

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

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# Disclosures

- John Costello has no non-financial disclosures
  - John Costello has no financial disclosures
  - John Costello is a salaried full time employee of Boston Children's Hospital
- 
- Peggy Dellea has no non-financial disclosures
  - Peggy Dellea has no financial disclosures
  - Peggy Dellea is a salaried full time employee of Boston Children's Hospital

# 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. Describe at least six AAC strategies that can be introduced proactively to people facing the loss of functional speech or computer access.
3. Discuss and define message banking vs. voice banking and know resources for implementation for both.



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

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

# Augmentative Communication Program



Amanda O'Brien, CFY



Alycia Berg, SLP



Jenny Abramson, SLP



Rachel Santiago, SLP



Jennifer Buxton, OTR, ATP



Katie O'Neill, SLP



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Christina Yu, SLP - CFY





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what i think



what i say

Mohamed Ghoneimi

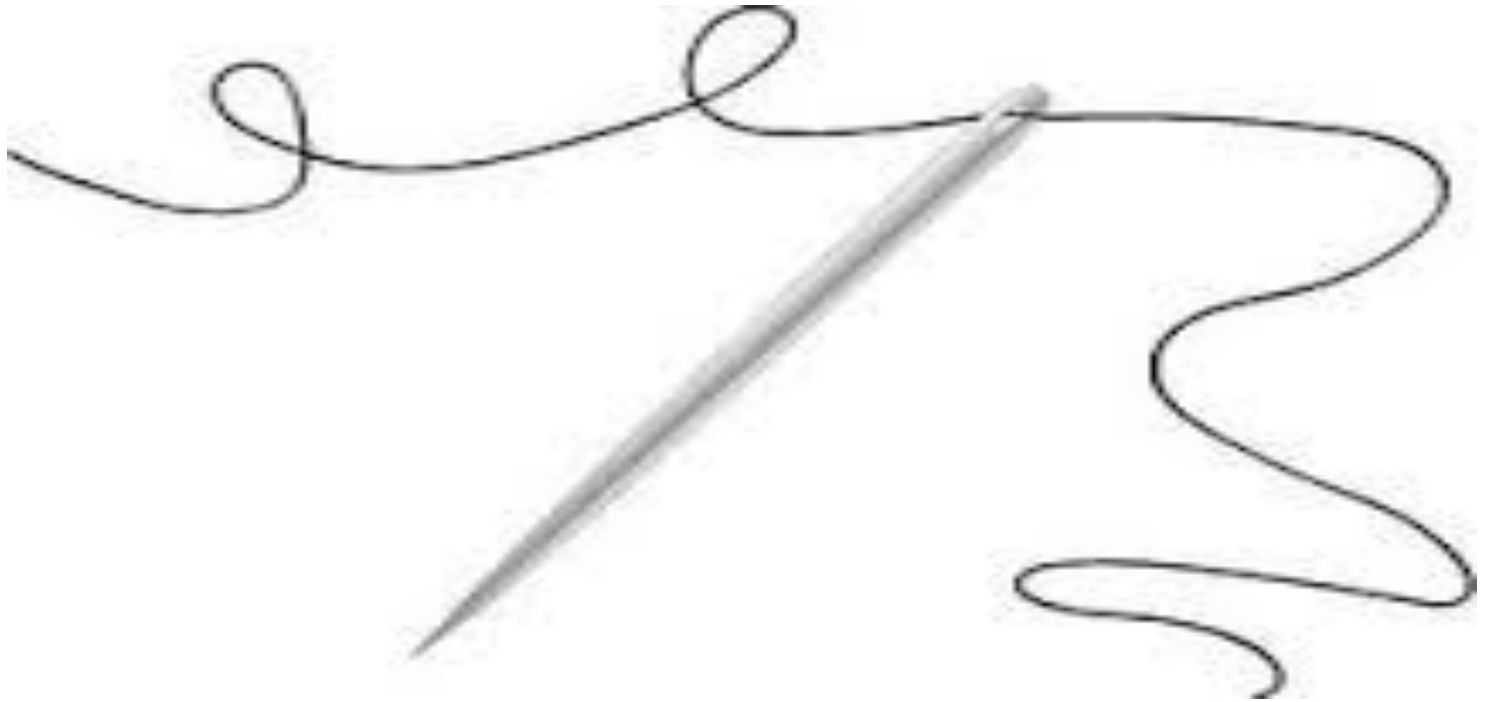


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***Communication* is the  
thread that connects us  
all**



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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](mailto: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

## **A little history**

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



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



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Patient videos

Patient videos

Patient videos

Patient videos

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

Print in landscape mode.

M i c h a e l  L  12.27 1997		mom Dad	friends here?	wat' beth' 	suck'n 	PAIN medicine 	bathroom 	When are we going? 	ask if help 	How am I doing? 
		Nana		cell phone 	pink stick 	ur' medicine 		television 	ear D' music 	NEWSPAPER 
		Annie	thank you	SUCKS!	? 	hospital bed 	DRESSING 	SOCKS 	open able close 	Base Red Sox 
		YES	NO	OK	ugh 	uncomfortable 	cold 	hot 	handsome 	pen and paper 





## 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.



Patient videos

Dear John, Amalya 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 precious gift. At the risk of embarrassing John, after that visit I started talking to John. I had not an email or a card. Thank's



Patient videos

## 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

# 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





# 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)



ALJAZEERA  
AMERICA

# TechKnow

SATURDAY 7:30E/4:30P



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Begin with  
**THANK YOU**  
to many extraordinary  
people with ALS



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***Opening statement:***

***“My goal is to  
waste your time”***



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***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



# Resources

located at our new website. Will be live by end of December 2016.

The screenshot shows the website for the ALS Augmentative Communication Program at Boston Children's Hospital. At the top, the hospital logo and tagline "Until every child is well" are visible, along with navigation links for "International Visitors", "MyChildren's Patient Portal", and "Donate". A blue navigation bar contains links for "Patient Resources", "Clinician Resources", "Centers + Services", "Research + Innovation", "Conditions + Treatments", and "Ways to Help", along with a search bar. The main heading is "ALS Augmentative Communication Program" with a breadcrumb trail: "Home > Centers + Services > Programs and Services > ALS Augmentative Communication Program Overview". Below this is a dropdown menu "How Can We Help You?". The main content area features a sidebar with "Overview", "Meet Our Team", "Patient Resources", and "Contact Us". The "Overview" section includes social media icons and a description: "Boston Children's Hospital ALS Augmentative Communication Program provides comprehensive augmentative communication and assistive technology assessment, trials and training to people with ALS from the time of diagnosis through the lifespan." A yellow call-to-action box says "Contact the ALS Augmentative Communication Program" with the phone number "781-216-2229". Below the text is a video player showing three people in a clinical setting. The video player controls show a duration of 0:00 / 4:48.



# SPEECH STRATEGIES



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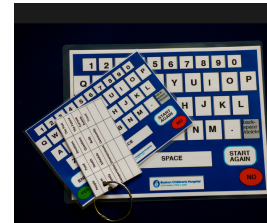


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# Speech strategies

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- 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



# 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**

# Topic Cue board

<b>People</b>	<b>Food</b>	<b>Emotions</b>
<b>Places</b>	<b>Colors</b>	<b>Questions</b>
<b>Animals</b>	<b>Entertainment</b>	<b>Body</b>
<b>School</b>	<b>Home</b>	<b>Community</b>

# Identification/explanation card for car

A	B	C	D	E	F	 <p>For more information, contact The ALS Association, National Office, 27001 Agoura Road, Suite 250, Calabasas Hills, CA 91301-5014 (800) 782-4747 www.als.org</p>
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		
<p>ALS is a neurodegenerative disease that attacks the nerves that control voluntary muscle movement, including the muscles that control speech and swallowing.</p> <p>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.</p>						
<p>Every day 15 people in the U.S. are diagnosed with ALS, two-thirds the incidence of multiple sclerosis.</p> <p>Donations to The ALS Association support:</p> <ul style="list-style-type: none"> <li><input type="checkbox"/> Educational programs and literature</li> <li><input type="checkbox"/> Basic science and clinical management research</li> <li><input type="checkbox"/> Programs and services to help individual patients and families</li> <li><input type="checkbox"/> Advocacy that improves benefits and services for people with ALS</li> </ul> 						
<p>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.</p> 						
<p>Emergency Contact Person: _____</p> <p>Telephone number: _____</p> <p>My name is: _____</p> <p>My telephone number is: _____</p>						

<http://alsworldwide.org>



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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5808 Dawley 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.

# 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

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- 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.

