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

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https://www.facebook.com/ACPCHBoston

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Augmentative Communication Program at Boston Children's Hospital

Update Page Info

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

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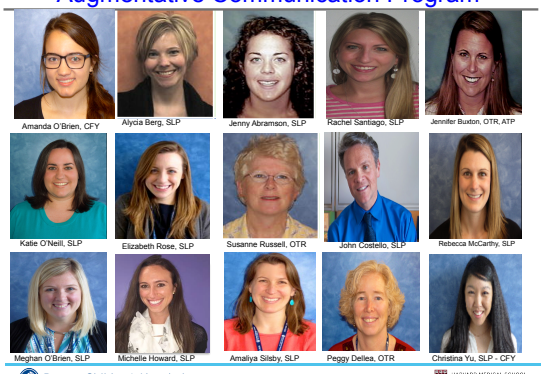
Augmentative Communication Program



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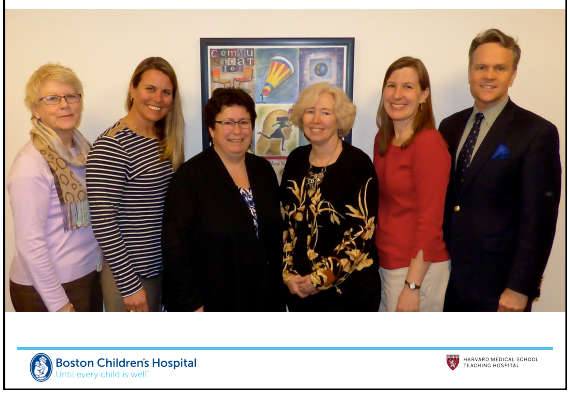

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BOSTON CHILDREN'S CHILDREN'S HOSPITAL

Background and Overview of AAC Service

- BCH:
  - 400 beds
  - 4 ICUs
  - Ongoing plans for expansion & increased # of beds
- Established **outpatient** AAC clinic for nearly 40 years
- AAC Service provision in ICU/acute care for 25+ years
- Formal inpatient position for ~10 years
- Current positions
  - 2x 1.0 FTE, 2 SLPs
  - Inpatient grew from Augmentative Communication Program
  - Focus on AAC implementation through the continuum of care
  - Equipment closet with a variety of AAC tools and materials
  - Average caseload: variable; ~30 patients on a given day and rising!

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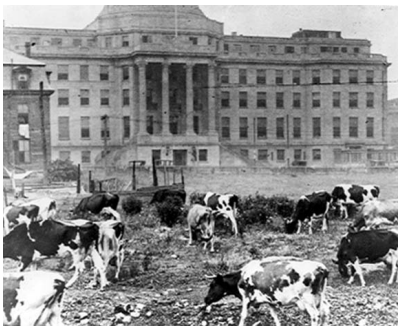

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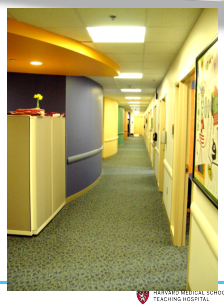
Children's Hospital Boston at Waltham



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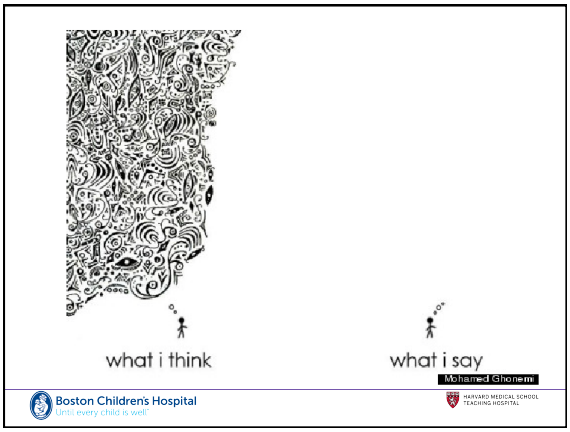

From: Melissa B>
Date: September 3, 2014 at 3:25:28 PM EDT
To: "Costello, John (Otolaryngology)" <john.costello@childrens.harvard.edu>
Subject: update

Hi John,

I just wanted to let you know Mom passed away yesterday afternoon. Dad and I were both able to be with her and although we are terribly sad, our family is glad she is no longer suffering.

I hope to reconnect with you soon to tell you in person how much we really, really appreciate all the kindness and hard work you put into helping Mom. You not only gave her tools to help, but showed compassion and made her feel safe and cared for. Your ability to gently convince her to learn to use the communication boards you developed early on, even though she didn't know why they would be important, was so important. THOSE tools turned out to be our only connection with her in the end. YOU knew that would be the case all along, but we didn't know until it was all we had left. Perhaps most importantly, you gave her her authentic voice when it would have been gone…and now we have it to cherish.

Thank you for all your support.

Melissa

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My Ice bucket challenge

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A little history

How does a Children's Hospital end up having a dedicated ALS-AAC Program?

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Long history of Proactive Intervention at Boston Children's that now supports people with ALS

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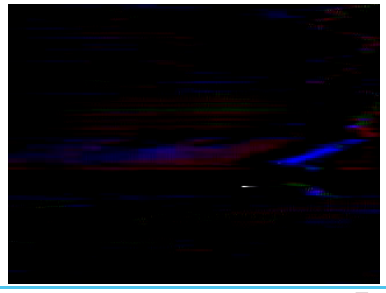
Patient photo or video

Patient photo or video

Patient photo or video

Prepare in advance (you can do this at school or at home)



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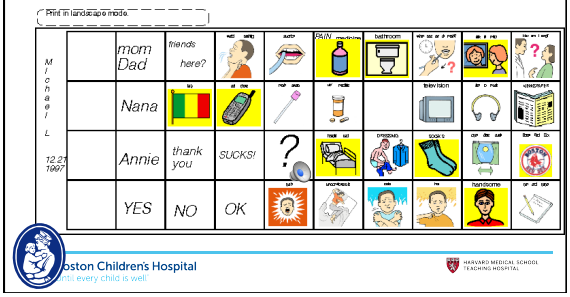
Patient photo or video

Patient photo or video

Patient photo or video

Sometimes I was tempted to 'reject' but I learned a valuable lesson from an 11 year old!



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.

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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."

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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.

