ALS and AAC: Proactive Assessment, System Design and Implementation

John M. Costello, MA CCC-SLP
Director, Augmentative Communication Program and
ALS Augmentative Communication Program
Boston Children’s Hospital

For more information, handouts and Video links go to:

http://www.childrenshospital.org/ALSaugcomm
For lots of related resources, Join us on Facebook at:
https://www.facebook.com/ACPCHBoston

We need to do an updated ALS Team photo!!
Objectives

Participants will be able to:

1. List no-tech, low-tech and high-tech augmentative communication strategies
2. Detail the steps for pro-active message banking
3. Describe the feature matching process for assessment and evidence based trials
Program Mission:

The mission of the ALS Augmentative Communication Program is to provide comprehensive augmentative communication/assistive technology assessment, trials and training to people with ALS from the time of diagnosis through the lifespan.
Program Goal:

“Our goal is to support communication and daily functional needs, sustain personal control and dignity, facilitate continued social and vocational goals and maintain quality of life through thoughtful implementation of solutions ranging from high technology to quick access/low tech tools and strategies. This is best accomplished by ACP-ALS clinicians constantly communicating and collaborating on how best to support patient-centered functional outcomes in the presence of changing physical abilities while providing support to a person with ALS and his/her family.”

What to expect:

Our team hopes to meet people as early as possible after diagnosis but remains eager to support people with ALS at any time during their journey.
Our assessment and intervention protocol has developed and evolved based on guidance and direction from people with ALS, their family and their care providers.

Our affiliation with many proactive neurologists and team members, initially through the MGH ALS Clinic, has given us the opportunity and honor to learn from many people with ALS who choose to meet with us early in the disease process.

This continues to inform our practice and evolve our protocol.

Begin with
THANK YOU
to so many extraordinary people with ALS
Opening statement:

“My goal is to waste your time”

Second statement:

“You are stuck with us”
For our purposes today:

Defining Communication

The ability to express oneself face to face, in group settings, via telephone, writing, email or text.

In addition: QUALITY OF LIFE indicators identified by people

• Maintain social connectedness
• Avoid or minimize changes to communication partners
• Continue to perform activities of interest/importance, even through modified means (including work)
Service delivery

- introduce strategies to minimize fatigue associated with speech including: strategies to enhance intelligibility or preserve energy, and may introduce varied voice amplifiers.

- partner with patient and family to create – over time – custom quick access communication tools

- May introduce our model of Message Banking and/or options for Voice Banking

Service delivery

- Introduce and assess various communication technologies to support face to face communication as well as communication through internet/telephone.

- Establish and coordinate evidence based trials

- assess and provide call systems to meet individual needs.
Service delivery

• Provide partner training
• Home-based services may be available when patient can no longer travel to the center.
• Tele-support
• Web based training modules on select topics (to launch Summer 2017)
• Web based downloadable templates (launched and growing)

AAC/Speech Pathology Protocol of Assessment Considerations

Speech strategies
Amplification considerations
Amplification while using BiPAP
Partner training
Call system for emergency and attention
Quick access encoding strategies (non-electronic)
Electronic encoding
Quick access encoding strategies (non-encoding)
Writing strategies
Message Banking
Voice Banking
Speech Generating Device assessment
Speech Generating Device trial for Practice Based Evidence
Training, implementation/integration
Occupational therapy/Assistive Technology Protocol of Assessment Considerations (wait for Peggy Delleal)

- Positioning/support
- Access to mobile technology
- Phone access
- Call system/attention signal access
- Environmental control
- Access to books (hardcopy or digital)
- Computer access: keyboard
- Computer Access: mouse
- Computer Access: speech/voice
- Speech Generating Device Access
- Training

Speech Strategies
Environmental strategies:

a. Speaking with competing noise in the environment is difficult under any circumstance. For people with ALS, trying to speak when there is lots of noise can be extremely difficult. While you should consider using a voice amplifier throughout the day (link to voice amplifier page) here are some other considerations: a. Make sure you have your partner’s attention
b. Mute the television, radio or other sound source when speaking

c. Make sure your communication partner can SEE your face and hear you (in the event partner has hearing loss) as you are speaking. Not only can seeing you speak make it easier to understand words or sounds that are not clear but also gestures, facial expressions and your eyes add a great deal of information to the message.

