

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

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 ALS Augmentative Communication Program
 Boston Children's Hospital



ALS Augmentative Communication Program
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Overview | ALS Augmentative Communication Program

The Mission of the ALS Augmentative Communication Program
 We provide comprehensive augmentative communication and assistive technology assessments, trials and training to people with ALS from the time of diagnosis through the lifespan.

Program Goals
 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-accessible low-tech tools and strategies. This is best accomplished by providing support to a person with ALS and his/her family.

Program Description
 For more than three decades, the Center for Communication Enhancement has had the honor of supporting people with ALS. Through the generosity of philanthropy, the ALS Augmentative Communication Program was established in 2016. The ALS Augmentative Communication Program team includes Speech-Language Pathologists who specialize in augmentative communication, Occupational Therapists with alternative access and assistive technology expertise, administrative professionals and graduate trainees. The ALS/ACCP staff collaborates with local, regional and national resources to provide the highest quality services for individuals with ALS. In addition we collaborate with regional, national and international clinical leaders, engineers, developers and ALS care providers/teams to bring our innovation as well as the innovation of others to people with ALS and their families.

What to Expect: Our team hopes to meet people as early as possible after diagnosis but we understand the individual needs vary. We'll work with you to meet those needs.

Contact the ALS Augmentative Communication Program
 781-216-2209

<http://www.childrenshospital.org/ALSaugcomm>

For more information, handouts and Video links go to:



For lots of related resources, Join us on Facebook at:

<https://www.facebook.com/ACPCHBoston>

A group photo of six people (five women and one man) standing in front of a wall with a framed poster. To the right of the group photo is a plus sign followed by a smaller portrait of a woman with blonde hair.

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



what i think



what i say



Mohamed Ghonem

Being Proactive




Boston Children's Hospital
 ALS Augmentative Communication Program



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

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

Environmental strategies:

- 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.

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 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



Letter and Topic Cueing

Message Banking

Duik's Access and Low Tech Tools

Access and Occupational Therapy

Patient Resources

Contact Us

Presentations and Handouts

Related Clinical Services

Augmentative Communication Program

Center for Communication Enhancement

Department of Otolaryngology and Communication Enhancement

What to do: If your communication partner does not understand a word, use an alphabet board to point to the first letter of the target word AS you are speaking the word.

Letter cueing displays can be organized in many different ways. Below are a few examples:

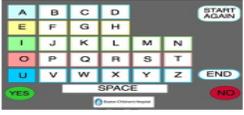
QWERTY format



QWERTY format with consonant blends



Alphabetical organization



Topic Cueing

Sometimes just knowing the topic can provide enough context to make a word or phrase understandable when it is not spoken clearly. Using a topic cue board, one may point to the general topic prior to speaking. This gives your communication partner a frame of reference when listening to you speak, making it easier to interpret speech that is not completely clear.

Below, is an example of a generic topic cueing board. A topic cueing board should feature some generic topics, but should also include topics that are very specific to you (not the topics in blue on example).

Place	People	Current Events	Emotions
Family	Body	Travel	The Past
Transportation	Entertainment	Community	The Future
Schedule	Health	Food	Question
Myself	Myself	Myself	Myself





A	B	C	D	E	F
G	H	I	J	K	L
M	N	O	P	Q	R
S	T	U	V	W	X
Y	Z	space		period	
Yes		No		Maybe	

Every day 15 people in the U.S. are diagnosed with ALS, two-thirds the incidence of multiple sclerosis.

Donations to The ALS Association support:

- Educational programs and literature
- Basic science and clinical management research
- Programs and services to help individual patients and families
- Advocacy that improves benefits and services for people with ALS



www.als.org



National Office, 27001 Agoura Road, Suite 250,
Calabasas Hills, CA 91301-5014 (800) 782-4747

For more information, contact The ALS Association, providing them with compassionate care and support.

Lou Gehrig's Disease and their families to live fuller lives by through global cutting-edge research, and to empower people with

The ALS Association mission is to lead the fight to cure ALS

control speech and swallowing.

ALS is a neurodegenerative disease that attacks the nerves that control voluntary muscle movement, including the muscles that



I am a person with ALS, better known as Lou Gehrig's Disease. My speech is slurred, or I am unable to speak, as a result of having this disease. I can hear and understand you. Thank you for your patience and understanding.



Emergency Contact Person: _____
 Telephone number: _____
 My name is: _____
 My telephone number is: _____







ALS
worldwide

T: 608-663-0920
alsworldwide.org

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 inside -

Important Personal Information

Emergency Contact Name _____

Emergency Contact Phone Number _____

Medications in use, etc.



ALS
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5008 Dawley Drive, Fitchburg, WI 53711
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Amplification Strategies