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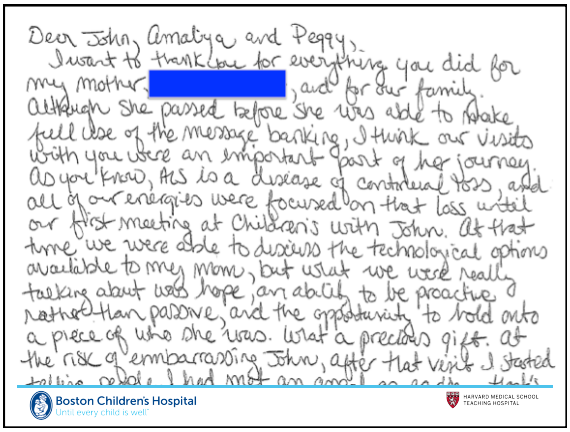

Dear John, Amatya and Peggy,

I want to thank you for everything you did for my mother [redacted], and for our family. Although she passed before she was able to make full use of the message banking, I think our visits with you were an important part of her journey. As you know, ALS is a disease of continual loss, and all of our energies were focused on that loss until our first meeting at Children's with John. At that time, we were able to discuss the technological options available to my mom, but what we were really talking about was hope, an ability to be proactive rather than passive, and the opportunity to hold onto a piece of who she was. What a priceless gift. At the risk of embarrassing John, after that visit I texted

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Patient photo or video

QUICK OVERVIEW OF ALS CLASSIFICATIONS

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Types of ALS/MND

- Sporadic - the most common form of ALS in the United States - 90 to 95% of all cases.
- Familial - occurring more than once in a family lineage (genetic dominant inheritance) accounts for a very small number of cases in the United States - 5 to 10% of all cases.

resource: http://www.alsa.org

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Onset

- Bulbar
- Spinal
- Atypical
  - Example: Brachial amyotrophic diplegia (man in the barrel): severe muscle involvement was confined to the upper limbs, predominantly the proximal portion and shoulder girdle, sparing the face and the legs until late in the disease's course or until the terminal stage.

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Bulbar onset Resource: ALS/CA fact sheet 2016

- What is it?
  - Bulbar ALS destroys motor neurons in the corticobulbar area of the brainstem in the early stages of ALS.
  - The corticobulbar area controls muscles of the face, head and neck.
  - Bulbar ALS usually progresses faster than limb onset
- **How Common is Bulbar ALS?**
  - observed in 20-30 percent of people with ALS.
  - Almost all people with ALS display bulbar symptoms at later stages

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Bulbar onset Resource: ALS/CA fact sheet 2016 (cont'd)

. **Symptoms Affecting Speech**
Changes in voice and speech.
- Harsh, hoarse or strained voice. -Breathy speech pattern.
- Poor articulation.
- Decrease in range of pitch and loudness of voice.

Other Symptoms
- Spasms in muscles of the jaw, face, voice box, throat and tongue.
- Inappropriate excessive laughing and crying.
- Brisk jaw jerks.
- Involuntary twitching in the muscles of the tongue.
- Dysphagia
- Vocal cord spasms causing the sensation that air cannot be moved in or out.

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Spinal onset

- Initial symptoms may affect only one leg or arm. Individuals may have awkwardness and stumbling when walking or running. They may have difficulty lifting objects or performing tasks that require manual dexterity (e.g., buttoning a shirt, tying a shoe, turning a key). Eventually, the individual will not be able to stand or walk, get in and out of bed without help, or use hands and arms to perform activities of daily living, such as washing and dressing.
- 70-80% of patients, symptoms begin with limb involvement
- Eventually develop bulbar symptoms

Resource: *Orphanet Journal of Rare Diseases*20094:3
DOI: 10.1186/1750-1172-4-3

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Spinal onset (cont'd)

- Upper motor neuron involvement include spasticity and exaggerated reflexes
- Patients with upper limb onset have twice the likelihood for onset in the dominant arm, compared with the nondominant arm
- Symptoms of lower motor neuron degeneration include muscle weakness and atrophy, muscle cramps, and fasciculations

- Current research data suggest that up to 50% of people with ALS will never develop significant changes in thinking or behavior, over and beyond normal psychological reaction to diagnosis and symptoms.
- Up to 50% of people with ALS will experience some degree of change in thinking or behavior, with approximately 25% of those people with ALS developing a full blown dementia.

ALS Association fact sheet rev 2014

Fronto-temporal dementia

- Fronto-temporal refers to the forward part of the brain that sits above the eyes and behind the temples. Lowering of the function of this region can lead to impulsive, compulsive, and emotional behavior.

There have been many clinic-based studies of cognitive and behavioral impairment in ALS, using cross-sectional cohorts of patients. These studies show

- up to 20% of ALS patients demonstrate dementia,
- roughly 30% of ALS patients develop impairment without dementia, and
- up to half of ALS patients are cognitively normal.

- Lomen-Hoerth, C., et al., *Are amyotrophic lateral sclerosis patients cognitively normal?* Neurology 2003. 60: p. 1094-1097.
- Murphy, J., et al., *Continuum of frontal lobe impairment in amyotrophic lateral sclerosis*. Arch Neurol, 2007. 64: p. 530-534.

http://www.alsa.org/als-care/resources/publications-videos/factsheets/fyi-cognitive-impairment.html

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A word about pseudobulbar affect

- Some people with ALS develop an unusual symptom called "pseudobulbar affect." They may cry or laugh at inappropriate times or discuss how once they start feeling an emotion, it is difficult to shut it off. Sometimes, pseudobulbar affect can be present when a person feels more emotionally reactive in general, with more intensity to the emotion that is experienced than normal. Pseudobulbar affect is common in ALS and is the result of a brain reflex that is no longer working correctly. It does not necessarily mean that a person is feeling anxious, sad, depressed, or emotionally distraught. People with ALS can have pseudobulbar affect and no other cognitive, behavioral, or psychological symptoms.

ALS Association fact sheet rev 2014

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As appropriate, Speech-Language Pathology will:

- introduce strategies to minimize fatigue associated with speech including: strategies to enhance intelligibility or preserve energy, and may introduce varied voice amplifiers.
- May introduce our model of Message Banking and/ or options for Voice Banking,
- partner with patient and family to create – over time – custom quick access communication tools

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As appropriate, Speech-Language Pathology will (cont'd):

- 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.
- Provide partner training

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Also provide:

- Home-based services may be available when patient can no longer travel to the center.
- Tele-support
- Web based training modules (late 2016)
- Web based downloadable templates (late 2016)

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Begin with
THANK YOU
to many extraordinary people with ALS

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Patient photo or video

Opening statement:

"My goal is to waste your time"

Second statement:

"You are stuck with us"

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AAC/Speech Pathology Protocol of Assessment Considerations	
Speech strategies	
Partner training	
Amplification considerations	
Amplification while using bipap	
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	

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Occupational therapy/Assistive Technology Protocol of Assessment Considerations **(NOT part of today's discussion)**	
Physical Access Control Site assessment	
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	

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Based on assessment of current voluntary motor abilities, Occupational Therapist/AT specialist:

- **identify adaptations and tools to facilitate continued physical access to daily activities.** A wide spectrum of options exist, ranging from minor modifications to one's computer keyboard and mouse to hands free control of a computer, tablet and smartphone.
- In addition to supporting hand function as much as possible**, voluntary movements of one's eyes, head and feet are explored to minimize the overuse** of any one muscle group.

