ALS and Augmentative Communication: Seeking Improved Outcomes Through Early Engagement in Assessment, System Design, and Implementation

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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
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

Objectives
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.

Dear ALS Clinic provider,

Thank you for allowing us to care for your patients by making referrals to the ALS Augmentative Communication Program.

When introducing the idea of an augmentative Communication assessment to a person with ALS it may be most useful to offer the following information:

“Communication is a pretty broad word. It obviously includes speaking with people one-on-one and in groups, but it also includes writing, talking on the telephone, using a keyboard/computer, using the internet, social media or texting – even if you are having problems with your hands. We all use multiple methods of communication other than speech; we all use augmentative communication strategies.

This program will partner with you to monitor your communication success across all methods of communication. The goal is to be proactive and provide as much information as possible and have you drive all the decisions. If something is becoming more challenging, they will collaborate with you to increase your success by introducing and assessing tools and strategies to support you.”
Since January 2016

- 240 new referrals for AAC evaluation and treatment
- 610 completed appointments

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AAC as part of best practice in ALS patient Care

*Recommendation of Bulbar committee of NEALS*

- These survey findings highlighted the need to develop a standardized set of best practice guidelines, for the clinical assessment and monitoring of bulbar function throughout the disease course. Therefore, the aim of this symposium was to develop a practical consensus based bulbar assessment protocol feasible for implementation in all ALS multi-disciplinary clinics for speech, swallowing, and augmentative communication.

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AAC as part of best practice in ALS patient Care

*Recommendation of Bulbar committee of NEALS*

- The Augmentative communication assessment should focus on assessment of success for communication participation across a variety of communication functions, proactive introduction of voice and message banking, early consideration of low tech/quick access strategies and exploring strategies to maintain functional use of telephone, texting, keyboarding, internet access as well as standard methods of face to face and distance communication.
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

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Occupational therapy/Assistive Technology Protocol of Assessment Considerations (*wait for Peggy Dellea!*)

- 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.

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.
Speech Production strategies:

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
Letter Cue board

THE WORD BEGINS WITH....

Q W E R T Y U I O P
A S D F G H J K L
Z X C V B N M

Start again

br cr fr gr tr
bl cl fl gl sw dw
sl sc sk sm sn sp
sw squ spl spr scr

Next word

End word

Start again
**Topic Cue board**

<table>
<thead>
<tr>
<th>People</th>
<th>Food</th>
<th>Emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Places</td>
<td>Colors</td>
<td>Questions</td>
</tr>
<tr>
<td>Animals</td>
<td>Entertainment</td>
<td>Body</td>
</tr>
<tr>
<td>School</td>
<td>Home</td>
<td>Community</td>
</tr>
</tbody>
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Every day 70 people in the U.S. are diagnosed with ALS, two-thirds the number of multiple sclerosis.

Donations to the ALS Association support:
- Educational programs and literature
- Basic science and clinical management research
- Programs and services to help individuals, patients and families
- Advocacy that informs benefits and services for people with ALS

I am a person with ALS, my name is [Person's Name].

ALS [Letter]

Emergency Center Phone:

My name is [Person's Name].

My telephone number is [Person's Phone Number].
Amplification Strategies

Often will be told:

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

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
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
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
Holly on predicting (or being inpatient)

Bob (assessing dwell-less keyboard) discussing people reading over his shoulder

Calling/attention systems
When using in the same house...

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
Training video

Partner – Assisted Spelling using an AEIOU configuration

Partner assisted scan spelling
Etran
Video courtesy of ALS association (Iowa Chapter YouTube)

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
Video tutorial on Customized tabbed flipbook
Holly - need all the tools quick access AND high tech

Writing

Writing strategies

- Notepad
- Notebook
- Boogie board
- iPad/android – note apps
  - Finger
  - Rubber tipped stylus
  - Jet stylus
  - Apple pen
We prefer the Jot version as the erase button is easier to press.
Message Banking: What is it

“Digitally record and store words, phrases, sentences and personally meaningful sounds and/or stories using one’s natural voice, inflection and intonation.”

Costello, J.M. 2010
**Legacy Messages™: What is it**

"Legacy messages are those messages, often delivered with unique intonation and prosody that are unique or particular to you. They are your ‘isms’. 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 a unique and personal meaning to only you and a loved one. A legacy message does not have to be real words to be meaningful.”

Costello, J.M. 2010

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"Our voice is our ACoustical fingerprint"

Costello, J.M. 2010

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**History of Message Banking™**

- Premiered Boston Children’s Hospital Model for Augmentative Communication in the Intensive Care Unit in 1994.
- Consulted with Cystic Fibrosis Team, Heart Transplant Team, Pulmonology, Craniofacial Team and Otolaryngology and Tracheostomy Team to identify and pre-op refer patients who will likely be unable to speak post-operatively.
- Referral sources grew to the teams throughout the medical center within twelve-months of initiating services.
- A cornerstone of the model, based on proactive education, engagement and system selection and training became ‘Message Banking’.