Patient videos



## 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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ALS Augmentative Communication Program © 2016



Patient videos

Patient videos

# AMPLIFICATION CONSIDERATIONS



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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



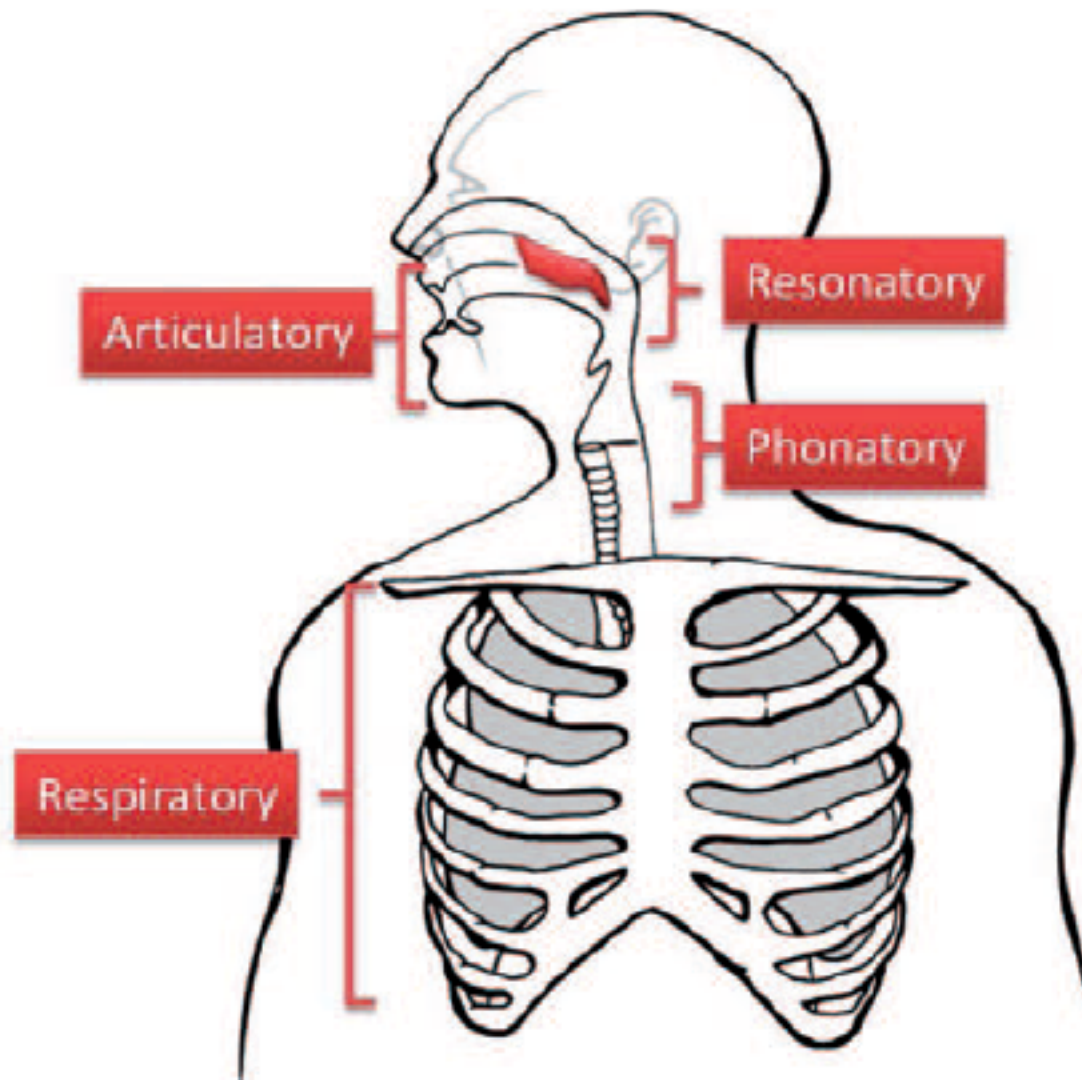
## Often will be told:

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

# Speech production requires:

- Articulation
- Phonation
- Resonation
- Respiration





# 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)



# Articulation

Highly coordinated movement of  
lips, tongue and jaw



# Resonance

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





Patient videos

Patient videos

Patient videos

Patient videos

# AMPLIFICATION WITH BIPAP



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# Amplification while using bi-pap

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Assessment of transdermal microphone options



Patient videos

# EMERGENCY CALL



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When using in the same house....



# Home alone and calling 911 when speech is difficult

## The Silent Call Procedure

If you need to call 9-1-1 and you are unable to speak for any reason, once the call is answered:

Press

1

If you need police



2

If you need fire



3

If you need an ambulance



If the 9-1-1 dispatcher asks questions, press

4

For YES ✓

5

For NO ⚡

Source: MA State 911 Department and the Executive Office of Public Safety and Security

Mass.gov

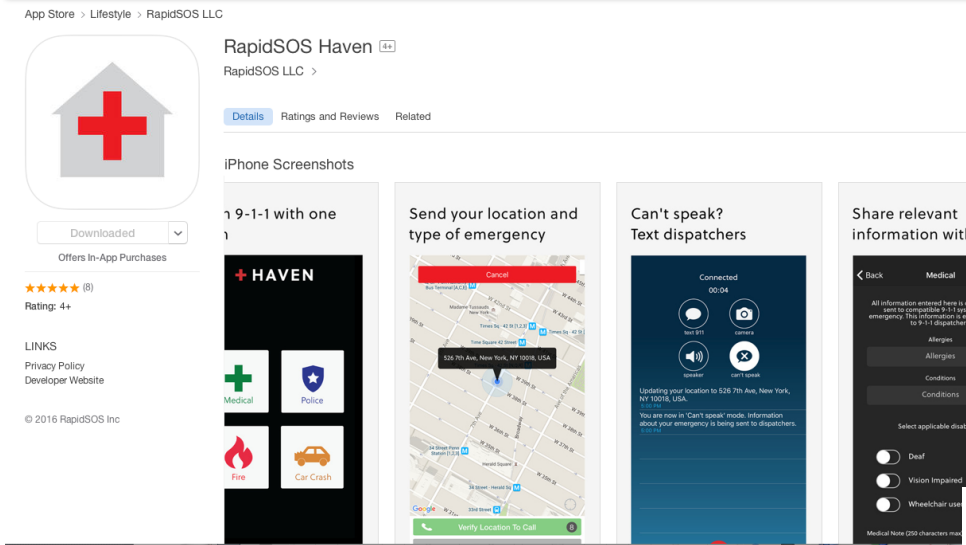


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# Phone app for emergency requiring no speech



## + Tap

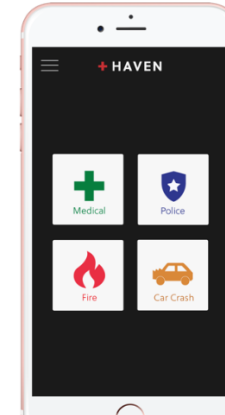
With one touch, inform 9-1-1 of the type of emergency you are facing, enabling help to get to you sooner.

## 📍 Confirm

Provide GPS location and relevant data to 9-1-1 dispatcher systems.

## 📶 Connect

Intelligent connectivity provides you with the strongest connection available, even if you have poor service or a depleting battery.



## 📄 Send

Haven sends relevant medical and demographic data to assist life-saving efforts.

## 💬 Text

Text first responders when you can't speak or need to get help discreetly.

## 📢 Alert

Alerts your loved ones and provides them with key information about your emergency, keeping your family connected.

## 🌐 Travel

One touch emergency calling in 250+ countries and territories.