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Based on assessment of current voluntary motor abilities, Occupational Therapist/AT specialist

- Accommodations to minimize fatigue and facilitate function often include a combination of:
  - **positioning mounting adaptations,**
  - **low and high tech adaptive pointers,**
  - **alternative computer mice and switches**
- In addition to facilitating one's access to written and spoken communication, **email, the Internet and social media, options for independent access to reading, television operation and other leisure time activities can also be addressed**.

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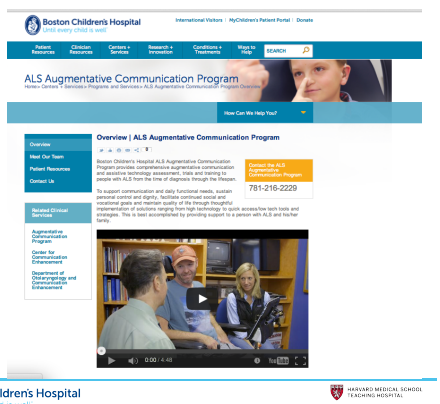

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SPEECH STRATEGIES

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Speech strategies

- Pacing/segmenting with breath control
- Breathing awareness (diaphragmatic vs. clavicular)
- Reduce gravel with quieter voice (in concert with amplifier)
- Over articulation (without strain)
- Economizing
- Stretching – 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

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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	pl	str	*Next word*		
bl	cl	fl	gl	sw	dw	tw	*End*		
sl	sc	sk	sm	sn	sp				
sw	squ	spl	spr	scr					

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Topic Cue board

People	**Food**	**Emotions**
Places	**Colors**	**Questions**
Animals	**Entertainment**	**Body**
School	**Home**	**Community**

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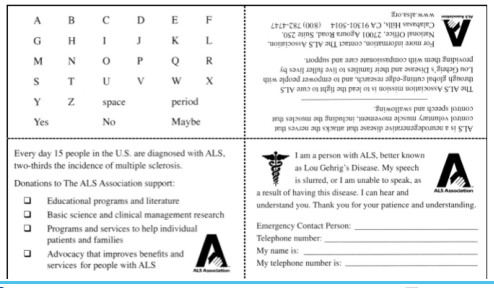
Identification/explanation card for car



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

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 is a neurodegenerative disease that attacks the nerves that control voluntary muscle movement, including the muscles that control speech and swallowing.

THE ALS Association mission is to lead the fight to cure ALS through global cutting-edge research, and to empower people with Lou Gehrig's Disease and their families to live fuller lives by providing them with compassionate care and support.

For more information, contact The ALS Association, National Office, 2700 Agoura Road, Suite 250, (Calabasas Hills, CA 91301-5014 (800) 782-4747 www.alsa.org

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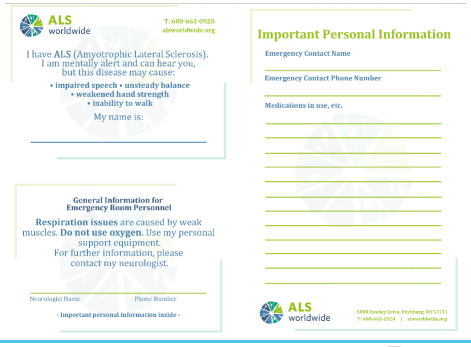
http://alsworldwide.org



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.

_____
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ALS worldwide
5988 Bentley Drive, Fitchburg, WI 53711
T: 608-663-0920 | alsworldwide.org

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Many patients now ask about medications and we ALWAYS refer them back to their physician

Nuedexta - Improving Quality of Life for ALS/MND Patients January 12, 2016

By: ALS Worldwide

Nuedexta, known for minimizing psuedo-bulbar affect, also is now recommended for improving chewing and swallowing, control of facial muscles, speech, and respiration.

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While we do not focus on feeding swallowing…

HOW TO SAVE YOUR OWN LIFE: THE SELF-HEIMLICH MANEUVER

Published 10.30.2013 by nfosdadmin

Byline: Roya Sayadi and Joel Herskowitz

Illustration: Anet James from "Swallow Safely"

[NFOSD note: This article is for informational purposes only and should not be used as a substitute for consultation with and expert training by an appropriate health care professional. Also, an Internet search on "Self Heimlich maneuver" will result in additional articles and videos on this topic.]

We read in newspapers or online every day about someone's heroism in administering the Heimlich maneuver to someone choking on food.

But suppose that other person were not present? What then? Would they simply choke to death? If that person were YOU, what would you do?

If you can't speak, breathe, or cough, do the Heimlich maneuver — on yourself.

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PARTNER TRAINING

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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.

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Patient photo or video

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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.

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Patient photo or video

Patient photo or video

AMPLIFICATION CONSIDERATIONS

Amplification considerations

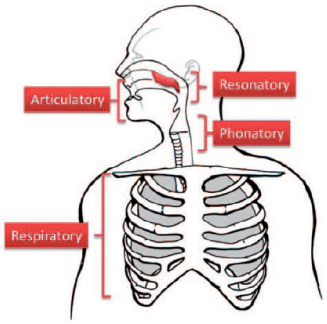
- Counsel regarding impact of speech efforts on fatigue
- Discuss pro-active approach (as appropriate) to preserving energy
- Introduce amplification options
- Identify microphone headset placement considerations with head movement

Often will be told:

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

Speech production requires:

- Articulation
- Phonation
- Resonation
- Respiration



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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'

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Phonation

Perceptive changes in voice quality and loudness may be first symptoms

Attempts to compensate may exhacerbate issue

(sound more gravely when trying to speak louder)

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Articulation

Highly coordinated movement of lips, tongue and jaw

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Resonance

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

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AMPLIFICATION WITH BIPAP

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Amplification while using bi-pap

Assessment of transdermal microphone options

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Patient photo or video

EMERGENCY CALL

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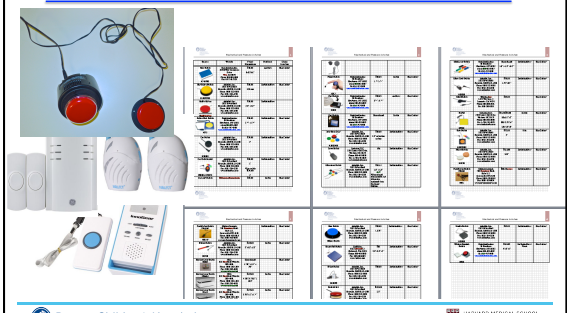
Call system(s)/switch control



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When using in the same house….