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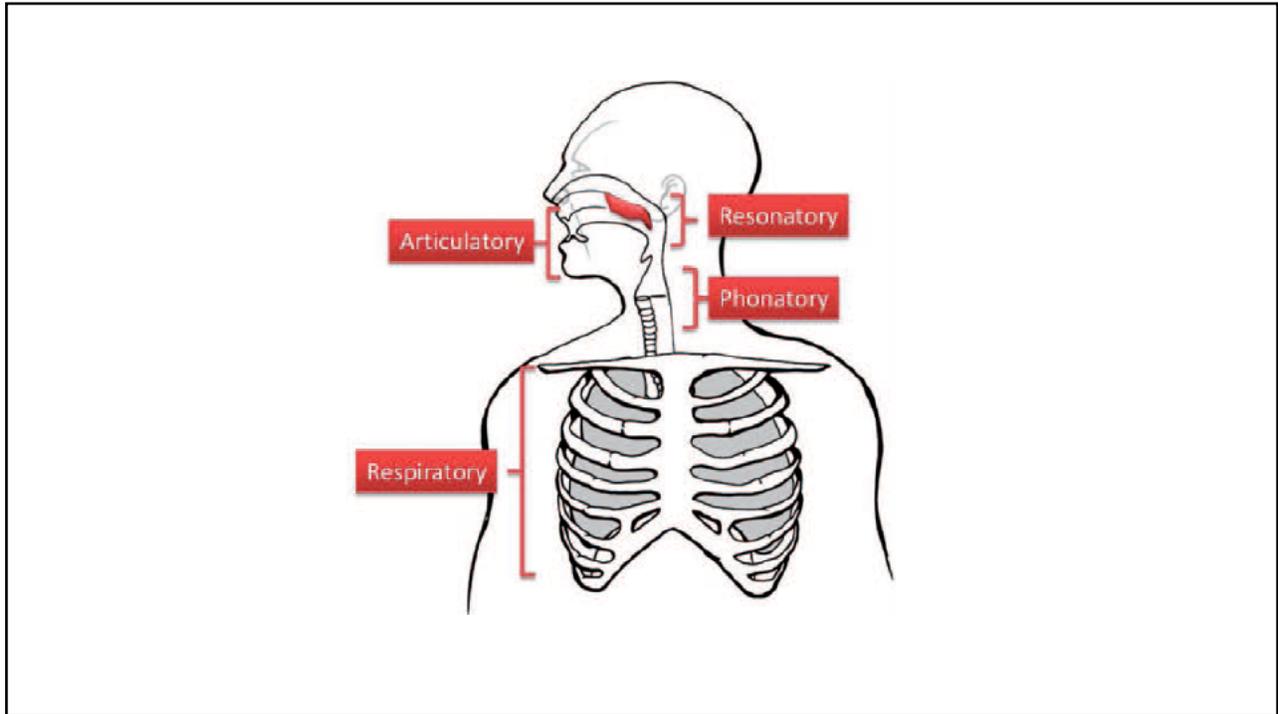
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Amplification considerations:

- 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

MICROPHONES COMPATIBLE WITH SPOKEMAN AMPLIFIER

MODEL NAME (PRICE); PURCHASE INFORMATION	FEATURES
HM-100 by LuminAid (\$80) purchase information 	<ul style="list-style-type: none"> • fits over the ears • microphone attaches on the right side only • headband is not adjustable for head size • cord is 45" long
Super-Lite by LuminAid (\$90) purchase information 	<ul style="list-style-type: none"> • low-profile, lightweight option • fixed length microphone wire (non-adjustable) • wire hooks around both ears • may fit smaller head better • cord is 42" long
Hi-Gain 3-Way Headband Microphone (\$85) purchase information 	<ul style="list-style-type: none"> • can be worn in 3 ways • can bend slightly to adjust tension/pressure • may order customized headband for smaller heads (see website for measurement instructions) • cord is 45" long

*This list does not include all available options. Please consult with your SLP to discuss available technologies and accessories.

**Prices and availability subject to change. Information included in this resource updated on 5/10/2017.

<p>XIAOKOA Wireless Bluetooth-enabled headset (\$29.99) wireless BT purchase information</p> 	<ul style="list-style-type: none"> • 40 meter connection (unimpacted) • charge time: <4 hours (must charge ear piece and exchange plug) • working time: >8 hours on full charge • comes with 6.35mm exchange plug to pair with Spokeman amplifier • on/off slide buttons on ear piece and exchange plug
<p>AV-JEFE TR-15 Throat Transdermal Microphone (\$26.99) transdermal purchase information</p> 	<ul style="list-style-type: none"> • dual microphones positioned to each side of the larynx augment vibrations • requires a firm fit • clarity can be affected by amount of adipose tissue on the neck • may augment speech while one wears a full face mask (BIPAP, CPAP)



***SAFETY NOTE: per LuminAid (manufacturer of the Spokeman voice amplifier):
THERE IS A 200 GAUSS MAGNETIC FIELD ON THE BACK OF THE SPOKEMAN'S PLASTIC CASE. AT 10" THE FIELD IS BARELY PERCEPTIBLE. PEOPLE WITH PACEMAKERS SHOULD CONSULT WITH THEIR HEART DOCTORS BEFORE USE AND KEEP THE SPEAKER BELOW WAIST LEVEL AS A PRECAUTION.

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Mr. D.

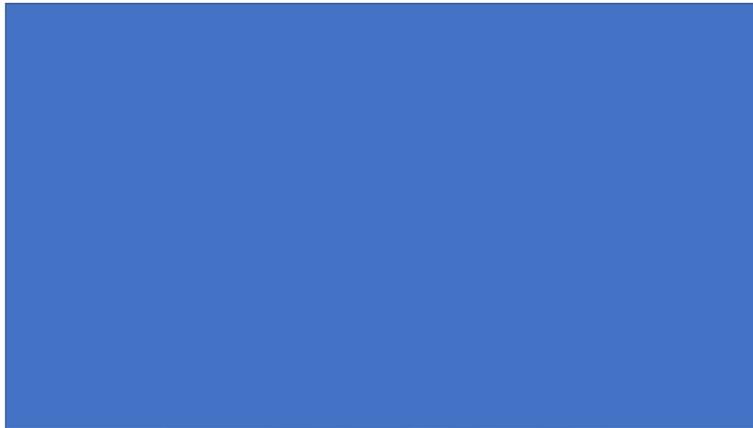
2



Amplification with BiPAP

Amplification while using bi-pap

Assessment of transdermal microphone options



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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.

Overview

Meet Our Team

Protocol of Assessment Considerations

Speech Strategies

Partner Training

Voice Amplification

Letter and Topic Cuing

Message Banking

Quick Access and Low Tech Tools

Access and Occupational Therapy

Patient Resources

Contact Us

Presentations and Handouts

Partner Training

Communication experiences and tips from people with ALS and their communication partners

"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

The change in communication skills that comes with ALS not only impacts the person with ALS, but also impacts the communication partners. The rhythm of communication is changed, whether a person with ALS is using natural speech, quick access tools or a sophisticated high tech system. In such situations, communication partners often try to reduce the burden or lessen possible frustration by interpreting, guessing or in some instances simply speaking for a person who has ALS.