## 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.

# QUICK ACCESS ENCODING (NON-ELECTRONIC)



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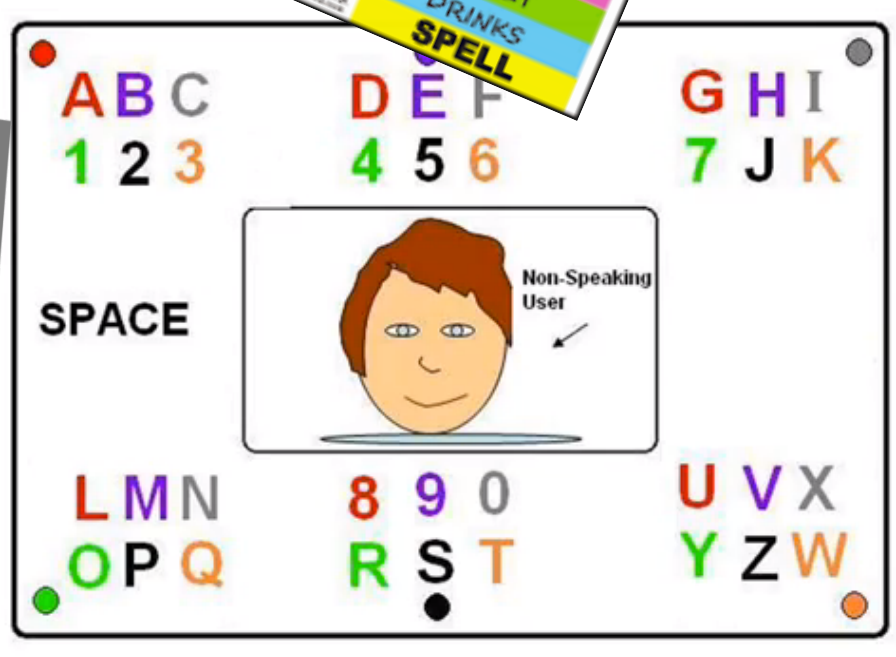
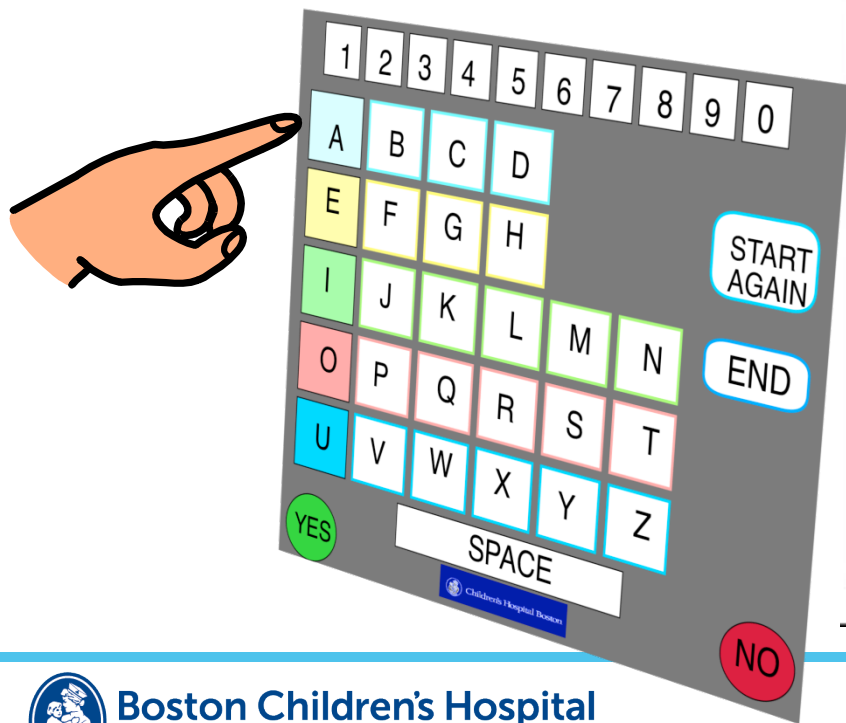
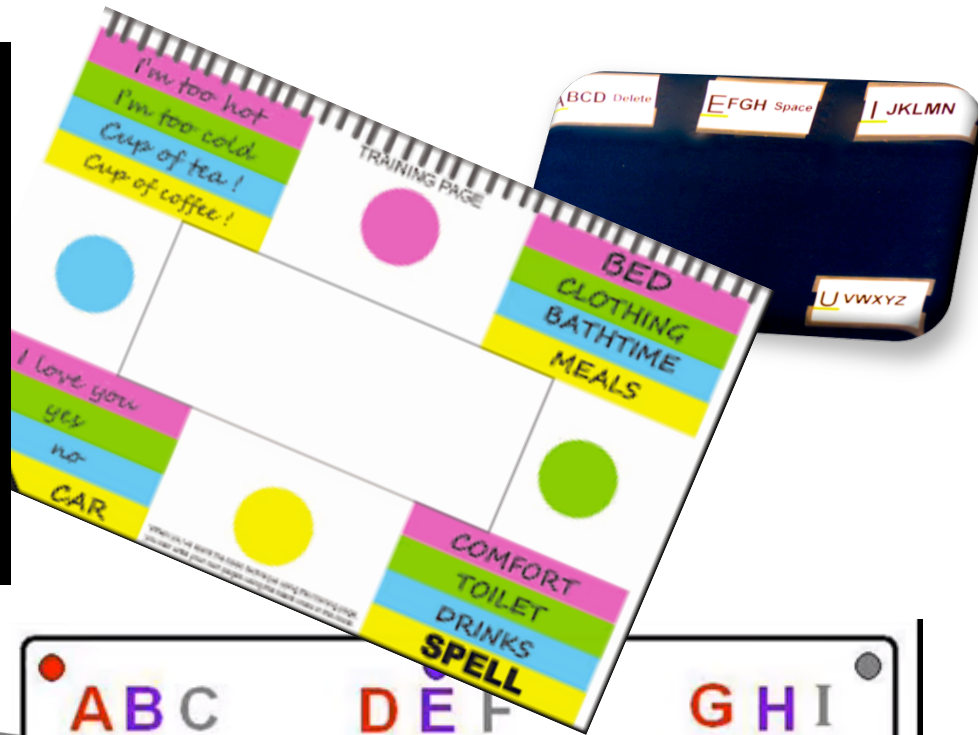
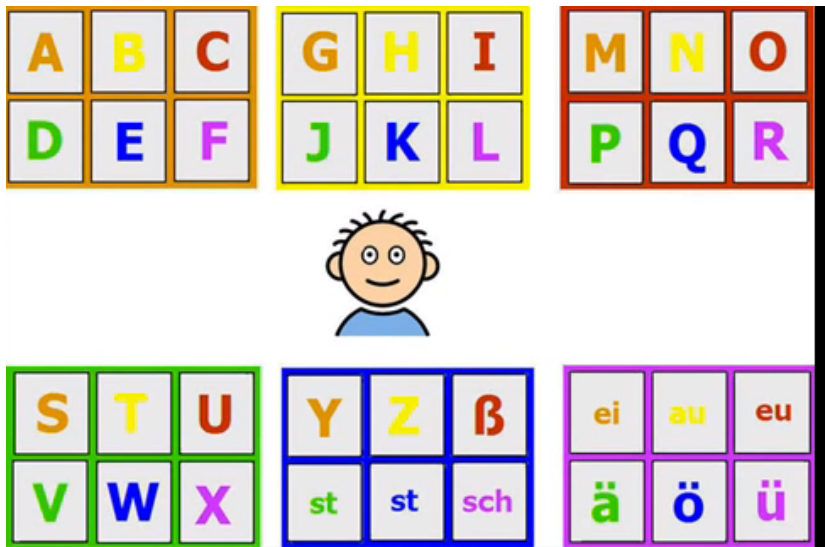


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# Quick Access Encoding

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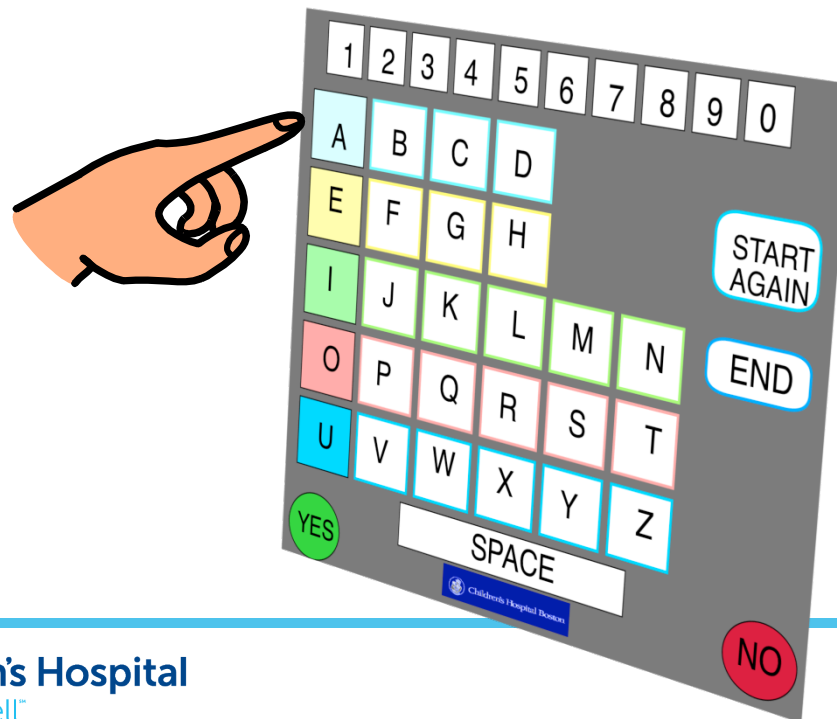
- Standard Etran two-step encoding
- eye gaze and partner assist combination (AEIOU)
- Alpha – color encoding
- EyeSpeak board





# Partner Assisted Scanning

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



Patient videos

# Partner assist scan



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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

YES Delete SPACE END NO

0 1 2 3 4 5 6 7 8 9

**itchy** **hurts**

Two human figures are shown. The left figure is labeled 'itchy' and has a hand scratching its arm. The right figure is labeled 'hurts' and has a sunburst over its head with a crying face.

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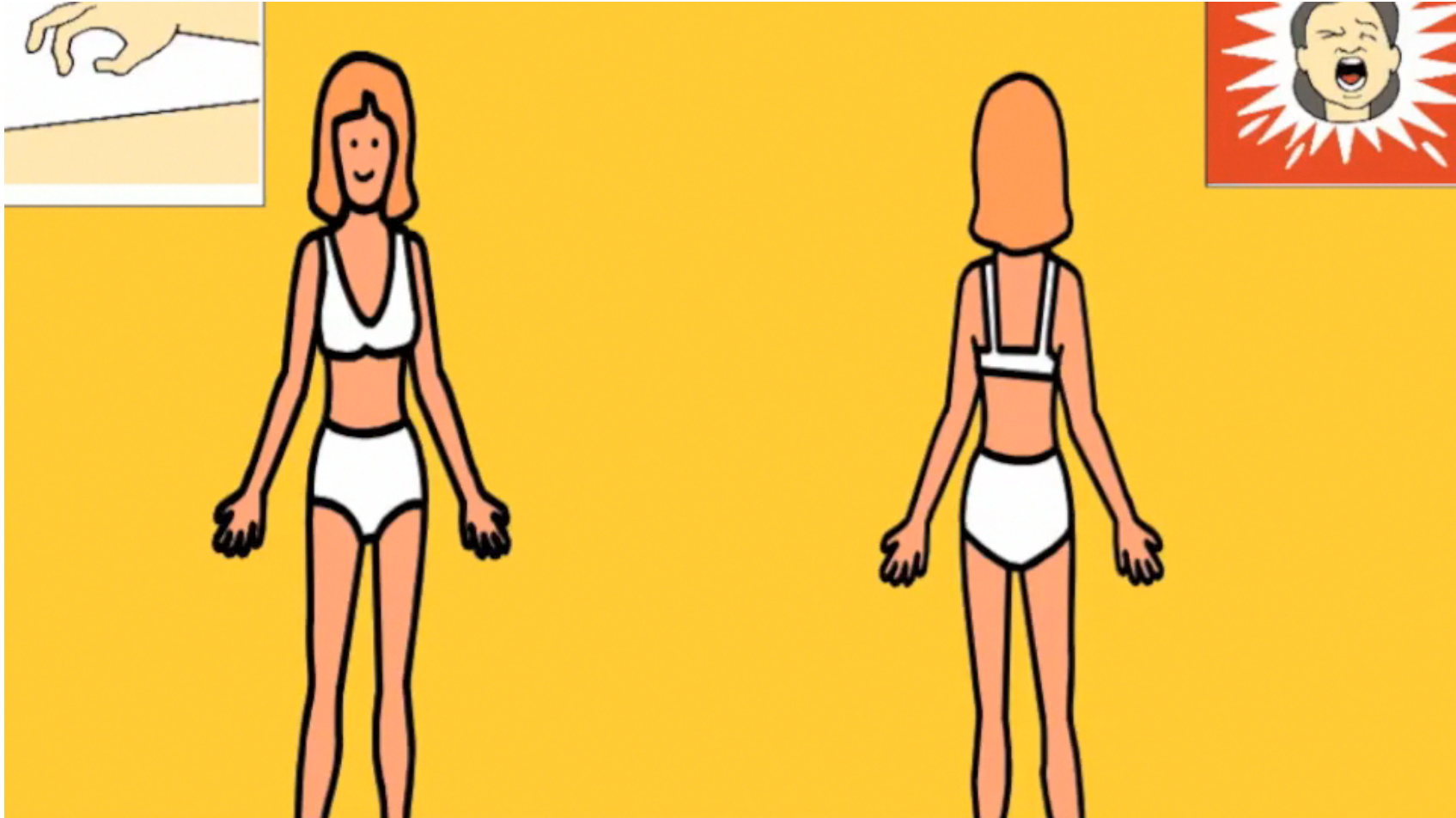
**Yes** **NO**