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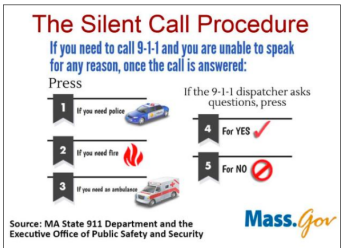
Home alone and calling 911 when speech is difficult



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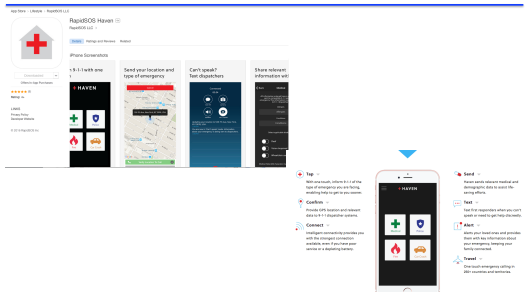
Phone app for emergency requiring no speech



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Hands Free Voice-controlled access of Iphone.
Good, but not great (yet).

In September, the announcement came out:

Apple's voice-controlled personal assistant Siri becomes even more powerful with iOS 8, including an entirely hands-free mode that allows users to ask questions and accomplish tasks by simply first saying the words "Hey, Siri."

What we have learned so far by supporting many people to use this feature....

PHONE CHARGING STATUS:

The phone must be plugged in/charging. Others have had difficulty and/or failure if using a portable charging station or car charger. It is consistent if plugged into the wall or the computer. Some power wheelchair manufacturers are now advertising that they are incorporating charging ports for idevices into the controls (or it is an add-on feature). When we have inquired whether HeySiri treats this charging port as a 'portable battery' and fails to function, the manufacturer reps we have contacted have told us they have not yet tried it. So, the jury is still out on using HeySiri with the charge working off the wheelchair battery.

MAKING IT FUNCTIONAL FOR PHONE CALLS (BUMPS WE'VE ENCOUNTERED):

1. I Say "Hey Siri" and then tell Siri the number to call
2. Siri calls the number and the phone rings.

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QUICK ACCESS ENCODING (NON-ELECTRONIC)

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Quick Access *Encoding*

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

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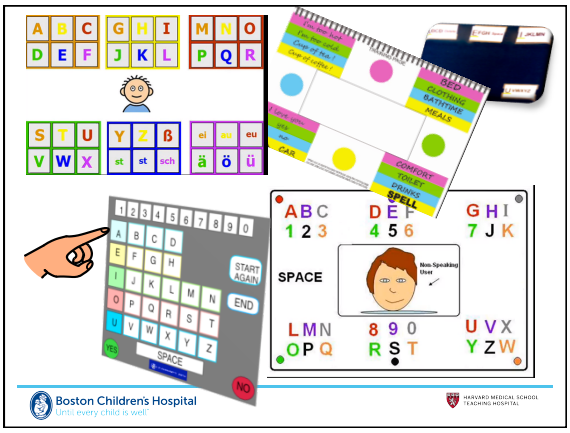
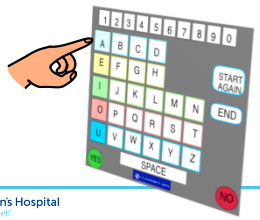


Partner Assisted Scanning

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



Patient photo or video

Partner assist scan

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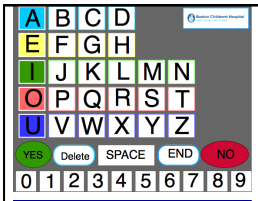

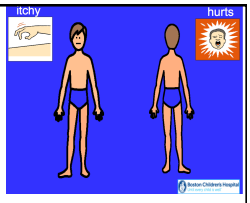

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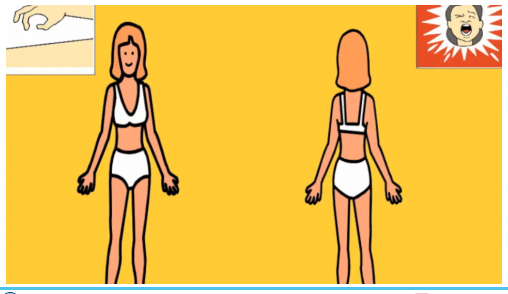
Review of 'body board'



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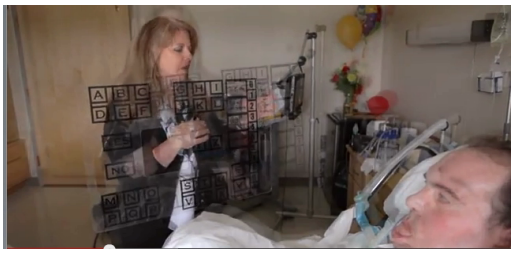
Etran

Video courtesy of ALS association (Iowa Chapter)



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ELECTRONIC ENCODING

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Electronic encoding

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

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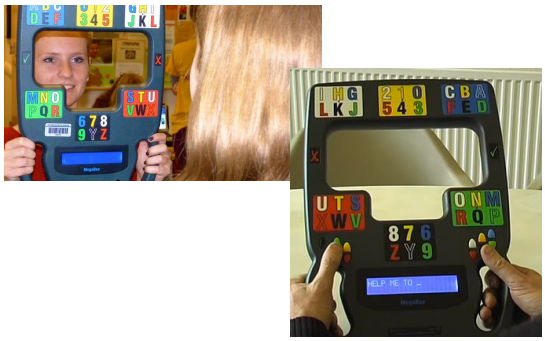

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Abbreviated expansions with Logical Letter Encoding/Salient Letter Encoding

- 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

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SENIOR CITIZEN TEXTING CODE....

ATD~At The Doctors
BFF~Best Friend Fell
BTW~Bring the Wheelchair
BYOT~Bring Your Own Teeth
FWIW~Forgot Where I Was
GGPBL~Gotta Go Pacemaker Battery Low
GHA~Got Heartburn Again
IMHO~Is My Hearing-Aid On
LMDO~Laughing My Dentures Out
OMMR~On My Massage Recliner
OMSG ~Oh My! Sorry, Gas
ROFLACGU~Rolling On Floor Laughing And Can't Get Up
TTYL..Talk To You Louder

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QUICK ACCESS COMMUNICATION (NOT ENCODING)

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Quick Access (non-electronic continued)

- Personal tabbed flip chart
- Alphacore displays or others with direct selection by:
  - Hand
  - Stylus
  - Safe laser

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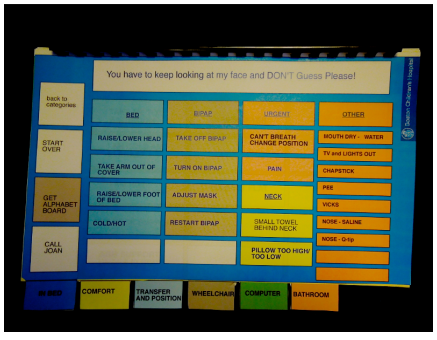

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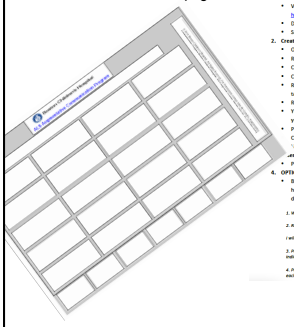
On our new ALS webpage