It is important for partners to remember first and foremost, that the person with ALS is the same person but is unable to speak clearly or communicate as quickly. Yes, this is a simple and obvious statement but most often people change their behavior when communicating with someone who has a hard time speaking. People with ALS report experiences such as:

- People talk to my husband about me and refer to me as "her" when I am right there!
- While I am putting a message together, someone jumps in and speaks for me!
- If people "guess" and "predict" for me, I still complete the message...even if they got it right. It is the only way to make it clear that I want to stay in charge of ME.

The following graphic has been sent to us by several people with ALS, reporting that this is what they feared was happening to them.



As communication partners, changing our behavior can really help reduce this fear.

In our ALS Augmentative Communication Program clinic, we've had LOTS of opportunity to listen to, encourage and often participate in conversations between people with ALS and their primary communication partners. We wanted to highlight some of the comments and suggestions here.

"I thought I was helping my husband by asking him lots of yes/no questions instead of making him have to create all the messages on his device. It wasn't until you (counselor in ACP) modeled how you waited and listened to him AND gently let me know that I was not letting him be in control at all, did I realize everything I was missing. I had to work to break old habits, but the realization that I was not letting HIM talk kept me on track. Before ALS, he was head of household. Now because I wait and I listen, he is again head of household! This was particularly good recently as he stepped in and grounded our son for his behavior and I am not a good disciplinarian." A.K., wife of S.P., age 54

"In our family, we have needed to change our style. We don't want to miss anything. He says so we are learning to just be present in the moment with him. He has tools and strategies that work for him if we give him time. We know not everybody can do this but for us, it is an obvious shift in the way we function. I wait my turn. Our kids wait their turn. The grand kids will learn to wait their turn." J.P., wife of M.P., age 76

"I mean, if you are impatient, I feel less willing to engage with you if you are rushing me through the process of trying to communicate!" L.L., age 58

When asked to provide suggestions to communication partners, people with ALS told us:

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ALS Augmentative Communication Program

Guidelines for Communication Partners
(Identified by young adults and adults who are losing ability to speak)

No rule fits everyone BUT these are some points to consider putting into practice.

THANK YOU for the generous guidance from so many of our ACP patients:

1. Don't talk louder just because I can't talk
2. Don't talk over me as I 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 ride 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. Recognize that when an efficiency 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 – even when I have a hard time holding up my end of the conversation - AS OPPOSED TO NOT talking with me because you know I have a hard time responding.

*Oh, I'm sorry...
Did the middle of my sentence interrupt the beginning of yours?*

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4

Bob on predicting

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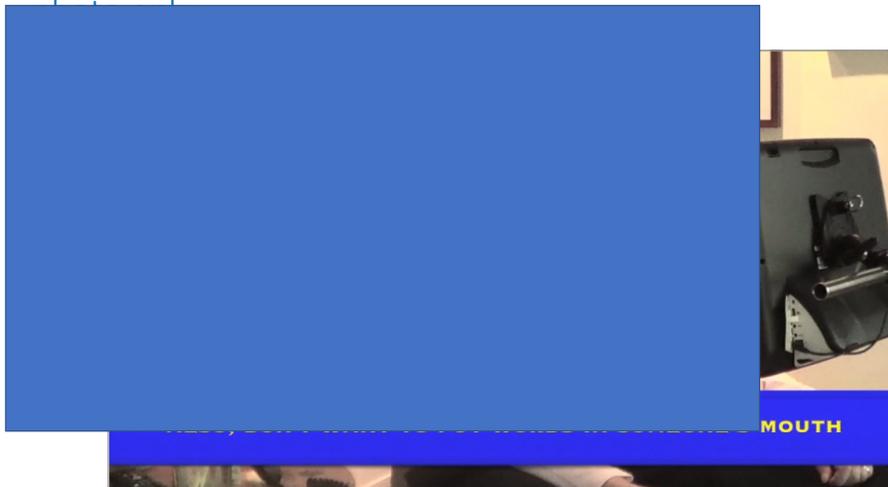
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When people predict/guess it strips me of my dignity (photo only).



Holly on predicting (or not being patient)



Calling/attention systems

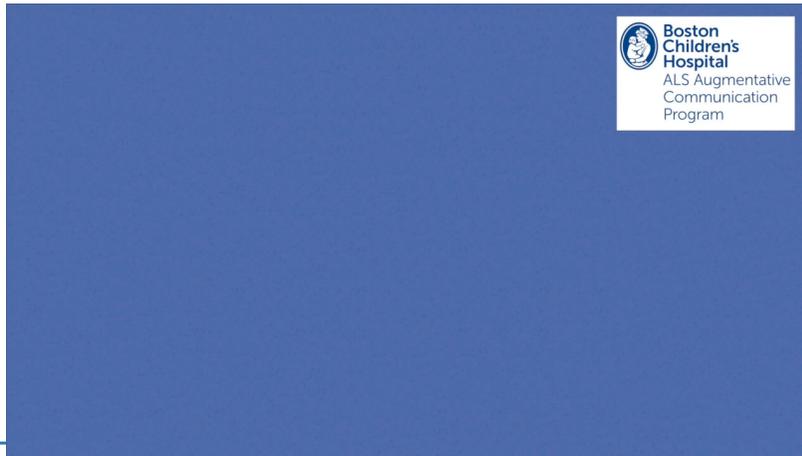
Call system(s)/switch control



Icon	Label	Function	Notes	Switch	Control
	Push Button				
	Call Phone				
	Base Unit				
	Mobile Phone				