something else/not sure/  
more info

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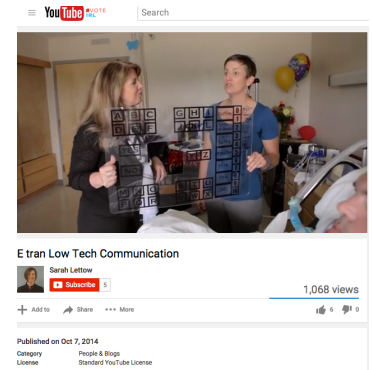
0 NO HURT  
2 HURTS LITTLE BIT  
4 HURTS LITTLE MORE  
6 HURTS EVEN MORE  
8 HURTS WHOLE LOT  
10 HURTS WORST

# Review of 'body board'



# Etran

Video courtesy of ALS association  
(Iowa Chapter YouTube)



# ELECTRONIC ENCODING



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# Electronic encoding

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





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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

## 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



# QUICK ACCESS COMMUNICATION (NOT ENCODING)



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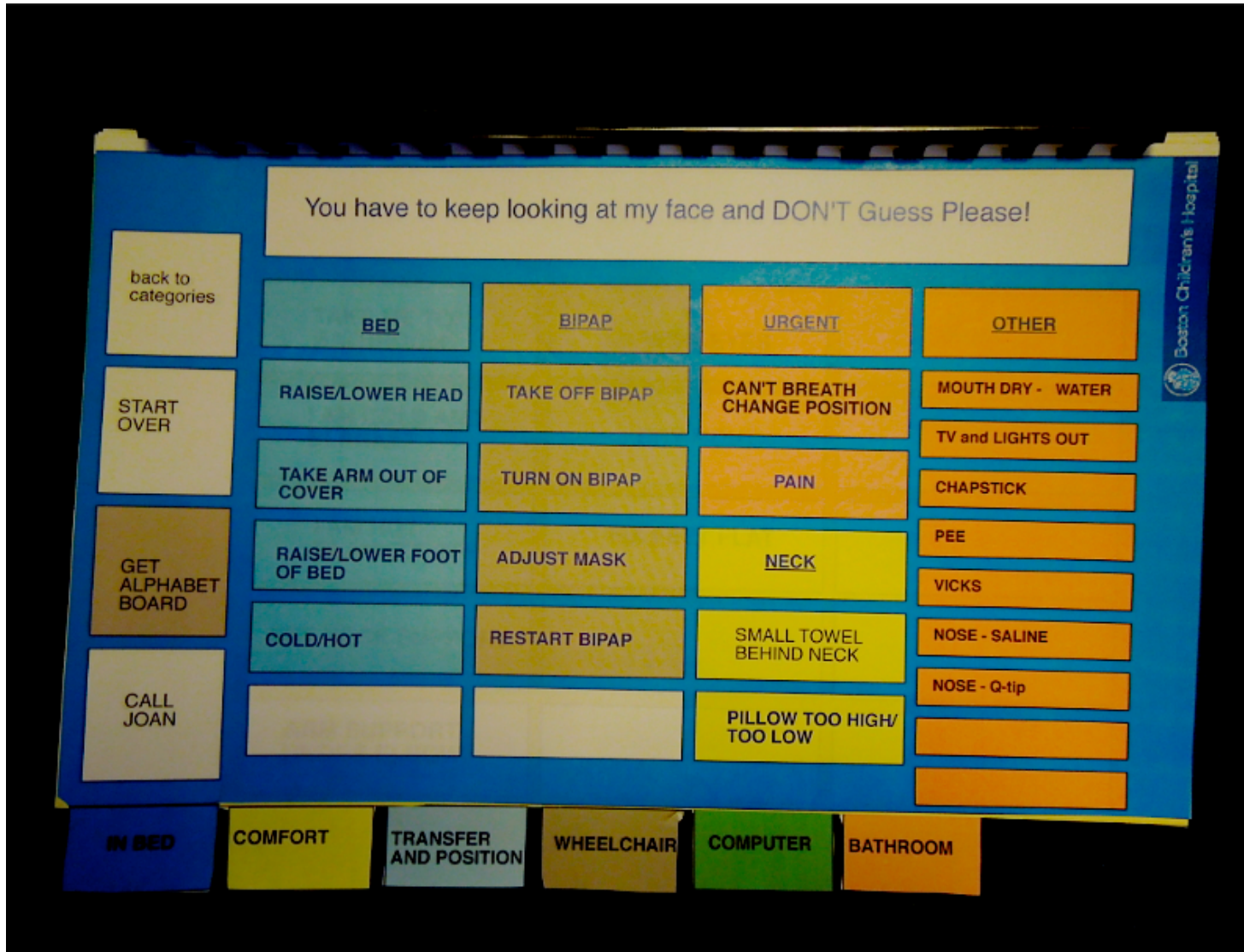


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# Quick Access (non-electronic continued)

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





# 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.  
Line up all pages to be certain ALL tabs are visible.

### 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:

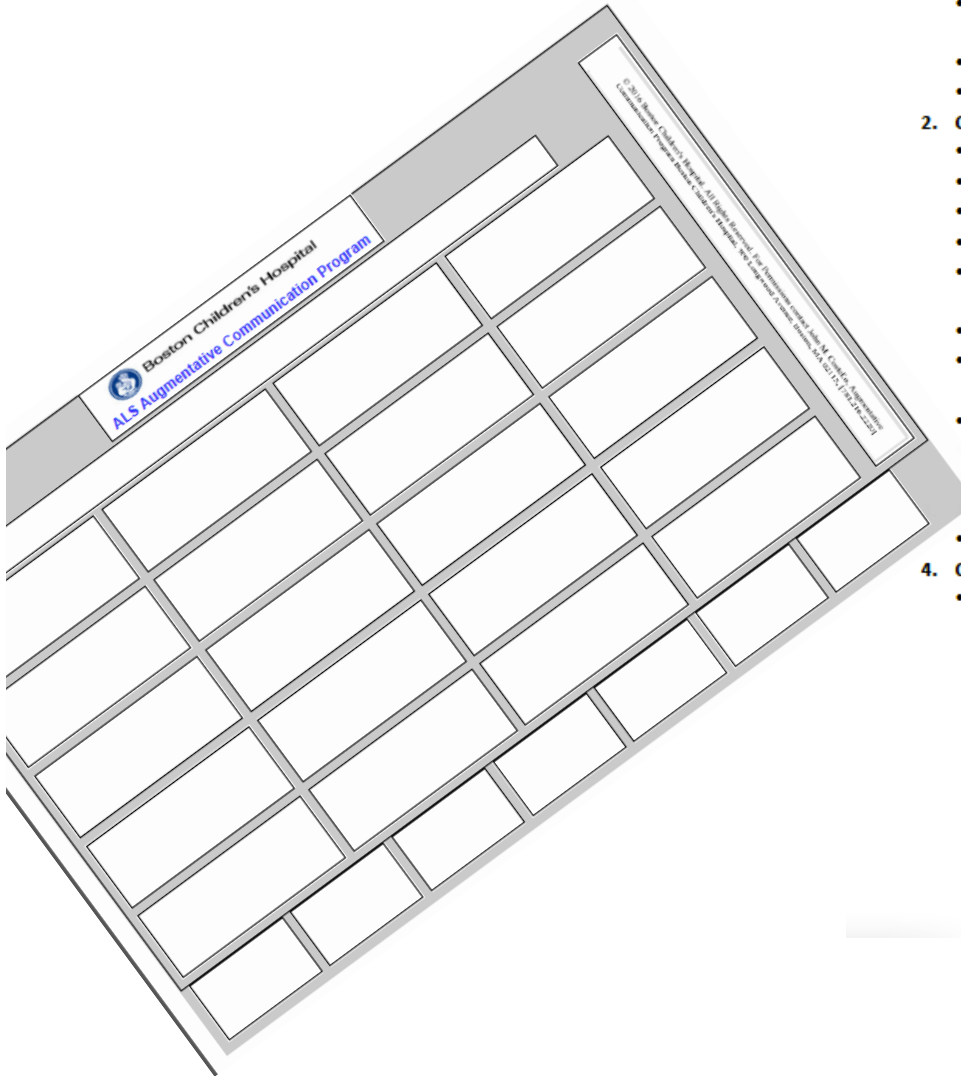
1. When I signal a need, if the message is not immediately understood, ask 'Is it on the flipbook?' If the answer is 'YES', then:

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.