Creating a customized flip chart for PARTNER ASSISTED SCANNING

(a partner reads through categories, turns pages and reads through messages on selected page for the communicator)

1. **Download and save template**
   - Verify your computer is running the most recent version of Adobe Acrobat Reader (free download from https://get.adobe.com/reader/)
   - Download flip book template from website (ADD LINK)
   - Save template to a convenient location on your computer
2. **Create topic-specific pages:**
   - Open saved template in Adobe Acrobat Reader
   - RENAME template to prevent loss of saved information (File →Save as → NEWNAMEFORFILE)
   - Click 'Fill and Sign' (on right of the screen)
   - Click on an empty 'TAB' at bottom and type desired topic category
   - Rename the page for the TAB name (you will ultimately have multiple pages saved, each for the tab/category name (example: food page, positioning page, bed page, personal care page, etc.)
   - Repeat this process to create as many pages as needed, staggering the TAB labels from left to right
   - You may then fill each page with appropriate messages (you may have to drag the text and center it after you type it).
   - Print each page
     Cut the excess paper and the blank tabs on each page so ONLY the labeled tab remains.
     *we up all pages to be certain ALL tabs are visible.
3. **Assemble flip chart:**
   - Place topic-specific pages with tabs staggered from left to right
4. **OPTIONAL DIRECTIONS PAGE**
   - Because many people have multiple communication partners, some of whom may not be familiar with how to use this customized flip chart, you may wish to add a 'directions' cover sheet. The following directions have been developed by and successfully used by many people with ALS and their partners:

1. When I signal a need, if the message is not immediately understood, ask 'Is it on the flipbook?' If the answer is 'YES', then:

2. Read through and point to each topic 'tab'.

I will select by (enter appropriate method...blink, nod, vocalize, etc.) indicating what I want to say is on that page.

3. Point to each row on that page. I will select the row by_____. To save energy, I WILL NOT indicate NO, I will only indicate 'yes'...so continue to go through each item until I respond.

4. Point to each item in selected row. To save energy, I WILL NOT indicate NO, I will only indicate 'yes'...so continue to go through each item until I respond.

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Safe laser and core vocabulary

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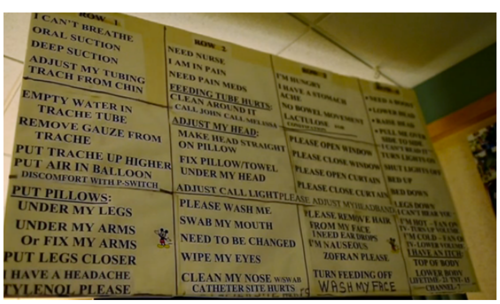

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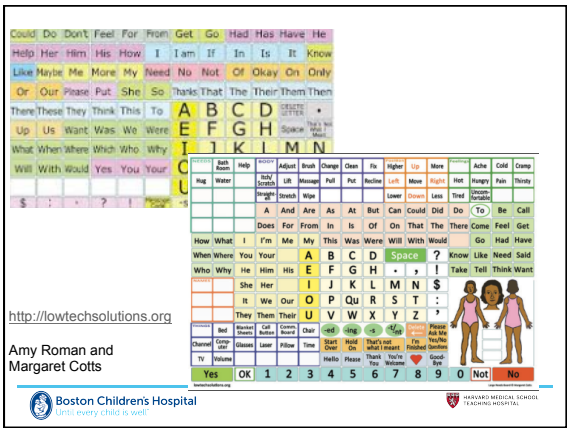

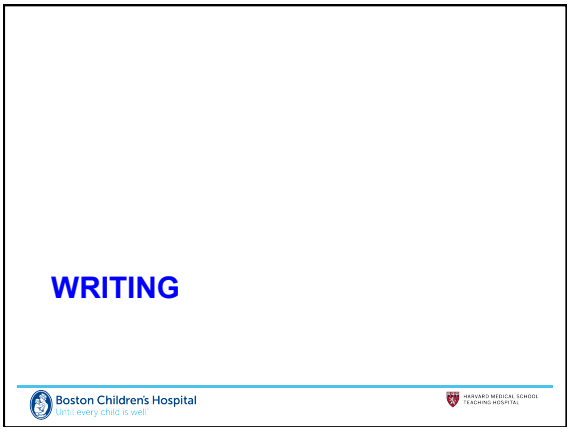

Boogie Board

- Used to write messages
- Can use fingernail
- Lightweight

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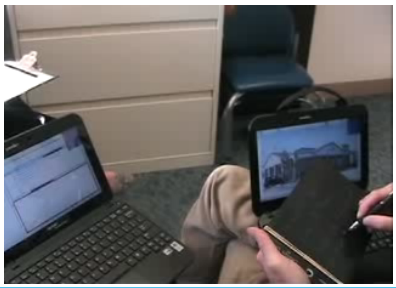
Boogie Board



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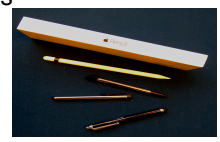
Writing strategies

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



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MESSAGE BANKING

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Message Banking

- Introduce concept/definitions and idea of *'technology agnostic'*
- Practice recording with a hand held recorder to support high quality recordings 'in the moment'.
- Share clinical stories and outcomes and provide concrete examples
- Provide full handout with definitions and thousands of examples from people with ALS
- Download, playback, label and store audio files, providing guidance for improving quality if needed.
- Review potential technologies that could accommodate message banking across varied platforms.
- Provide person with ALS with their own recorder to take home and use to functionally record.

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Message Banking .wav technology given to people with ALS

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

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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.

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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.

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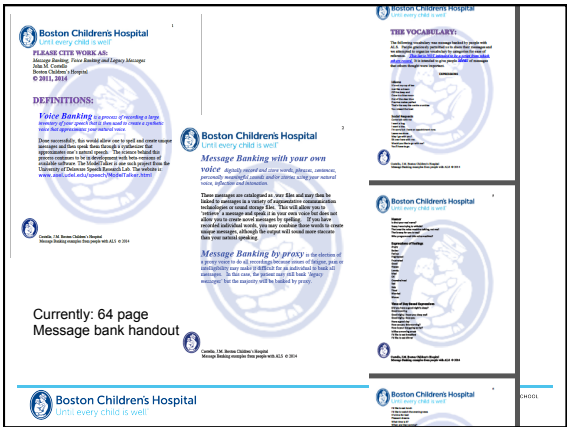

64 page handout will be on new ALS website but can be found now at:

- http://www.childrenshospital.org/~/media/messagebankdefinitionsandvocab201613.ashx?la=en

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Patient photo or video

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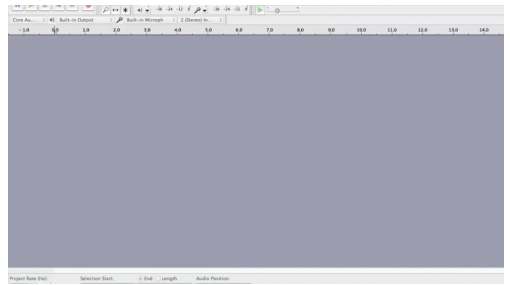
Patient photo or video