Alexa, Ask My Buddy and Voice Call

5



Something to assess for getting attention in the same house.. bluetooth speakers



SMALL, PORTABLE BLUETOOTH-ENABLED SPEAKERS

MODEL NAME (PRICE); PURCHASE INFORMATION	FEATURES
Mariboy Portable Mini Bluetooth Speaker (\$18.85) purchasing information: Mariboy 	<ul style="list-style-type: none"> small, portable, lightweight anti-slip base enhanced super bass 50 foot range (unimpeded) charges via standard USB to micro USB cable charge time: 5 hours battery life: 10 hours connects to one device at a time power on/off requires 2-3 second button hold 1 year limited warranty, lifetime technical support
ION Clipster Waterproof Bluetooth Speaker (\$29.99) purchasing information: Waterproof ION Clipster 	<ul style="list-style-type: none"> large, rubberized controls power on/off requires 2 second button hold tough rubber covering metal clip attaches to a backpack loop, belt loop, purse handle, etc. battery life: 3-4 hours at maximum volume, 15-20 hours at 50% volume charges via standard USB to micro USB cable waterproof level: protection from splashing at any angle
ION Clipster Bluetooth Speaker (\$15.99) purchasing information: ION Clipster 	<ul style="list-style-type: none"> large, rubberized controls power on/off requires 2 second button hold plastic clip attaches to a backpack loop, belt loop, purse handle, etc. battery life: 3-3 hours (volume at 70%) charges via standard USB to micro USB cable

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**Prices and availability subject to change. Information included in this resource updated on 5/10/2017.



New Bee Portable Bluetooth Speaker (\$18.99) purchasing information: New Bee 	<ul style="list-style-type: none"> 3W audio driver and passive subwoofer water resistant 33 foot range (unimpeded) charge time: 2 hours battery life: 5 hours charges via standard USB to micro USB cable
URB3T Bluetooth Speaker (\$32.98) purchasing information: URB3T 	<ul style="list-style-type: none"> super bass includes a hand strap power on/off requires 3 second button hold loud announcement volume is not adjustable (available with power on/off and when device is paired) 33 foot range (unimpeded) battery life: 6 hours charges via standard USB to micro USB cable weighs 0.57 pound (209g) dimensions 3.8 x 3.8 x 2.7 inches
blm Bluetooth Speaker (cost varies by color \$17.95.00) purchasing information: blm 	<ul style="list-style-type: none"> wearable speaker featuring adjustable wristband battery life: 6 hours



<http://www.childrenshospital.org/ALSaugcomm>

*This list does not include all available options. Please consult with your SLP to discuss available technologies and accessories.

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Quick access/low tech

Quick Access Encoding

- Standard Etran two-step encoding
- eye gaze and partner assist combination (AEIOU)
- Alpha – color encoding
- EyeSpeak board

The collage features several communication aids:

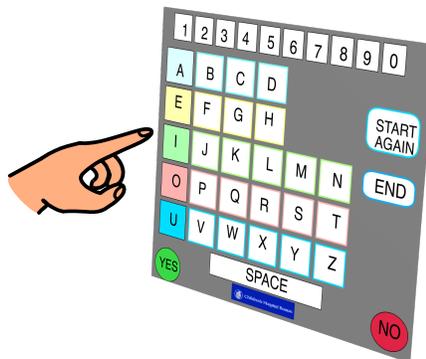
- Top left: A 2x3 grid of letters (A-C, G-I, M-O) and a 2x3 grid (D-F, J-L, P-R).
- Top right: A stack of topic cards with categories like 'COMFORT', 'TOILET', 'DRINKS', 'SPELL', 'CLOTHING', 'BATHTIME', and 'MEALS'.
- Middle left: A grid of letters (S-U, Y-Z, ß) and digraphs (ei, au, eu) and another grid (V-W-X, st, sch, ä, ö, ü).
- Middle right: A keyboard with a hand pointing to the 'A' key. It includes 'START AGAIN', 'END', 'SPACE', 'YES', and 'NO' buttons.
- Bottom right: A 'Non-Speaking User' interface with a face icon and a grid of letters (A-C, D-F, G-I, J-K, L-M-N, O-P-Q, R-S-T, U-V-X, Y-Z-W).

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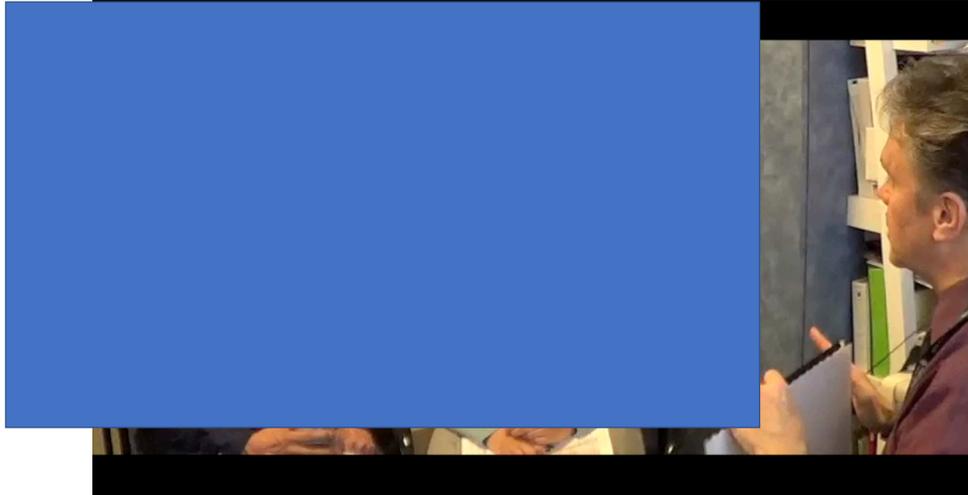
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Partner Assisted Scan spelling