d. When going to restaurants, consider choosing a table that is away that is in a quieter section of the restaurant.
Environmental strategies:

e. When in noisy environments such as grocery store, shopping plaza, sports events OR when in the car (even in a well insulated car, traffic and road noise can be significant), use a voice amplifier.

f. Avoid speaking while eating (when food is in your mouth) or drinking

Speech Production strategies:

By making some modifications to the way you speak, you can enhance the intelligibility of your speech. These modifications include:

a. Pace your speaking rate. Providing a brief stop after each word you speak can slow the pace of your speech and improve intelligibility. As one man with ALS recently stated to us: “When I think of all of my partners as non-English speakers, I naturally pause between each word and speak at a clearer pace”. Providing this pause after each word will also eliminate the merging/slurring of the last sound of a word and the first sound of the next word!

NOTE:
Pacing does not mean speak slowly! Speaking slowly will often require more energy and will likely be less intelligible! ALSO – Resist trying to talk louder! Speaking louder will only use more energy and does not impact your intelligibility.
Speech Production strategies:

b. **Produce each syllable of a word**: If it is difficult to speak clearly and sometimes parts of words are not intelligible. While the most important advice is to preserve your energy, consider producing multi-syllabic words in a deliberate and paced manner. This way, every part of the word is clear.

c. **Consider producing sounds that are sometimes ‘glossed over’ in words**: In American English, some words the ‘t’ sound is normally ‘softened’ when followed by a vowel, but with typical speech production they are understood. An example of this is the word ‘water’, which is most often produced ‘wader’ with the ‘t’ being distorted. For people with ALS, it may be helpful to produce some sounds more deliberately so, in this case, one may speak in a paced manner ‘wa – ter’. Examples of other words include: button, kitten, waiter, theater, etc.

d. **Economize/phrase words per breath**: Many people try to speak as many words per breath as possible. For the natural speaker, this often results in some words being softer or less clear. A person with ALS should ‘economize’ words per breath so each word has strong breath support. When pacing one’s speech, it can be easier to also speak fewer words per breath so, if you feel out of breath while speaking, consider pausing and taking a new breath.
Your positioning while speaking:

Growing up, many of us were told ‘sit up straight’ or ‘don’t slouch’. When it comes to clarity of speech and ALS, positioning is really key! To maximize breath support for speech production, be sure you are comfortably positioned. If you are sitting, be sure you are not leaning forward, you are not too reclined or leaning to the side as it will be harder to speak loud enough or clearly.

Additional speech related strategies:

• Stretching/limbering – NOT oral motor exercise/repetitive motion. ***Discuss issues of muscle recovery.

• Letter cueing

• Topic cueing

• Counsel on positioning/support

• Counsel on speech fatigue/over-use and difficulty with recovery
Amplification Strategies
Amplification considerations:

- Counsel regarding impact of speech efforts on fatigue
- Discuss pro-active approach (as appropriate) to preserving energy
- Introduce amplification options
- Identify microphone headset placement considerations with head movement

Often will be told:

“I can talk loud enough, I just get worn out by 2 in the afternoon and am too fatigued”
Articulation

Highly coordinated movement of lips, tongue and jaw
Respiration

An often noted symptom is patient taking more frequent and longer pauses between words or word clusters when speaking.

*** many people continue to try to speak as many words as possible on a breath and ‘trail off’

Phonation

Perceptive changes in voice quality and loudness may be first symptoms

Attempts to compensate may exacerbate issue
(sound more gravely when trying to speak louder)
Resonance

- Velopharyngeal muscle weakness leads to continual opening of velopharyngeal port during speech

**MICROPHONES COMPATIBLE WITH SPOKESMAN AMPLIFIER**

<table>
<thead>
<tr>
<th>MICROPHONE</th>
<th>FEATURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Wireless Built-in</td>
<td>Allows for easy placement of microphone in the mouth</td>
</tr>
<tr>
<td>Wired Built-in</td>
<td>Provides stability and ease of use</td>
</tr>
<tr>
<td>Wireless with Headset</td>
<td>Offers maximum comfort and portability</td>
</tr>
</tbody>
</table>

**WARNING:**
- Use microphones positioned in each side of the lips to prevent speech distortion.
- Keep the hands close to the mouth.
- Be aware of the microphone's location.

**SAFETY NOTE:**
- Use caution when handling the microphone and amplifier.
- This device is not recommended for use near water.