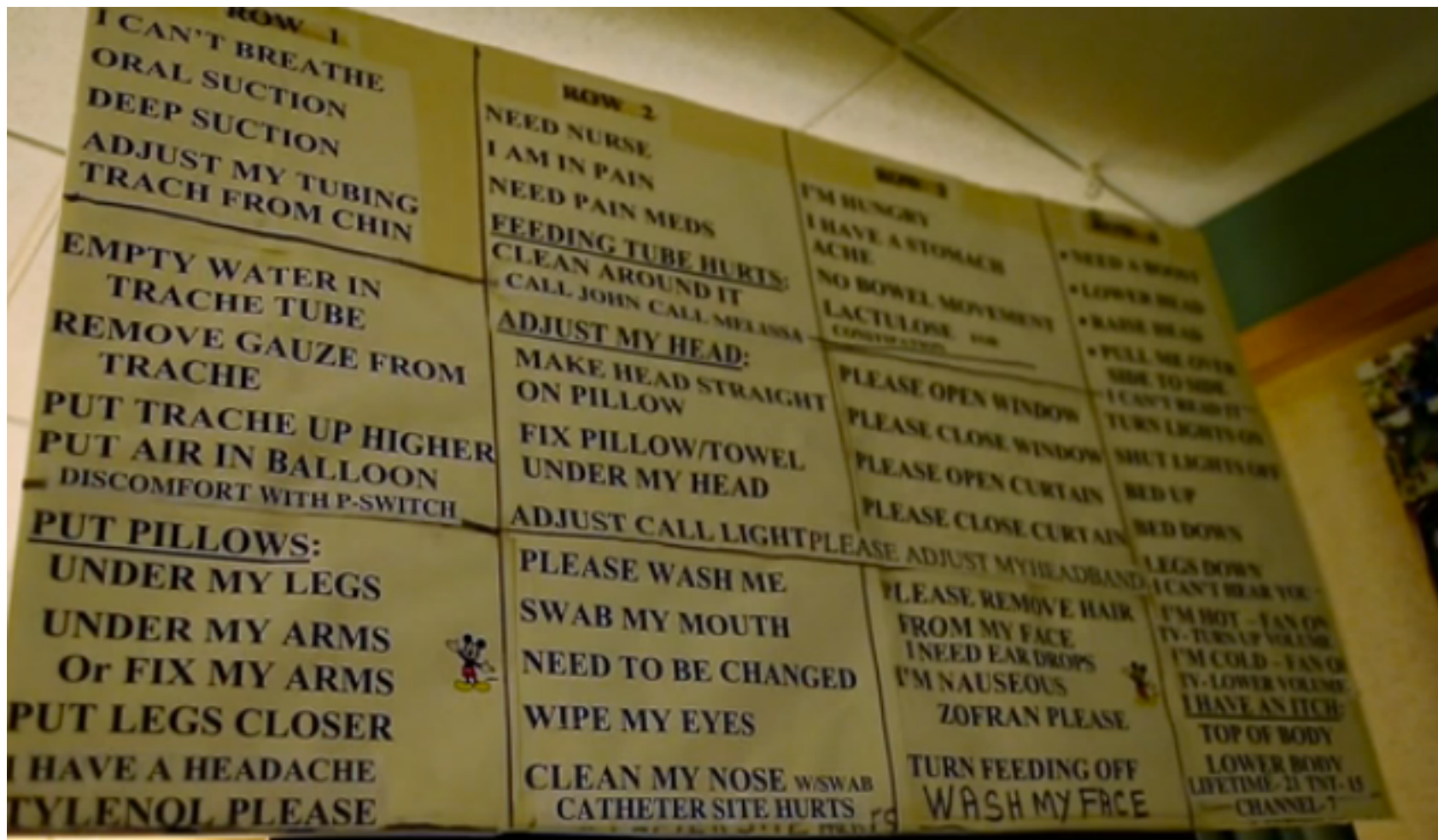
# Safe laser and core vocabulary





Patient videos

Patient videos



Could	Do	Don't	Feel	Far	From	Get	Go	Had	Has	Have	He
Help	Her	Him	His	How	I	I am	If	In	Is	It	Know
Like	Maybe	Me	More	My	Need	No	Not	Of	Okay	On	Only
Or	Our	Please	Put	She	So	Thanks	That	The	Their	Them	Then
There	These	They	Think	This	To	A	B	C	D	DELETE LETTER	.
Up	Us	Want	Was	We	Were	E	F	G	H	Space	This is not what I Mean!
What	When	Where	Which	Who	Why	I	J	K	L	M	N
Will	With	Would	Yes	You	Your	O	P	Q	R	S	T
\$	:	.	?	!	-s	U	V	W	X	Y	Z

NEEDS	Bath Room	Help	BODY	Adjust	Brush	Change	Clean	Fix	POISON	Higher	Up	More	Feelings	Ache	Cold	Cramp
Hug	Water		Itch/Scratch	Lift	Massage	Pull	Put	Recline	Left	Move	Right	Hot	Hungry	Pain	Thirsty	
			Straighten	Stretch	Wipe				Lower	Down	Less	Tired	Uncomfortable			
			A	And	Are	As	At	But	Can	Could	Did	Do	To	Be	Call	
			Does	For	From	In	Is	Of	On	That	The	There	Come	Feel	Get	
How	What	I	I'm	Me	My	This	Was	Were	Will	With	Would		Go	Had	Have	
When	Where	You	Your		A	B	C	D	Space	?	Know	Like	Need	Said		
Who	Why	He	Him	His	E	F	G	H	.	,	!	Take	Tell	Think	Want	
NAMES		She	Her		I	J	K	L	M	N	\$					
		It	We	Our	O	P	Qu	R	S	T	:					
		They	Them	Their	U	V	W	X	Y	Z	'					
THINGS	Bed	Blanket Sheets	Call Button	Comm. Board	Chair	-ed	-ing	-s	-t/-nt	Delete	Please Ask Me	Yes/No Questions				
Channel	Computer	Glasses	Laser	Pillow	Time	Start Over	Hold On	That's not what I meant	I'm Finished							
TV	Volume					Hello	Please	Thank You	You're Welcome	♥	Good-Bye					
Yes	OK	1	2	3	4	5	6	7	8	9	0	Not	No			



<http://lowtechsolutions.org>

Amy Roman and Margaret Cotts



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Patient videos

# WRITING



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# Boogie Board

- Used to write messages
- Can use fingernail
- Lightweight







Patient videos

# Writing strategies

---

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



# MESSAGE BANKING



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“Our voice is our ACOUSTICAL fingerprint”



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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.



# Message Banking .wav technology given to people with ALS







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



# *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.



**PLEASE CITE WORK AS:**

*Message Banking, Voice Banking and Legacy Messages*  
John M. Costello  
Boston Children's Hospital  
© 2011, 2014

**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](http://www.asel.udel.edu/speech/ModelTalker.html)



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Message Banking examples from people with ALS © 2014

Currently: 64 page  
Message bank handout



***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.

***Message Banking by proxy** is the election of a proxy voice to do all recordings because issues of fatigue, pain or intelligibility may make it difficult for an individual to bank all messages. In this case, the patient may still bank 'legacy messages' but the majority will be banked by proxy.*



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Message Banking examples from people with ALS © 2014



**THE VOCABULARY:**

The following vocabulary was message banked by people with ALS. People graciously permitted us to share their messages and we attempted to organize the vocabulary by categories for ease of reference. [This list is NOT intended to be a proxy from which you are record.](#) It is intended to give people **ideas** of messages that others thought were important.

**EXPRESSIONS**

**Idioms**  
It's not my cup of tea  
Just the way  
Off the deep end  
Close to the moon  
Out of the blue  
Practice makes perfect  
That's the way the cookie crumbles  
You missed the boat

**Social Requests**  
Come talk with me  
I want a hug  
I need a lift  
Do you feel I have an appointment time?  
Leave me alone  
May I go with you?  
Oh how time with me  
Would you like to go with me?  
You'll have to go.



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Message Banking examples from people with ALS © 2014



**Humor**  
Is that your real name?  
Some / something to while (at)  
That one like when machine talking, normal?  
That's easy for you to say!  
Who programmed this robot/math?  
Who programmed this robot/math?

**Expressions of feelings**  
Angry  
Bitter  
Fed up  
Frightened  
Frustrated  
Glad  
Happy  
Lonely  
Mad  
Sad  
Chambelmad  
Sad  
Shy  
Dread  
Worried  
Worse

**Time of Day Based Expressions**  
Did you have a good night's sleep?  
Good morning  
Good night, I hope you sleep well  
Good night, I love you  
Have a good day  
How was your this morning?  
How is your day going so far?  
I'd like a morning snack  
I'd like to eat breakfast  
I'd like to eat dinner



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Message Banking examples from people with ALS © 2014



I'd like to eat lunch  
I'd like to watch the evening news  
It's time for bed  
Please turn down  
What time is it?  
When are they coming?