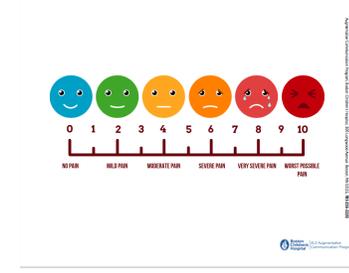
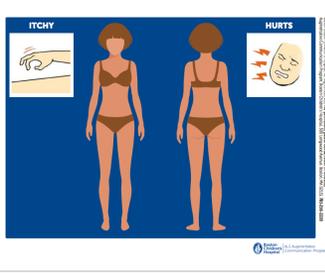
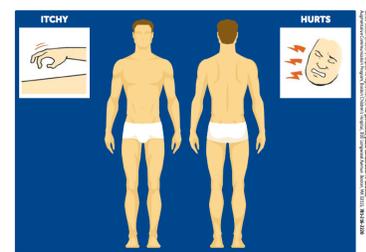
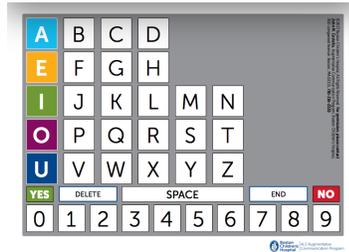
- Establish patient's "yes/no" response
- Scan by row/column to identify target



Partner assisted scan spelling



6



Etran (photo only)

Video courtesy of ALS association
(Iowa Chapter YouTube)



E tran Low Tech Communication



Sarah Lettow

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Electronic encoding



Electronic encoding

- Minimize working memory demands for communicator and partner
- Provide a visual script/reminder of message progress

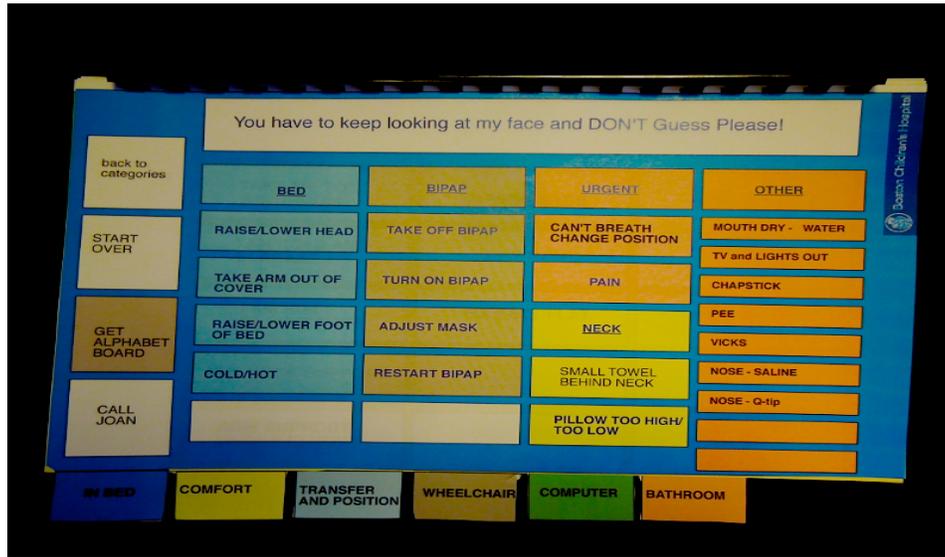


Efficiency strategy when using encoding

- * 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



Overview

- A Note From the Director
- Meet Our Team
- Protocol of Assessment Considerations
- Speech Strategies
- Partner Training
- Voice Amplification
- Letter and Topic Cueing
- Message Banking
- Quick Access and Low Tech Tools
- Patient Customized Communication Tabbed Flipbook
- Speech Generating Devices
- Access and Occupational Therapy
- Patient Resources
- Contact Us
- Presentations and Handouts

Related Clinical Services

- Augmentative Communication Program
- Center for Communication Enhancement
- Department of Otolaryngology and Communication

Patient Customized Communication Tabbed Flipbook

Why did we create the Patient Customized Communication Tabbed Flipbook?

We have had so many people with ALS express frustration with trying to quickly communicate (often with speech) a simple and often repeatedly communicated and predictable message. Examples include: "Adjust the strap on the BIPAP mask" or "put pillow behind my neck" or "don't forget to lock the brakes". Similarly communication partners have reported being very frustrated and often feeling very guilty when they can't understand a message, especially when they realize that the message is a communicated regularly in the same context, often multiple times a day. One man stated to us: "Why did I make her say it five times and why did I make my voice in frustration when I couldn't understand? I should have known exactly what she was saying because she says it all the time in that same context".

Initially, we encouraged people to write down such messages when they occurred so a list could be created; but nobody did that. So, in 2011, in an effort to create a format for people to use, we created a blank, tabbed flipchart. We bind the pages together and we give them to people with ALS and their families.

Typical instructions to person with ALS and their communication partner(s):

1. Identify situations or context throughout the day in which you say the same thing and you want to make sure people always understand exactly what you are saying.
2. Write each context on one of the tabs at the bottom of the flipchart. A few examples include: positioning, food, personal care, bed, technology, social, bathroom.
3. As you think of a predictable message you communicate in each context – write that message down (or direct someone to write it down) in one of the boxes on the appropriate page.
4. Add messages as they occur to you over time.
5. Invite your communication partners to make suggestions, especially for contexts in which they are typically with you and may be supporting you.
6. When you think you have a good start, give us a copy of what you have done and we will make your pages, laminate them and bind them together.
7. After we give you a clean copy of your customized communication tabbed flipbook, try using it.
8. Identify a way you are going to let your communication partner 'yes' when they scan through your flipbook with you.

Typical instructions to communication partners:

1. If you don't understand what is being said, report that you cannot understand and ask "Is it on your flipbook?"
2. If the answer is yes, read through and point to each of the tabs until you are told 'yes' (you have already established together what that 'yes' signal will be).
3. Turn to the appropriate page and then go through each of the messages. Some people have preferred to first review columns (ie if column one?, column two?, etc.) while others prefer to quickly read through each message on the page.

The Patient Customized Tabbed Flipbook will likely need to be updated regularly. Some contexts will be added as medical status changes, while others may be removed (add a 'tab' page while possibly removing or significantly modifying the 'flip' page).