**http://www.childrenshospital.org/ALSaugcom**

This information is subject to change. Information included in this resource was updated on 11/30/2013.
Amplification with BiPAP
Amplification while using bi-pap

Assessment of transdermal microphone options
Partner Training

“I’ve noticed that people are uncomfortable with silence and feel the need to fill it, even as I am putting together a message. Because I am slower, other conversations start or people ask me lots of yes/no questions and not only do I lose the opportunity to complete my message but I also lose the opportunity to be part of the conversations happening while I am putting my message together”  R.H., age 55
Partner training

- Identify communication partners/supports
- Share anecdotal feedback from people with ALS and families
- Share handout on “Guidelines to Communication Partners”
- Discuss strengths and major challenges with asking yes/no questions
- Discuss the pros and cons of prediction and permissions that should be in place.
Bob on predicting
Hollyton predicting (or being inpatient)
Bob (assessing dwell-less keyboard) discussing people reading over his shoulder

Calling/attention systems
Call system(s)/switch control

Alexa Voice Call
Alexa, Ask My Buddy

Something to assess for getting attention in the same house.
bluetooth speakers
Quick access/low tech

Quick Access Encoding

• Standard Etran two-step encoding
• eye gaze and partner assist combination (AEIOU)
• Alpha – color encoding
• EyeSpeak board
**Partner Assisted Scan spelling**

- Establish patient’s “yes/no” response
- Scan by row/column to identify target
Etran
Video courtesy of ALS association
(Iowa Chapter YouTube)

Electronic encoding
Electronic encoding

- Minimize working memory demands for communicator and partner
- Provide a visual script/reminder of message progress
Efficiency strategy when using encoding

* With electronic encoding it auto expands

** With non-electronic encoding you need a ‘cheat sheet’

- A logical relationship exists between the key words of the phrase or sentence and the code selected

- O D  = Please open the door
- J  C  = My name is John Costello

Quick access: NOT encoding
You have to keep looking at my face and DON'T Guess Please!

RED
BLUE
GREEN
CANT BREATHE
CHANGE POSITION
TUM ON BIPAP
TAKEN OFF BIPAP
RAISE/LOWER HEAD
RAISE/LOWER FOOT OF BED
COLD/HOT
DECK
SMALL TOWEL
DEEP BREATHE
FLEX TOO HIGH
TOO LOW

IN BED
COMFORT
TRANSFER AND POSITION
WHEELCHAIR
COMPUTER
BATHROOM

Back to looking at face
START OVER
GET ALPHABET BOARD
CALL JOHN

Patient Customized Communication Tabbed Flipbook

Why did we create the Patient Customized Communication Tabbed Flipbook?

We were told that in many people with ALS access to face-to-face communication was the only way they could communicate. After using the flipbook, we saw that:

- Access to flipbook was limited to those who can hold and turn the pages.
- The flipbook could be used by others to communicate with the person with ALS.
- The flipbook could be used by others to communicate with the person with ALS.
- The flipbook could be used by others to communicate with the person with ALS.
- The flipbook could be used by others to communicate with the person with ALS.
- The flipbook could be used by others to communicate with the person with ALS.

Typical instructions to communicate partners:

1. Always be clear and to the point when communicating with the person with ALS.
2. Always be clear and to the point when communicating with the person with ALS.
3. Always be clear and to the point when communicating with the person with ALS.
4. Always be clear and to the point when communicating with the person with ALS.
5. Always be clear and to the point when communicating with the person with ALS.

Typical instructions to communication partners:

1. Always be clear and to the point when communicating with the person with ALS.
2. Always be clear and to the point when communicating with the person with ALS.
3. Always be clear and to the point when communicating with the person with ALS.
4. Always be clear and to the point when communicating with the person with ALS.
5. Always be clear and to the point when communicating with the person with ALS.

Typical instructions to communication partners:

1. Always be clear and to the point when communicating with the person with ALS.
2. Always be clear and to the point when communicating with the person with ALS.
3. Always be clear and to the point when communicating with the person with ALS.
4. Always be clear and to the point when communicating with the person with ALS.
5. Always be clear and to the point when communicating with the person with ALS.
Video tutorial on Customized tabbed flipbook

http://lowtechsolutions.org

Amy Roman’s boards
Sold by Margaret Cotts
Writing
Writing strategies

- Notepad
- Notebook
- Boogie board
- Ipad/android – note apps
  - Finger
  - Rubber tipped stylus
  - Jot stylus
  - Apple pen

We prefer the Jot version as the erase button is easier to press
Message banking

“Our voice is our ACOUSTICAL fingerprint”
**Message Banking**

Digital recording of spoken words, phrases, and sentences.