Patient photo or video

Edit one audio file into multiples

Audacity

Hi D.D. coffee Ride great



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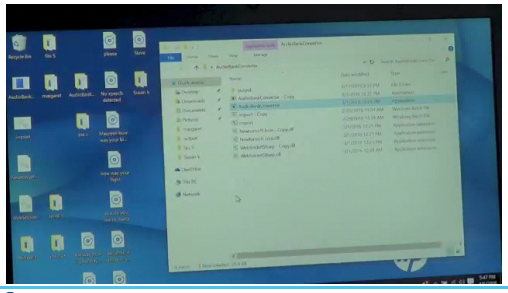
Audio conversion beta.1 (will be free to all)



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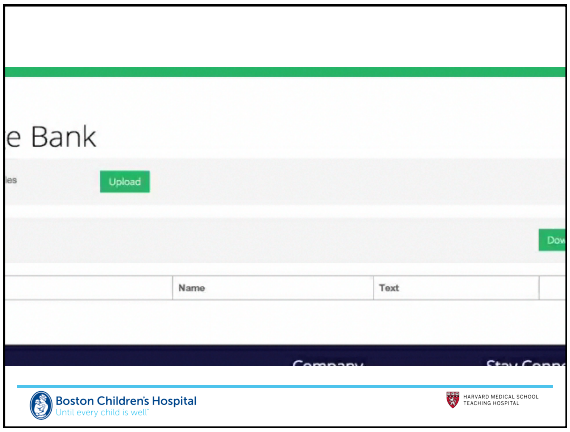
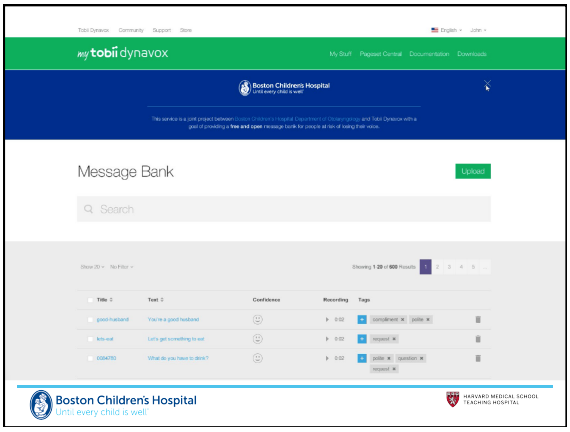
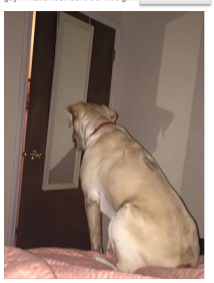




Stu is in the process of 'voice banking' where he records messages in his own voice, should he be robbed of it, due to ALS. Tonight's job was to record Swanson's commands. She was banished to stay with me behind closed doors, because she kept responding to all of his commands. The last, 'Swanson, fetch' caused her to run out to the kitchen and bring anything she could find...a bag of cough drops. She is not at all happy because she can still her her commands and can't get out to help her guy. What a hoot. Love our little girl!!



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Patient photo or video

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Patient photo or video

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Patient photo or video

Vocabulary

- Vocal play with children
- Many loving messages to children
- Many messages to wife
- Vacation/quality family time messages
- Anger
- Defending self dignity anticipating severe disability
- Directives to anticipated staff
- Changes in physical state
- Refusal of medical treatment

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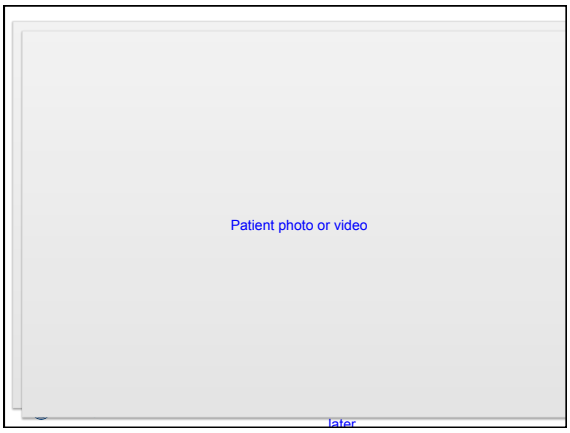
Patient photo or video



update

Nancy

Sent: Monday, August 8, 2016 12:56 PM

To: Costello, John (Otolaryngology)

Cc: g hoo.com)

It is no exaggeration to say the Tobli board makes me want to live!

I sang Happy Birthday to my one year old grandchildren on Saturday. I cracked some hysterical jokes.

I made my husband weep for joy on our anniversary.

It works well enough outside at church. Here I mostly say I love you over and over.

Keep up the good work,

Nancy

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Patient photo or video

VOICE BANKING

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Voice Banking

- Provide definition and description of process
- Provide examples of voices created

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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.*

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

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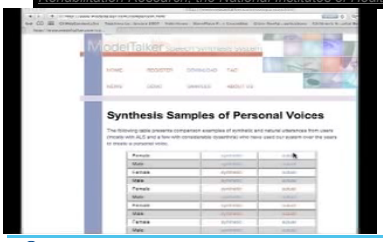
ModelTalker
http://www.modeltalker.com

The ModelTalker System was developed by the Nemours Speech Research Laboratory located at the Alfred I. duPont Hospital for Children with funding from the National Institute for Disability and Rehabilitation Research, the National Institutes of Health, and Nemours



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http://www.modeltalker.com/comparison.html

https://www.modeltalker.org/build-your-voice/

ModelTalker

Build Your Voice

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

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

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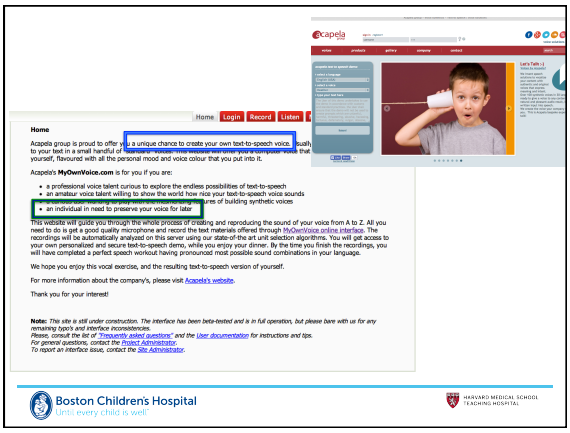
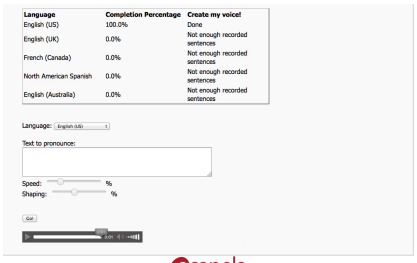