Download a Flipbook

This tool has been extremely useful to many people. Because so many people have asked for it, we have created an on-line template you can fill and print. Please note, the document will be downloaded as a PDF and can be edited in Adobe. [Download your customizable](#)

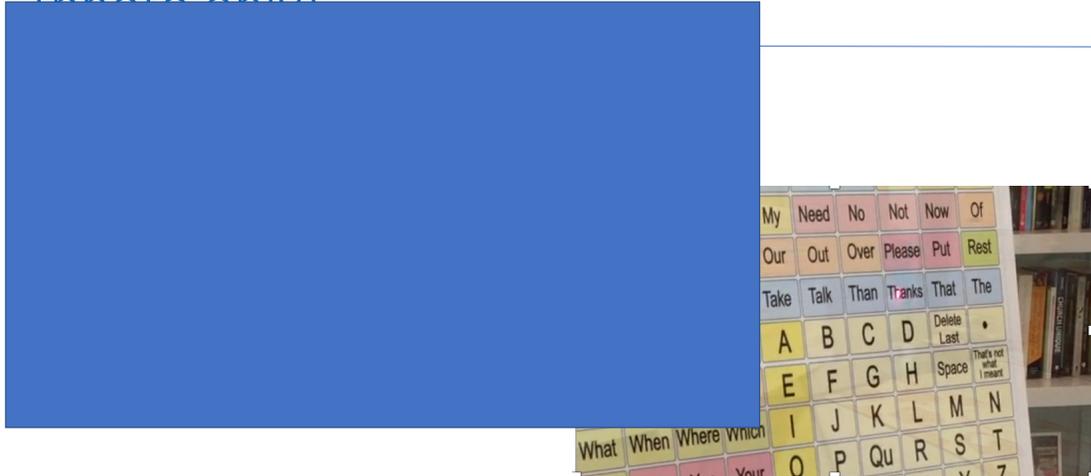
Video tutorial on Customized tabbed flipbook (photo only)



<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



...e moments; bed,
...quickly things
...you need all of the



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™

 **Boston Children's Hospital**
ALS Augmentative
Communication Program

 HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

“Our voice is our ACOUSTICAL fingerprint”



 **Boston Children's Hospital**
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Communication Program

 HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

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Message Banking

Message Banking™

"When dealing with ALS, so much goes so quickly. You don't realize how much and what you will miss. To be able to hear my husband's voice again through his hundreds of banked messages - his enthusiasm, intonation, humor, and tone is priceless. As more and more of his ability to traditionally communicate are lost, it is comforting to know that his voice and a part of his identity will always be preserved."

- Paty C, wife of G.C. age 62

The ability to communicate is essential to human interaction. Of all the challenges ALS brings, many people tell us that one of the most devastating is the loss of speech. People with ALS have told us that losing the ability to speak is like losing an important part of self-identity. We believe that the greatest contributor to loss of identity and self when speech is difficult, is the loss of one's authentic voice. Our voices define us, our voices is our 'knowable fingerprint'. How many times have you heard someone say "it is so good to hear your voice"? We are able to provide comfort, establish personal connection and bring the spectrum of emotions to people around us with our voice and our unique intonation, prosody and passion.

In 1991, one of the nurses from our tracheostomy program came to us and said there are kids who wake up in the ICU after surgery who are absolutely terrified and they can't communicate. Our augmentative communication program began to meet children at bedside but immediately recognized that many children had a planned procedure and we could anticipate a compensating condition prior to hospitalization. Boston Children's initiated a first of its kind program that supported children to bank messages and then have access to those messages in their own voice using digital technology when they awaken in the ICU. We called this process Message Banking and have updated and modified the process to support people with ALS. We define Message Banking as: *Digitally recording and storing words, phrases, sentences, personally meaningful sounds using one's natural voice, inflection and intonation.* These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or sound 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 it will sound more staccato compared to your natural voice

Watch Holly, a patient, use Message Banking.



Contact the ALS Augmentative Communication Program

781-216-2209

generating device, based on feedback from many people with ALS and the desire to have more direction with content to bank, we introduced the term **Legacy Messages™**.

Legacy Messages™

Legacy Messages™ are messages banked with unique intonation and prosody that are unique or particular to you. Some people have told us they are their 'let's!' 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 and tenderness. Similarly, legacy message may be that stereotypical thing you say after your favorite sports team scores, it might be a movie quote that you use all the time 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.

Many people with ALS have invited us to share the messages they banked with the hope it will give other people some ideas in their own journey with message banking. We tried to create general categories for ease of review. Please note that this is intended to be a document to give ideas, it is not a script of messages to record.

Download the 60+ pages of messages banked here.

Other Resources

Click here to go to the free Message Banking site we have developed in collaboration with TobiiDynamox for use with any technology.

Watch video of a USSAAC/ISAAC webinar we did on the topic of Message Banking™.



Bostonchildrens.org/ALSMessageBanking





Message Banking™ with your own voice

digitally record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.

These messages are catalogued as .wav files and may then be linked to messages in a variety of augmentative communication technologies or sound 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.





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



PLEASE CITE WORK AS:
Message Banking™, Voice Banking and Legacy Messages™
John M. Costello
Boston Children's Hospital
© 2011, 2014, 2016, 2017

DEFINITIONS:

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

Message Banking- with your own voice digitally record and store words, phrases, sentences, personally meaningful sounds and/or stories using your natural voice, inflection and intonation.



Worse
Time of Day Based Expressions
Did you have a good night's sleep?



Boston Children's Hospital
Message Banking examples from people with ALS © 2017

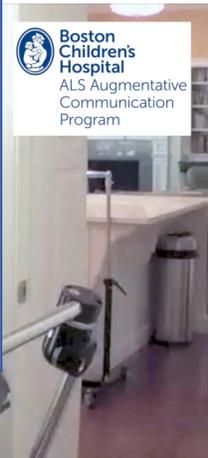


ALS Augmentative Communication Program

Good morning
Good night, I hope you sleep well
Good night, I love you
Have a good day
How are you this morning?
How is your day going so far?
Is like a morning snack
I'll like to eat breakfast
I'll like to eat dinner
I'll like to eat lunch
I'll like to watch the evening news
It's time for bed
Passport dreams
What time is it?
When are they coming?
When are we leaving?
When do we start?