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History (cont'd)

• 2000, Published first paper on voice/message banking highlighting outcomes from over 100 patients seen at Boston Children's Hospital
  (Costello, J.M. AAC, Sept 2000)

• Initially used the term voice banking but transitioned to term 'message banking' as technologies such as Model Talker were unveiled in 2003/2004 focused on creating synthetic voices that approximate one's biological voice or 'voice banking'

• In 2009, applied the BCH model of Message Banking for short term loss of speech to people with motor neuron disease and other conditions such as oral/orofacial cancers, who are at risk of permanent loss of speech
Our Message Banking Model

- Technology/platform agnostic
- Bank with as much or as little structure/"hand holding" as you would like
- Continue over time for as long as you would like. As life and the disease progress, new messages become evident.
- You are never ‘finished’ but also you have no quota. Focus on what is important to you.

Our Message Banking Model

- Provide a 64 page handout with examples and categories of messages banked by people with ALS
- Discuss legacy messages with many examples
- Review ‘relationship vocabulary’
- Sounds
- Laughter
- Same word or phrase/different intonation
- ‘Iisms’
**Message Banking .wav technology given to people with ALS**

- Set at 16/44 baud rate
- Must use wind guard
- Hold close to mouth for best quality
- Practice timing of push - speak
  - push

**Typical message banking introduction session:**

- 90-120 minutes
- Introduce concept of voice and message banking
- Discuss process of authentic message banking throughout day
- Intro portable .wav recorder and why .wav
- Describe and demonstrate use and integration into different platforms
- Compare voice and message bank (web video)
- Download, playback, label and store audio files, providing guidance for improving quality if needed.
- Demonstrate the edit process and highlight we will manage
- Demonstrate the Message Banking site as option for self management
Other Message Banking Models

**Other Message Banking Models**

A direct result of our experience at Children's Hospital and other hospitals, we have seen how valuable and effective voice messaging can be in supporting patients and families in a variety of settings.

For more information, please visit our website at [www.messagebankingmodels.com](http://www.messagebankingmodels.com).

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Other Message Banking Models

The "Message Banking" app can be used on any desktop, laptop, or tablet that runs Windows 8.1 or above. The app is designed to help people with message banking by capturing messages, making it easy to add your own unique messages (by using the "+" symbol at the bottom of the page) and editing them as you are recording in the right format. If you have any questions or need any support, please let me know if you have any other questions.
Other Message Banking Models

- Record directly to augmentative communication software on a device
- Record directly to an augmentative communication software on app

*** We have concerns and have seen some difficult situations when someone has been advised to acquire a device or software and message bank prior to knowing it is the right match to their authentic needs

AAC Feature Match

Some of the technology in our ALS AAC Clinic for assessment and/or evidence-based trials/loans

Considering vocabulary lists
Voice vs message banking

Voice Banking: What is it?

Voice banking is a process of recording a large inventory of your speech following a pre-determined script designed to capture a sampling of all co-articulated sounds in the language. The completed collection of recordings is then used to create a synthetic voice that approximates your natural voice.

Costello, 2011

- ModelTalker
- Cereproc (Edinburgh Scotland)
- Edinburgh Voice Banking and Reconstruction project
- Acapela
- VOCALiD
Acapela from 30 minutes of non-scripted message bank *(double dipping!)

Speech Generating Device Assessment and Trials
Some of the technology in our AAC Clinic for assessment and/or evidence based trial/loans
Feature match to minimize need for new learning

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

"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
LANGUAGE FEATURES:
- primary/secondary language
- core vocabulary • phrase
- single words • Alphabet
- message organization (grid, list, taxonomic, contextual, etc.). • see/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

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

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/sizes/etc.)
- expand/zoom

Integration Features:
- transition from communication to web to email to other functions
**SOME considerations for Speech Generating Device Assessment and trial(s)**

**Integration features:**
- Internet
- Telephone
- Television
- Text
- Custom software
- System mirroring (Splashtop, TeamViewer, etc.)

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

**Data collection during assessment and trial**

- **Linguistic:** Receptive and expressive language skills, as well as the ability to use the symbolic system (text, symbols, etc.) of a communication system to create messages with complex meanings.

- **Operational:** Technical skills to operate AAC systems, which includes the organizational system and hardware and access method(s).

- **Social:** Skills in the social rules of interaction, knowledge and judgment needed to initiate, maintain, and terminate interactions, engage with familiar and less familiar partners.

- **Strategic:** Compensatory strategies that users of AAC require to overcome communication breakdowns including encoding strategies, rate of communication, use of prediction or other endemic efficiency strategies.
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 cannot 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 cannot 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 SGD’s with commercial voice controls
Language organization for Environmental Control

Amazon Alexa activated by synthetic speech and responding appropriately.

Alexa and Hue Lighting

For more information, handouts and video links go to:

http://www.childrenshospital.org/ALSaugcomm
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