Richmond AT program has acquired a 3D printer which prints objects in the same tough plastic that LEGO bricks are made from. Used together with 3D computer modeling software the printer will be used to create items such as:

- custom mounting solutions for AT devices on a patient's wheelchair or bed,
- enclosures for multiple devices and wiring mounted on patient's power wheelchair,
- enclosures for ECU systems which house

multiple devices and lots of wires,

- quick fixes for a patient's broken AT until a replacement can be acquired,
- modifications to patient's AT to simplify and ruggedize for use by inpatient staff,
- and lastly AT research and development as the rehab engineers work on new ideas based on clinical need.

The AT program is excited to see this technology begin to make its way into the clinical rehab environment and looks forward to collaborating with patients and staff to create uniquely suited AT solutions for our veterans.