These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or storage files. This will allow you to ‘retrieve’ a message and speak it in your own voice but does not allow you to create novel messages by spelling. If you have recorded individual words, you may combine those words to create unique messages, although the output will sound more staccato than your natural speaking.

Visit the message repository at Bostonchildrens.org/ALSMessageBanking for more information.
TERMINOLOGY:

Legacy Messages™ are those messages, often delivered with unique intonation and prosody that are unique or particular to you. It may be a ‘trademark’ message you say or it may be a trademark delivery of a message that many people say. A legacy message does not need to be meaningful to the general population instead it may have unique and personal meaning to only you and a loved one. Further, a legacy message does not need to be real words to be meaningful. It may be the way you clear your throat in a sarcastic manner to communicate “I told you so” or it might be the invented pet name you have for a loved one delivered with your unique voice, intonation and prosody. Similarly, legacy message may be that stereotypical thing you say after your favorite sports team scores or it may be a unique greeting you deliver to friends. Those close to you may be helpful with identifying these Legacy Messages because sometimes they are so naturally part of socially relating with others, you may not even be aware you are ‘known’ for them.

64+ page guide to considering Message Banking
Holly and Walker
Auto label, categorize, store and download for use of ANY SGD that will accept .wav files
**Voice Banking** is a process of recording a large inventory of your speech that is then used to create a synthetic voice that approximates your natural voice.

Done successfully, this would allow one to spell and create unique messages and then speak them through a synthesizer that approximates one’s natural speech. The science behind this process continues to be in development with beta-versions of available software. The ModelTalker is one such project from the University of Delaware Speech Research Lab. The website is:

www.asel.udel.edu/speech/ModelTalker.html

- ModelTalker
- Cereproc (Edinburgh Scotland)
- OKI Electronic Industry Co Japan
- Edinburgh Voice Banking and Reconstruction project
- Acapela
- VOCALiD
https://www.modeltalker.org/build-your-voice/

Build Your Voice

We're here to help you create a personal synthetic voice that you can use in your communication device or app. Here's what you will need to do:

1. Register with us to create a secure account.
2. Choose the recording method you want to use: MTVR (Windows only) or our web-based recording tool.
   - If using MTVR, install it, go through the tutorial, and get set up to record.
   - If using the web recorder, follow our interactive online training.
3. Record 10 screening sentences, upload them to our server, and wait for an email from us.
   - If everything is fine, we will provide instructions for moving on to step 4.
   - If we see any problems, we can suggest ways to fix them and may ask you to repeat step 3.
4. Record the full inventory of 1,600 sentences and upload them to our server.
5. Request your voice in a downloadable form for your computer, mobile device, or speech generating device.

If you are ready to have us walk you through the steps, let’s Get Started.

https://www.myownvoice.org

My-Own-Voice

Multi OS support
Preserve the voice identity
Capture recognizable voice characteristics
Through user friendly interface at home with your PC

For individuals diagnosed with speech or language disorders

KEEP YOUR ABILITY TO SPEAK

13 languages available
1500 sentences to record
Comparing voice bank and message bank
Speech Generating Device Assessment and Trials
“The feature matching process focuses on identifying the strengths, skills and needs (current and future) of a person who is a candidate for augmentative communication and matching the features of available (or potentially available) augmentative communication tools, devices and strategies to that person”

- Shane and Costello, 1994
Assessment Domains: Preparing for today and tomorrow

• Historic
• Patient centered
• Family centered/partner centered
• Medical
• Sensory
• Motor (access and seating/positioning)

• Speech
• Language(s)
• Environmental
• Cognitive
• Social/cultural
• Financial

SOME considerations for Speech Generating Device Assessment and trial(s)

**Language Features:**
• primary/secondary language
• core vocabulary • phrase
• single words • Alphabet
• message organization (grid, list, taxonomic, contextual, etc.) • text/symbol/both

**Encoding strategies**
• Abbreviation expansion
• prediction (word, grammar, morphology) • letter stream prediction (Dasher)