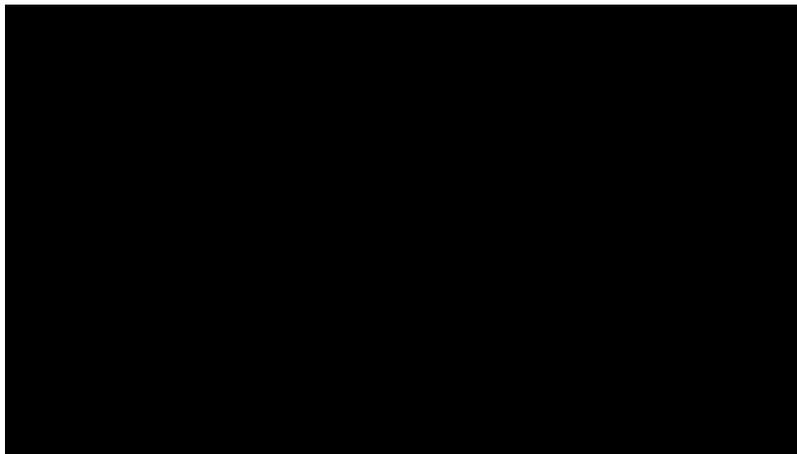
Topic Continuations
Amazing
Amazing
And then...
Good
I know it
I see
Isn't that wonderful?
Keep going
Oh yeah
Okay
Really
Right
Tell me more
That's good to know
That's great
That's interesting
Uh huh
Wow

Nancy exploring banked messages



7

Holly and Walker



8

Auto label, categorize, store and download for use of ANY SGD that will accept .wav files

mytobiidynavox.com/messagebank

mytobiidynavox Store Pageset Central Support Comm

Boston Children's Hospital ALS Augmentative Communication Program

Message Bank **Beta** Download All Upload

Learn more about the public beta.

Search

No messages found.

Contact Us
Tobii Dynavox
2100 Wharton Street
Suite 400
Pittsburgh, PA 15203
Phone: 1 (800) 344-1778
Fax: 1 (412) 381-0241
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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.

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- ◆ 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: MTRV (Windows only) or our web-based recording tool.
 - If using MTRV, 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 1600 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](#)



my-own-voice
my-own-voice, the voice banking solution by aspeaks-prod.com

NEW! Update to MOV Recorder
My-own-voice is now available in a new, flexible version with 'MOV recorder'



For individuals diagnosed with speech or language disorders

Multi OS support

13 languages available
1500 sentences to record

Through user friendly interface at home with your PC

Preserve the voice identity

Capture recognizable voice characteristics.





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

Photo only







Comparing voice bank and message bank

Text to pronounce:

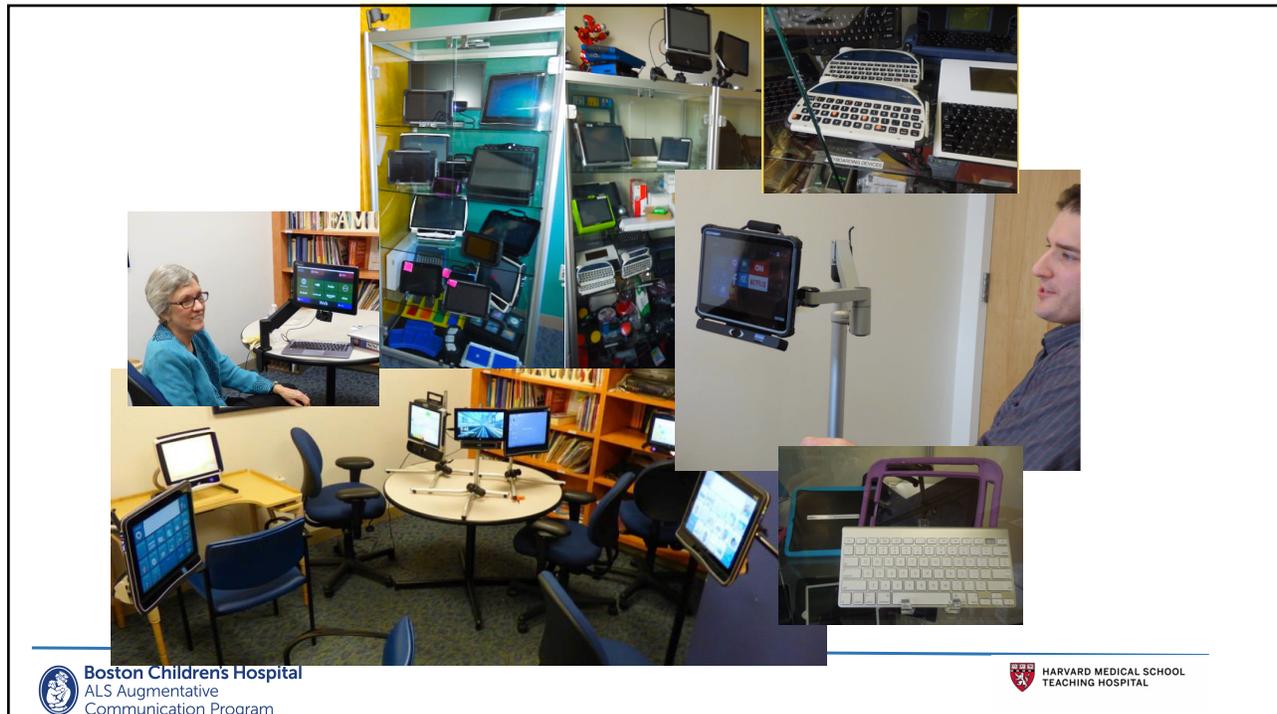
Yo|

Speed: %

Shaping: %

10

Speech Generating Device Assessment and Trials



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TEACHING HOSPITAL

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)



