Augmentative Communication Supports: A Comprehensive and Proactive Approach for People with ALS

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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

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

Participants will be able to:

1. Discuss benefits of proactive intervention to successful use of AAC strategies throughout the course of the ALS disease.

2. List no-tech, low tech, mid tech and high tech augmentative communication strategies

3. Describe at least six AAC strategies that can be introduced proactively to people facing the loss of functional speech or computer access

4. Describe the feature matching process to AAC Assessment

5. Detail the steps for proactive message banking
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

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We will not have time today to cover Occupational therapy/Assistive Technology Protocol of Assessment Considerations

- 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 we 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
I have ALS (Amyotrophic Lateral Sclerosis). I am mentally alert and can hear you, but this disease may cause:
- impaired speech
- unsteady balance
- weakened hand strength
- inability to walk

My name is.

General Information for Emergency Room Personnel
Respiration issues are caused by weak muscles. Do not use oxygen. Use my personal support equipment. For further information, please contact my neurologist.

- Neurologist Name
- Phone Number

Important Personal Information

- Emergency Contact Name
- Emergency Contact Phone Number
- Medications in use, etc.

Amplification Strategies

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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.
Mr. D.

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

1. Don't talk louder just because I can't talk.
2. Don't talk over me as try to communicate. My speech is compromised and it takes too much energy to continue to try to get my message across while you interrupt/over rule me.
3. Don't interrupt—PLEASE let me finish my thought, otherwise it sends the message that you don't value what I have to say.
4. Recap that when an apologizer strategy is used by someone with compromised speech (using fewer words or speaking in a direct manner) it should not be confused with a lack of sophisticated linguistic competence or social skill.
5. If you didn't call me 'dear', 'honey', or other terms of endearment before my disease, don't change the way you talk with me now unless we have recently developed a more intimate relationship.
6. Don't touch me (move my arm, etc.) or my chair without letting me know you are going to and requesting permission.
7. I know you are trying to be efficient or save me from fatigue by speaking FOR me, but please ask my permission before sharing information related to me.
8. Even though you may know the requested information ALWAYS ask me if I want you to speak for me so everyone in the conversation is clear that I am in charge.
9. I'd rather you talk with me, tell me stories and fill me in on your life—then when I have a hard time holding up my end of the conversation—ASK OPPOPOS TO NOT talking with me because you know I have a hard time responding.

*Bob's Oaths of Loyalty*

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When people predict/guess it strips me of my dignity (photo only).

Holly on predicting (or not being patient) (photo only)
Calling/attention systems

Call system(s)/switch control
Alexa, Ask My Buddy and Voice Call

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
Partner assisted scan spelling
Etran (photo only)
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
Video tutorial on Customized tabbed flipbook (photo only)

http://lowtechsolutions.org

Amy Roman's boards
Sold by Margaret Cotts
Nancy, core board and laser pointer (photo only)
Holly – need all the tools quick access AND high tech

“Tech is not an answer to the intimate moments; bed, bath, breathing tell the story of how quickly things change so there is a moment when you need all of the tools”
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

Message Banking is a technology that allows you to create and store messages using your natural voice, inflection and intonation. These messages are stored as .wav files and can 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.

Bostonchildrens.org/ALSMessageBanking
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 a 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
Nancy exploring banked messages

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/
Dr. Rupal Patel, VOCALiD
with Samantha Grimaldo
http://www.vocalid.co/how

Photo only
Comparing voice bank and message bank

Speech Generating Device Assessment and Trials

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Speech Generating Device Assessment and trial(s)

**Language Features:**
- core vocabulary
- phrase
- single words
- Alphabet
- message organization (grid, list, taxonomic, contextual, etc.)

**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
- Scanning
  - Single switch
  - Two switch
  - Use of switch interface for technologies
  - Software vs. tech access options within tech (accessibility features)
Speech Generating Device Assessment and trial(s) continued

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’)

Language organization for Environmental Control

Amazon Alexa activated by synthetic speech and responding appropriately
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

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