64 page handout will be on new  
ALS website but can be found now  
as the first comment under the  
announcement of USSAAC  
webinar

(dated 11.9.17)

on our clinic facebook page:

[https://www.facebook.com/](https://www.facebook.com/ACPCHBoston/)

[ACPCHBoston/](https://www.facebook.com/ACPCHBoston/)



Patient videos

Patient videos

Patient videos



Patient videos

# Edit one audio file into multiples



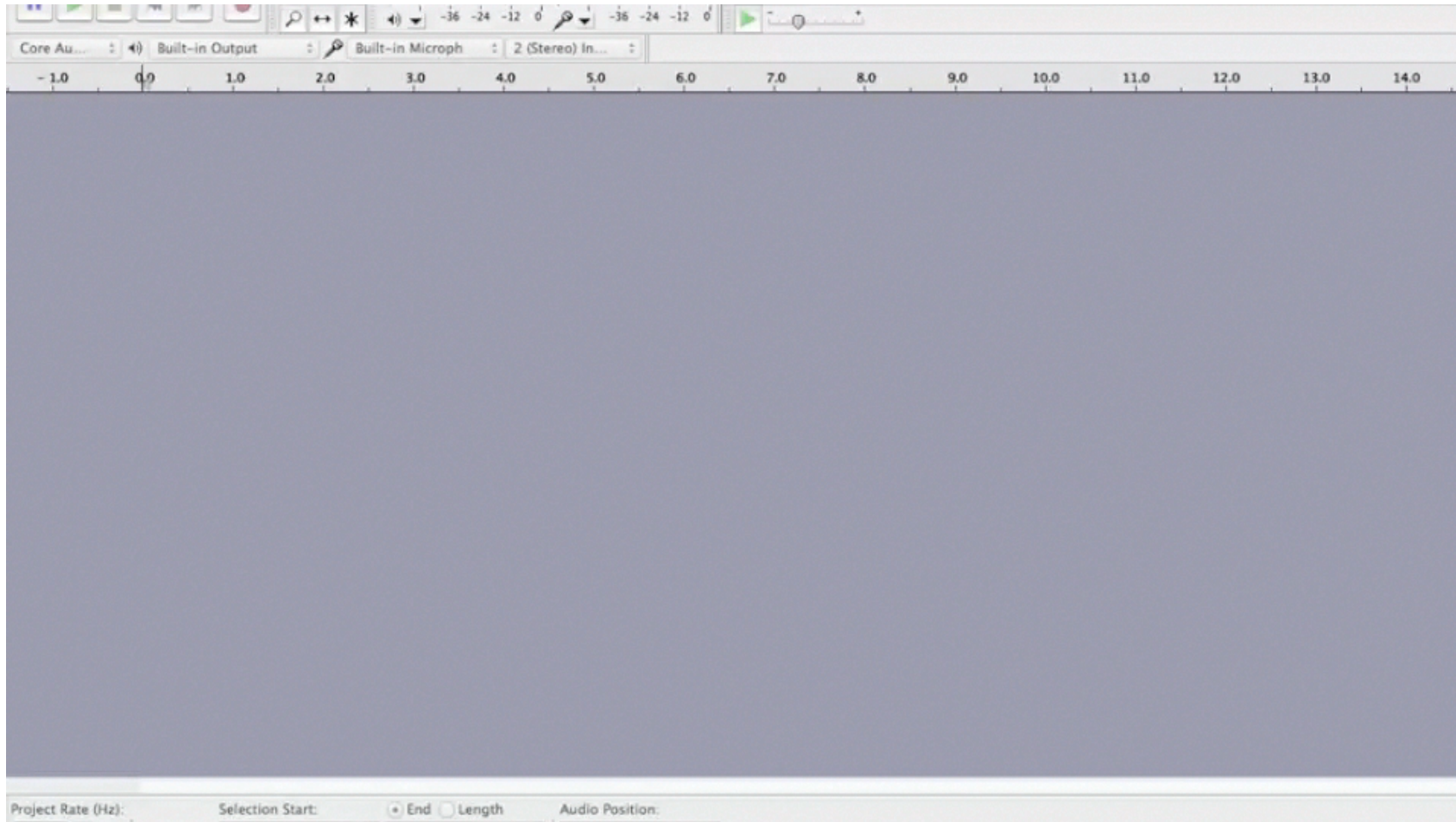
Hi



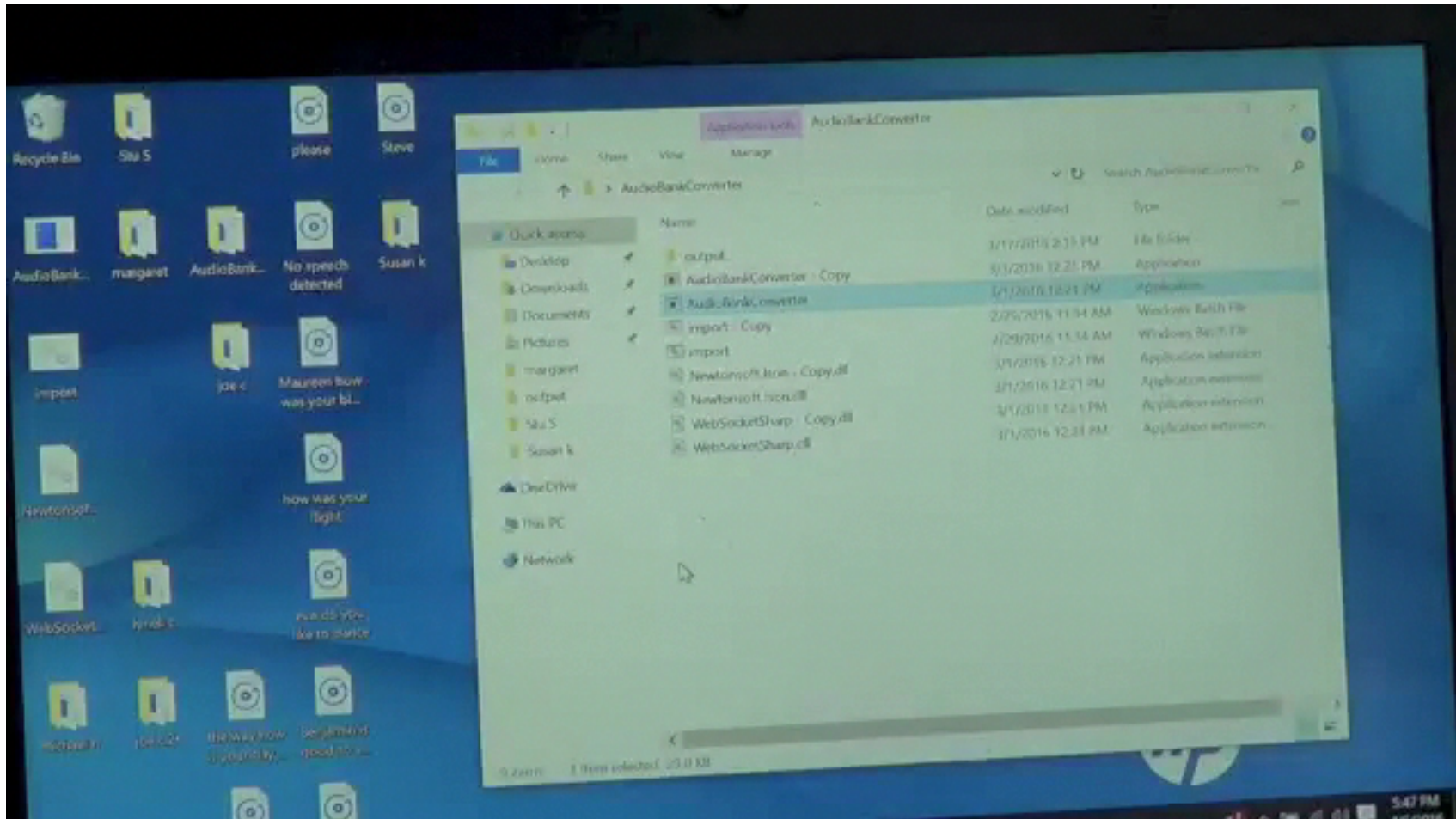
D.D. coffee



Ride great



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



# Image Bank

files

Upload

Download

Name	Text
------	------



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This service is a joint project between Boston Children's Hospital Department of Otolaryngology and Tobii Dynavox with a goal of providing a free and open message bank for people at risk of losing their voice.

# Message Bank

Upload

Search

Show 20 No Filter

Showing 1-20 of 600 Results 1 2 3 4 5 ...

<input type="checkbox"/> Title	Text	Confidence	Recording	Tags	
<input type="checkbox"/> good-husband	You're a good husband	😊	▶ 0:02	+ compliment ✕ polite ✕	🗑️
<input type="checkbox"/> lets-eat	Let's get something to eat	😊	▶ 0:02	+ request ✕	🗑️
<input type="checkbox"/> 0084780	What do you have to drink?	😊	▶ 0:02	+ polite ✕ question ✕ request ✕	🗑️

www.tobii.com/mytobii/dynavox

mytobii dynavox

Store | Pageset Central | Support | Community

# Message Bank

Search

Showing 1 - 16 of 16 results

ID	Title	Text	Confidence	Reverting	Type
1	test	test	100%	000	Text
2	dynavox page	test & dynavox	100%	000	Text
3	cancel	I like to cancel	100%	000	Text
4	do not do	I wish you wouldn't do that!	100%	000	Text



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**BETA GOING LIVE BY First week of December!!!!**



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# Message Bank

Upload

Search

Starting with a clean slate

Showing 0 - of results

« « 1 2 3 » »

No messages found.