AssistiveWare Video July 2012

Custom voice created by Scottish company 'Cereproc'
http://www.cereproc.com/en/home



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

- Model Talker
- Cereproc (Edinburgh Scotland)
- OKI Electronic Industry Co Japan
- Edinburgh Voice Banking and Reconstruction project
- Acapella project
- VOCALiD

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SPEECH GENERATING DEVICE ASSESSMENT

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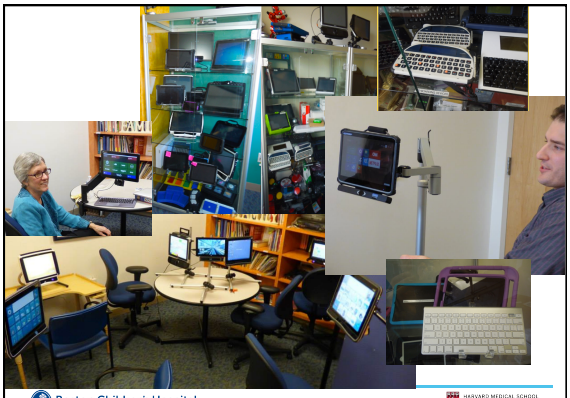

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Speech Generating Device Assessment and trial(s)

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)

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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')

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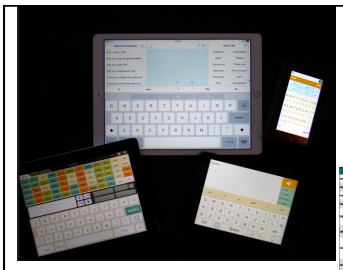

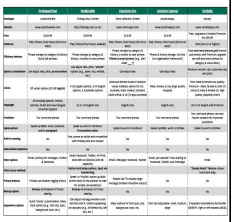

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Predictable (Therapy Box):

Import audio in Predictable

NOTE: You will not be able to hear the recorded voice until the end of the process

1. open itunes
2. click on the idevice
3. select the 'app' tab
4. then scroll to the bottom where you can see the 'file sharing' section
5. click on 'the predictable'
6. then select 'add to'
7. find and select the audio you with to import into Predictable
8. you can select a group of recordings
9. format can be .wav or others
10. from the app go to phrases
11. select the pencil icon
12. then select the phrase you wish to pair with the recording OR add new phrase
13. scroll through until 'choose from library'
14. the recordings will be listed alphabetically
15. select and it will pair with the text
16. exit edit mode to hear the recording

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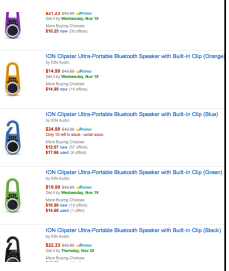
Ion Clipster
blue tooth speaker



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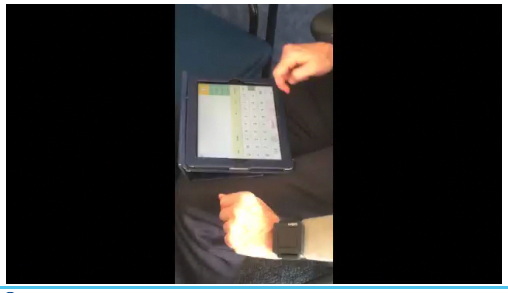
Wearable amplifier



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Occupational therapy/Assistive Technology Protocol of Assessment Considerations (over view as I am NOT an OT)	
Physical Access Control Site assessment	
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	

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Physical Access Control Site assessment

- Direct selection
- Non-direct selection
- Best control site (s) * don't over fatigue one control site:
  - Head, eyes, mouth, tongue, respiratory (sip/puff), voice, chin, shoulder, trunk, arm/hand, leg, knee, foot.
  - Pressure, excursion, range
- Neural access (neural switch), BCI

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General considerations for access selection:

(1)the range and control of movement

(2) the amount of training and practice required to use and

(3) the short and long-term costs/benefits of using access method

Phone Access

- Landline options
- Speaker phone options
- Smartphone use
- Hands-free cell phone use
- Switch scanning on iPhone
- Siri
- Mounting options

Call system/attention signal

- Commercial wireless doorbell
- Switch-adapted attendant alarm
- Baby monitor
- Portable speech output device with or without switch

Environmental control

- Enlarged TV remote controllers
- Switch access to TV functions, lights, fan
- Voice control for TV functions, lights, fan
- Control through SGD

Access to books (hardcopy or digital)

- Kindle/iBooks
- Hardcopy books/ book holders
- Page turners
- Audio books

Computer access: ***keyboard***

- Built in accessibility features
- Keyboard/key size
- Ergonomic keyboards
- Forearm supports
- Typing aids
- Word prediction software
- Onscreen keyboard software

Computer Access: *speech*

- Speech recognition software
- Dictation strategies to improve software recognition
- Built in commands
- Custom commands
- Voice mouse controls

Speech Generating Device Access

- Touch screen
- Stylus and stylus holders
- Keyboard
- Different computer mice
- And/or trackball
- Mouse
- Headtracking access (head mouse, gyro mouse, etc.)
- Adapted mouse
- Switch scanning
- Eyetracking access

Physical Access Control Site assessment (access method, access site, access settings)

- Direct selection
  - Preferred method – if possible
  - Positioning/mounting
  - Adaptive stylus
  - Computer adjustments
- Indirect selection
- Best control site (s)
  - Head, eyes, mouth, tongue, respiratory (sip/puff), voice, chin, shoulder, trunk, arm/hand, leg, knee, foot.
  - Pressure, excursion, range

Considerations for access selection:

- ❖ Motor control that is reliable and repeatable
- ❖ Motor control that is fine-tuned
- ❖ Include eye control and voice production
- ❖ Exploit the strengths and circumvent the weakness

(1) the range and control of movement
(2) the amount of training and practice required to use and
(3) the short and long-term costs/benefits of using access method

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Baker's formula….