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Communication Program



HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL

Speech Generating Device Assessment and trial(s) continued

Integration features:

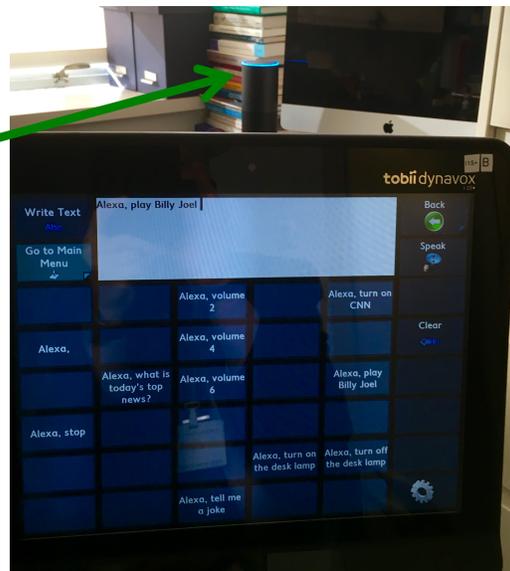
- Internet
- Telephone
- television
- text
- custom software
- system mirroring (Splashtop, Team Viewer, etc.)

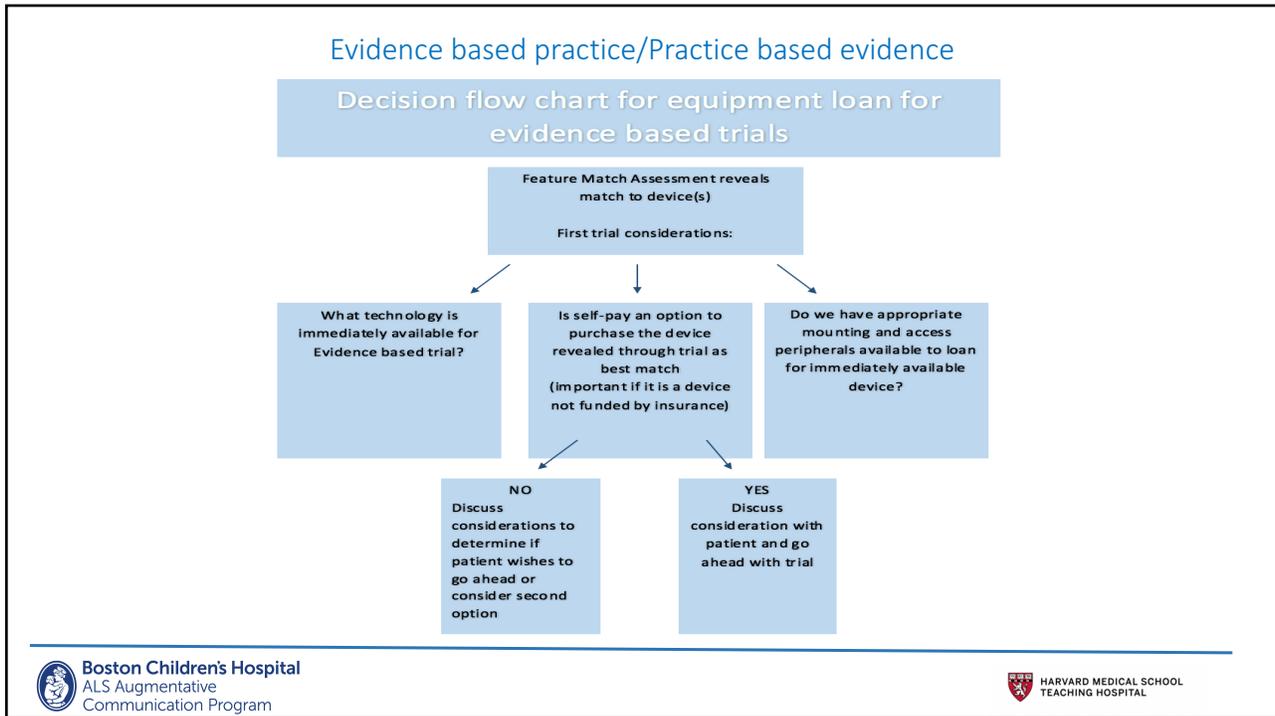
Other:

- 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







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Patient resources | Clinician resources | Centers + Services | Research + Innovation | Conditions + Treatments | Ways to Help | SEARCH

ALS Augmentative Communication Program

Home > Centers + Services > Programs and Services > ALS Augmentative Communication Program Overview

Request an Appointment
Request an Option
Find a Doctor
Find a Location

Overview | ALS Augmentative Communication Program

The Mission of the ALS Augmentative Communication Program

We provide comprehensive augmentative communication and assistive technology assessments, trials and training to people with ALS from the time of diagnosis through the lifespan.

Program Goals

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-accessible low-tech tools and strategies. This is best accomplished by providing support to a person with ALS and his/her family.



Program Description

For more than three decades, the Center for Communication Enhancement has had the honor of supporting people with ALS. Through the generosity of philanthropy, the ALS Augmentative Communication Program was established in 2016. The ALS Augmentative Communication Program team includes Speech-Language Pathologists who specialize in augmentative communication, Occupational Therapists with alternative access and assistive technology expertise, administrative professionals and graduate trainees. The ALS/ANCP staff collaborates with local, regional and national resources to provide the highest quality services for individuals with ALS. In addition we collaborate with regional, national and international clinical leaders, engineers, developers and ALS care providers teams to bring our innovation as well as the innovation of others to people with ALS and their families.

What to Expect: Our team hopes to meet people as early as possible after diagnosis but we cannot accept the responsibility to meet with all ALS or non-ALS patients. Please contact us at 781-216-2209.

Contact the ALS Augmentative Communication Program

781-216-2209

For more information, handouts and Video links go to:

<http://www.childrenshospital.org/ALSaugcomm>





Contact information:

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www.Bostonchildrens.org/ALSAugComm

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