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Upload multiple messages to the message bank from your Zoom H1 recorder

Upload

Name	Size	Date modified
ZOOM0007	3,351 KB	7/27/2010 4:25 PM
ZOOM0010	564 KB	1/5/2011 7:43 PM
ZOOM0011	601 KB	1/5/2011 7:43 PM
ZOOM0012	621 KB	1/5/2011 7:44 PM
ZOOM0013	559 KB	1/5/2011 7:44 PM
ZOOM0014	801 KB	1/5/2011 7:44 PM
ZOOM0015	641 KB	1/5/2011 7:44 PM
ZOOM0016	514 KB	1/5/2011 8:41 PM
ZOOM0017	497 KB	1/5/2011 8:45 PM
ZOOM0018	649 KB	1/5/2011 11:57 PM
ZOOM0019	1,012 KB	1/9/2011 2:30 PM
ZOOM0020	506 KB	1/9/2011 2:34 PM
ZOOM0021	1,688 KB	1/9/2011 3:29 PM
ZOOM0022	539 KB	1/9/2011 3:32 PM
ZOOM0023	415 KB	1/9/2011 7:25 PM
ZOOM0024	707 KB	1/11/2011 12:35 PM
ZOOM0025	628 KB	1/12/2011 6:28 PM
ZOOM0026	1,146 KB	1/12/2011 6:55 PM
ZOOM0027	555 KB	1/12/2011 6:55 PM
ZOOM0028	626 KB	1/12/2011 7:15 PM
ZOOM0029	481 KB	1/14/2011 12:51 AM
ZOOM0030	713 KB	1/18/2011 2:46 PM

Showing 1 - 20 of 26 results

Confidence	Recording	Tags
99%	0:01	[+]
97%	0:01	[+]
74%	0:02	[+]
58%	0:01	[+]





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## Message Bank

Selected messages are queued for upload

Upload

ZOOM0016.WAV	0%
ZOOM0017.WAV	0%
ZOOM0018.WAV	0%
ZOOM0019.WAV	0%

Upload Cancel

<input type="checkbox"/>	Title	Text	Confidence	Rec		
<input type="checkbox"/>	ZOOM0019	%HESITATION world leaders I'm tracking AAC	68%			
<input type="checkbox"/>	ZOOM0016	hostilities to baby	61%	0:02		
<input type="checkbox"/>	ZOOM0018	this marshmallow is good	100%	0:03	+	x
<input type="checkbox"/>	ZOOM0017	thank you for making that for me	100%	0:02	+	x
<input type="checkbox"/>	ZOOM0010	I think that is correct	99%	0:03	+	x
<input type="checkbox"/>	ZOOM0012	do you want to go out for a beer	97%	0:03	+	x
<input type="checkbox"/>	ZOOM0011	I wish you wouldn't do that	94%	0:03	+	x
<input type="checkbox"/>	i-cant-wait	I can't wait	99%	0:01	+	x
<input type="checkbox"/>	can-you-keep-a-secret	can you keep a secret	97%	0:01	+	x
<input type="checkbox"/>	did you close the dog door	did you close the dog door	74%	0:02	+	x
<input type="checkbox"/>	i agree	I agree				

Uploaded messages are transcribed and given a confidence score



Show 20 Show All

Showing 1 - 20 of 33 results

<input type="checkbox"/>	Title					
<input type="checkbox"/>	ZOOM0019	world leaders I'm				
<input type="checkbox"/>	ZOOM0016	Hasta la vista, baby!	68%	0:03		
<input type="checkbox"/>	ZOOM0018	this marshmallow is good	61%	0:02		
<input type="checkbox"/>	ZOOM0017	thank you for making that for me	100%	0:03		
<input type="checkbox"/>	ZOOM0010	I think that is correct	100%	0:02		
<input type="checkbox"/>	ZOOM0012	do you want to go out for a beer	99%	0:03		
<input type="checkbox"/>	ZOOM0011	I wish you wouldn't do that	97%	0:03		
<input type="checkbox"/>	i-cant-wait	I can't wait	94%	0:03		
<input type="checkbox"/>	can-you-keep-a-secret	can you keep a secret	99%	0:01		
<input type="checkbox"/>	did-you-close-the-dog-door	did you close the dog door	97%	0:01		
<input type="checkbox"/>	did-you-close-the-dog-door	did you close the dog door	74%	0:02		
<input type="checkbox"/>	i-agree	I carry				

Users can fix errors

Users listen to messages

Hasta la vista, baby!



<input type="checkbox"/>	Title	Text	Progress	Recording	Tags
<input type="checkbox"/>	ZOOM0019	%HESITATION wo tracking AAC	0:05		
<input type="checkbox"/>	ZOOM0016	Hasta la vista, baby!	0:02		
<input type="checkbox"/>	ZOOM0018	this marshmallow is good	100%  0:03		
<input type="checkbox"/>	ZOOM0017	thank you for making that for me			

Reviewed messages show acceptance



Show 20 ▾

Show All ▾

Showing 1 - 20 of 33 results

« < 1 2 > »

<input type="checkbox"/>	Title	Text	Confidence	Recording	Tags
<input type="checkbox"/>	ZOOM0019	%HESITATION world leaders I'm tracking AAC	68%	0:05	
<input type="checkbox"/>	ZOOM0016	hostilities to baby	61%	0:02	
<input type="checkbox"/>	ZOOM0018	this marshmallow is good	100%		
<input type="checkbox"/>	ZOOM0017	thank you for making that for me	100%		
<input type="checkbox"/>	ZOOM0010	I think that is correct	99%	0:03	
<input type="checkbox"/>	ZOOM0012	do you want to go out for a beer	97%	0:03	<input type="text" value="beer"/>
<input type="checkbox"/>	ZOOM0011	I wish you wouldn't do that	94%	0:03	
<input type="checkbox"/>	i-cant-wait	I can't wait	99%	0:01	
<input type="checkbox"/>	can-you-keep-a-secret	can you keep a secret	97%	0:01	
<input type="checkbox"/>	did you close the dog door	did you close the dog door	74%	0:02	
<input type="checkbox"/>	i-agree	I carry	58%	0:01	

Tag messages with one or more categories



This service is a joint project between Boston Children's Hospital Department of Otolaryngology and Tobii Dynamox with a goal of providing a **free and open** message bank for people at risk of losing their voice.

# Message Bank

Search

Show 20 ▾

Show All ▾

Showing 1 - 20 of 33 results



20 messages selected



ZOOM0019

%HESITATION world leaders I'm tracking AAC



68%



0:05



ZOOM0016

Hasta la vista, baby!



0:02



ZOOM0018

this marshmallow is good



100%



0:03



ZOOM0017

thank you for making that for me



100%



0:02



Select multiple messages to download text for offline proofing



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# Message Bank

Upload

Search

Select multiple messages to tag many at once

Show 20 ▾

Show All ▾

Showing 1 - 20 of 33 results



20 messages selected



ZOOM0019

%HESITATION world leaders I'm tracking AAC



68%



0:05



ZOOM0016

Hasta la vista, baby!



0:02



ZOOM0018

this marshmallow is good



100%



0:03



ZOOM0017

thank you for making that for me



100%



0:02





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# Message Bank

Search

Show 20 ▾

Show All ▾

Showing 1 - 20 of 33 results



20 messages selected

<input checked="" type="checkbox"/>	ZOOM0019	%HESITATION world leaders I'm tracking AAC	☹️	▶️	+	✕
			68%	0:05		
<input checked="" type="checkbox"/>	ZOOM0016	Hasta la vista, baby!	✅	▶️	+	✕
				0:02		
<input checked="" type="checkbox"/>	ZOOM0018	this marshmallow is good	😊	▶️	+	✕
			100%	0:03		
<input checked="" type="checkbox"/>	ZOOM0017	thank you for making that for me	😊	▶️	+	✕
			100%	0:02		

Select multiple messages to download a set





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# Message Bank

Search

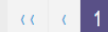
Upload

Select multiple messages to delete a set

Show 20 ▾

Show All ▾

Showing 1 - 20 of 33 results



20 messages selected



ZOOM0019

%HESITATION world leaders I'm tracking AAC



68%



0:05



ZOOM0016

Hasta la vista, baby!