Motivation

Physical Effort **Cognitive Effort** **Time**

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Patient photo or video

Access to iPad/Android tablets

- Position of device
- Use of finger and/or stylus
- Voice typing
- Siri
- Mounting options

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direct

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Patient photo or video

Computer Access: *mouse*

- Customizing computer mouse settings
- Adaptive/alternative cursor control options
- Hand –based
- Head-based
- Foot-based
- Eye-based
- Auto click software
- Switch click options

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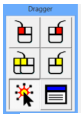

Example: Origin Head Mouse

Quha Zono Gyroscopic Air Mouse

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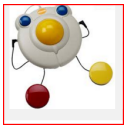
Foot Mouse

- Foot time mouse

- Trackball



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Head Mice

- Origin Instruments
- Quah Zono
- Natural Point
- Tracker Pro

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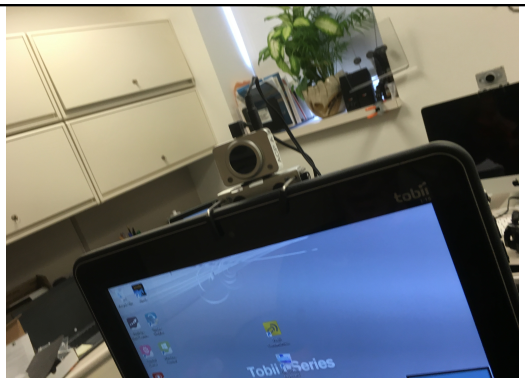

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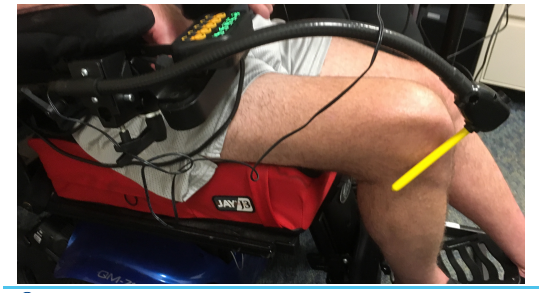
Switch selection



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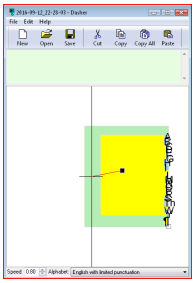
Video game style

- Dasher
  - Streaming letters Attack of the alphabet
  - Minimal movement
  - Word and phrase prediction



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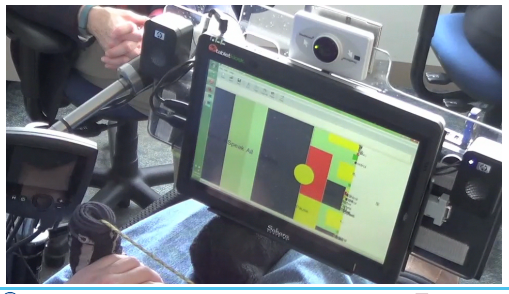

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Voice input

- (Hey) Siri
- OK Google
- Alexa
- Not intended as an accommodation for a disability. Will have difficulty with soft or dysarthric speech. Limited Functionality
  - Siri cannot voice answer an incoming call
  - Hey Siri may require the iPhone to be plugged in

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Voice input - computer

- Dragon Naturally Speaking
- Microsoft built in voice recognition software
- Not intended as an accommodation for a disability. Will have difficulty with soft or dysarthric speech.
  - Best for word processing
  - Custom commands available (Dragon)
  - Plan for a learning curve

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Eye Gaze Interface – The eyes have it

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Brain Computer Interface (BCI)

- Projects with which we are currently affiliated:
- Oregon Health Science Project RSVP
- National Center for Adapted Neuro Technologies Wadsworth Ctr. I NY

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Brain Computer interface

- Projects with which we are currently affiliated:
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Tele-treatment

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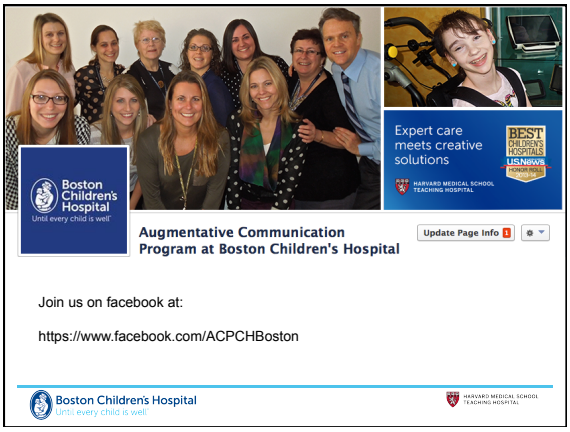

Feb 16, 2016

Dear John,

Thank you for our meeting last Tues. As we move forward slowly, I appreciate your intent to truly understand Eric and his desires. As you have surmised he is slowly processing what he wants, and " forcing" decisions does not work. I also greatly appreciate your passion and resulting offer to always be available, even to doing home visits. I later realized what relief I felt, knowing we would not somehow be abandoned because we could not resolve the next step in a timely manner. Truly...I was relieved of an anxiety I had not realized I had.

Amelia

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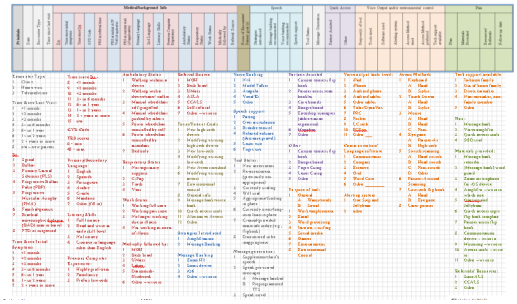

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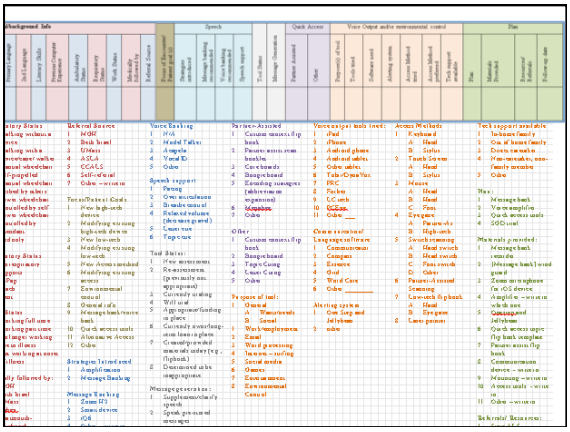

Mounting/positioning

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Wearable eye speak technology

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Introducing eye tracking to children: A developmental approach

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Calibrating at 14 months

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Page linking

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Very early Eye development:	
Eye tracking a slow moving object with jerky muscle movements	infant
Eye coordination and tracking (track a slow moving object with smooth eye movement)	By three months
Depth perception develops. Binocularity allows for development of three dimensional pereception	Three to five months
Seeing color: difficult to determine and likely infants are distinguishing brightness and contrast. DO distinguish between two highly contrasted colors such as black and white	By two to six weeks
Object and face recognition: At birth can see facial features at arms length BUT is attracted to borders so will gaze at edge of face or hairline	infant
Baby notices facial features such as the nose and mouth	Two to three months
Differentiate between mother's face and a stranger's face	Three to five months

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Eye FX from Tobii	Developmental considerations
Blank screen engagement (exploring with cause and effect) make something happen by looking anywhere	
Object displacement (learning to target, track and dwell) select to balloon to pop, spat, etc.	Perhaps black and white, high contrast edges,
Zoned focusing (developing control and accuracy) turn on all the light bulbs	
Active exploration (enhancing precision and timing)	
Controlled targeting (look and dwell)	

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