**Access features (in concert with OT)**
• Direct selection (unaided)
• **Direct selection (aided)**
  • headmouse
  • eye tracking
  • dwell, switch, blink, release
• **Scanning**
  • Single switch
  • Two switch
  • Use of switch interface for technologies
  • Software vs. tech access options within tech (accessibility features)
### SOME considerations for Speech Generating Device Assessment and trial(s)

<table>
<thead>
<tr>
<th>Sensory Features</th>
<th>Alert Features</th>
</tr>
</thead>
<tbody>
<tr>
<td>• vision status</td>
<td>• Auditory preview (different voice from communication voice)</td>
</tr>
<tr>
<td>• one eye or binocularity</td>
<td>• Click</td>
</tr>
<tr>
<td>• glasses</td>
<td>• Highlight (adjustable highlight color/size/etc.)</td>
</tr>
<tr>
<td>• ocular conditions</td>
<td>• expand/zoom</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Auditory Features</th>
<th>Voice Features</th>
<th>Integration features</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Voice output</td>
<td>• Synthetic options</td>
<td>• transition from communication to web to email to other functions</td>
</tr>
<tr>
<td>• volume</td>
<td>• voice bank integration</td>
<td></td>
</tr>
<tr>
<td>• auditory cue/prompt</td>
<td>• Message bank integration</td>
<td></td>
</tr>
<tr>
<td>• auditory scan</td>
<td>• hybrid voice integration</td>
<td></td>
</tr>
</tbody>
</table>

### Sensory Features:
- vision status
- one eye or binocularity
- glasses
- ocular conditions

### Auditory Features:
- Voice output
- volume
- auditory cue/prompt
- auditory scan

### Voice Features:
- Synthetic options
- voice bank integration
- Message bank integration
- hybrid voice integration

### Alert Features:
- Auditory preview (different voice from communication voice)
- Click
- Highlight (adjustable highlight color/size/etc.)
- expand/zoom
SOME considerations for Speech Generating Device Assessment and trial(s)

**Integration features:**
- Internet
- Telephone
- television
- text
- custom software
- system mirroring (Splashtop, Team Viewer, etc.)

**Other:**
- Language
- Text
- Symbols
- Synthesizer (and integration with environment such as ‘Alexa’)
- Warranty/tech support
- Funding options

**Other:**
- Size
- Weight
- Portability
- Mounting/stand
- Use in varied environments

Feature match is for apps too!
A few problems we have seen when a trial has not happened:

- People have come for initial visit with a NEW device recommended elsewhere and they can not use it (wrong access, does not address their goals, nobody can support)
- A person with ALS met a vendor or a clinician who knew one technology - insurance was (somehow) used to purchase it and person discovers it does not work well in their home (lighting, size/positioning, volume)
- Once purchased, the device can not be safely integrated/mounted with existing chair/environment

A few outcomes of trials that have led us to DIFFERENT technology that was successful:

- Throughout trial, continuous difficulty with setting up/positioning/charging and having authentic use
- Home lighting/windows interfere with camera for eye tracking
- Success is fleeting (possibly due to medication schedule)
- Communication partners can not hear the speech output
- FATIGUE (hand, foot, eyes or other access site; neck, shoulder, trunk, etc.) sets in after 30 minutes of use
- Care providers do not understand the language of the communication system (requiring bilingual options to address all partners needs).
INTEGRATING SWYPE Keyboard with app

Keyboard and audio feedback preference
Feature match to minimize need for new learning

Integrating SGD’s with commercial voice controls
Language organization for Environmental Control

Amazon Alexa activated by synthetic speech and responding appropriately

Ask My Buddy
Alexa voice call feature with SGD

Alexa and Hue Lighting
Evidence based practice/Practice based evidence

Decision flow chart for equipment loan for evidence based trials

Feature Match Assessment reveals match to device(s)
First trial considerations:

What technology is immediately available for evidence based trial?

Is self-pay an option to purchase the device revealed through trial as best match (important if it is a device not funded by insurance)?

Do we have appropriate mounting and access peripherals available to loan for immediately available device?

NO
Discuss considerations to determine if patient wishes to go ahead or consider second option

YES
Discuss consideration with patient and go ahead with trial

For more information, handouts and Video links go to:

http://www.childrenshospital.org/ALSaugcomm
Contact information:

John M. Costello, MA, CCC-SLP
Director, ALS Augmentative Communication Program
Boston Children’s Hospital
John.costello@childrens.harvard.edu
www.Bostonchildrens.org/ALSAugComm
O. 781 216 2220