100%



0:02



ZOOM0018

this marshmallow is good



100%



0:03



ZOOM0017

thank you for making that for me



100%



0:02



Patient videos









Patient videos

Patient videos

Patient videos

# 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 

Patient videos

Patient videos



Patient videos

Patient videos

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Patient videos

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Patient videos

← ↻ 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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# VOICE BANKING



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# Voice Banking

---

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

***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](http://www.asel.udel.edu/speech/ModelTalker.html)

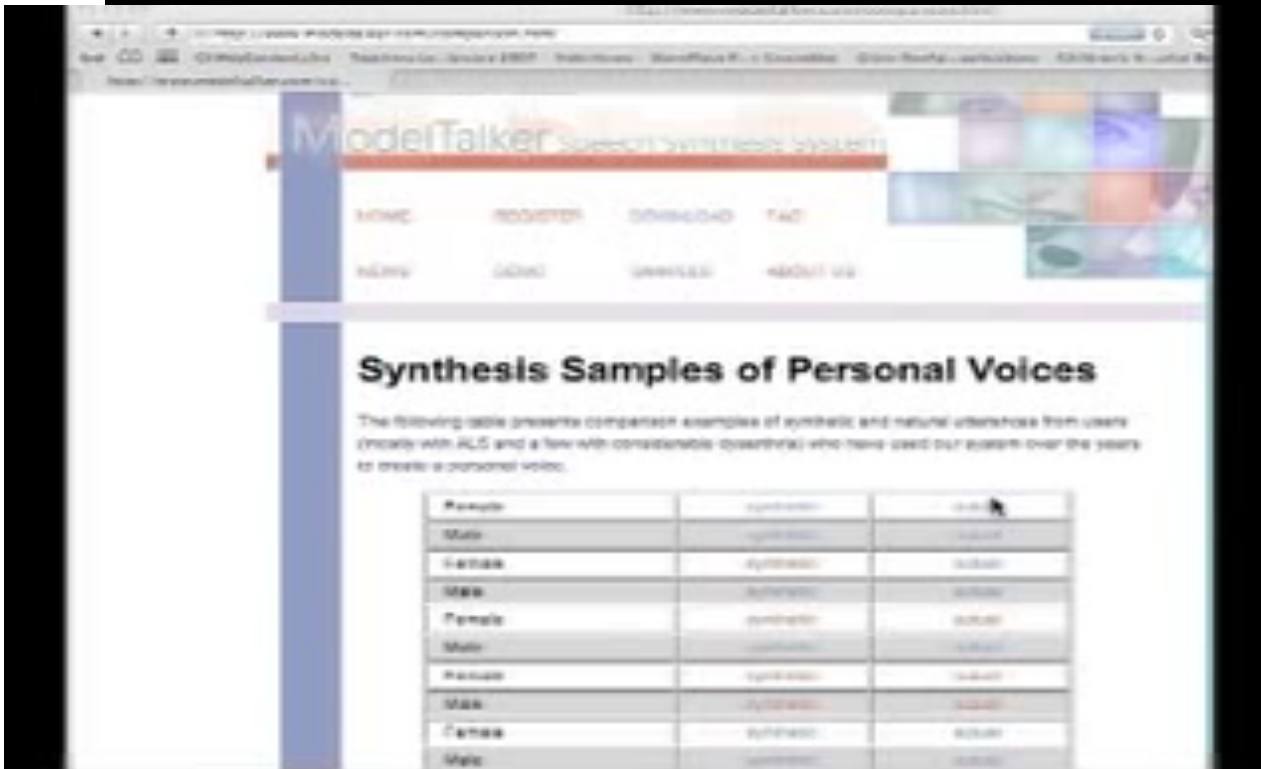




# ModelTalker

<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*



<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](#)

Acapela group - Voice synthesis - Text to Speech | voice solutions

acapela group [sign in](#) [register!](#)

username

voice solutions | [facebook](#) [google+](#) [twitter](#) [youtube](#) [rss](#)

voices products gallery company contact search

acapela text to speech demo

select a language  
English (USA)


select a voice  
Heather

type your text here

The User of this demo undertakes to use the demo in accordance with customs and standard practices; the User shall ensure that the demo will not be used to create prompts which are unlawful, harmful, threatening, abusive, harassing, tortuous, defamatory, vulgar, obscene, ...

listen

Like Share 10k terms & conditions



Let's Talk :-)  
Voices by Acapela!

We invent speech solutions to vocalize your content with authentic and original voices that express meaning and intent.

Over 100 synthetic voices in 30 languages ready to give a voice to any content natural and pleasant audio result, by written input into speech.

We create the voice your company needs. This is Acapela bespoke expert talk!

Home Login Record Listen M

## Home

Acapela group is proud to offer you a unique chance to create your own text-to-speech voice. Usually to your text in a small handful of "standard" voices. This website will offer you a computer voice that yourself, flavoured with all the personal mood and voice colour that you put into it.

Acapela's **MyOwnVoice.com** is for you if you are:

- a professional voice talent curious to explore the endless possibilities of text-to-speech
- an amateur voice talent willing to show the world how nice your text-to-speech voice sounds
- a curious user wanting to play with the mesmerizing features of building synthetic voices
- an individual in need to preserve your voice for later

This website will guide you through the whole process of creating and reproducing the sound of your voice from A to Z. All you need to do is get a good quality microphone and record the text materials offered through [MyOwnVoice online interface](#). The recordings will be automatically analyzed on this server using our state-of-the art unit selection algorithms. You will get access to your own personalized and secure text-to-speech demo, while you enjoy your dinner. By the time you finish the recordings, you will have completed a perfect speech workout having pronounced most possible sound combinations in your language.

We hope you enjoy this vocal exercise, and the resulting text-to-speech version of yourself.

For more information about the company's, please visit [Acapela's website](#).

Thank you for your interest!

**Note:** This site is still under construction. The interface has been beta-tested and is in full operation, but please bare with us for any remaining typo's and interface inconsistencies.

Please, consult the list of ["Frequently asked questions"](#) and the [User documentation](#) for instructions and tips.

For general questions, contact the [Project Administrator](#).

To report an interface issue, contact the [Site Administrator](#).



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# AssistiveWare Video July 2012





Language	Completion Percentage	Create my voice!
English (US)	100.0%	Done
English (UK)	0.0%	Not enough recorded sentences
French (Canada)	0.0%	Not enough recorded sentences
North American Spanish	0.0%	Not enough recorded sentences
English (Australia)	0.0%	Not enough recorded sentences

Language:

Text to pronounce:

Speed:  %

Shaping:  %



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# my-own-voice

my-own-voice, the voice banking solution by [acapela-group.com](http://acapela-group.com)



## NEW! Update to MOV Recorder

My-own-voice is now available in a new, flexible version with 'MOV recorder'



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Custom voice created by Scottish  
company 'Cereproc'

<http://www.cereproc.com/en/home>



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# Dr. Rupal Patel, VOCALiD *with Samantha Grimaldo*

<http://www.vocalid.co/how>



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

# SPEECH GENERATING DEVICE ASSESSMENT



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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

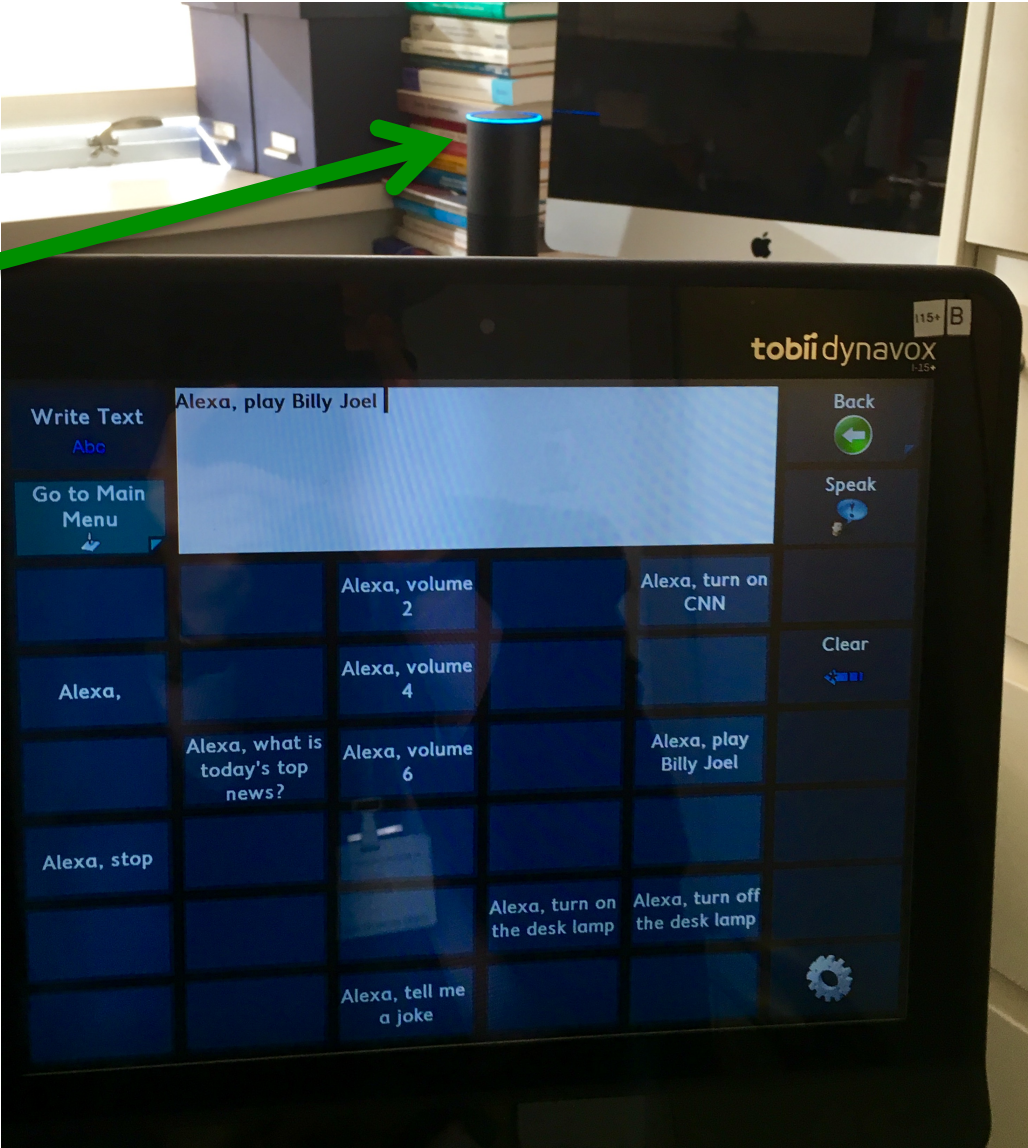
- Abbreviation expansion
- prediction (word, grammar, morphology) • letter stream prediction (Dasher)

## Access features (in concert with OT)

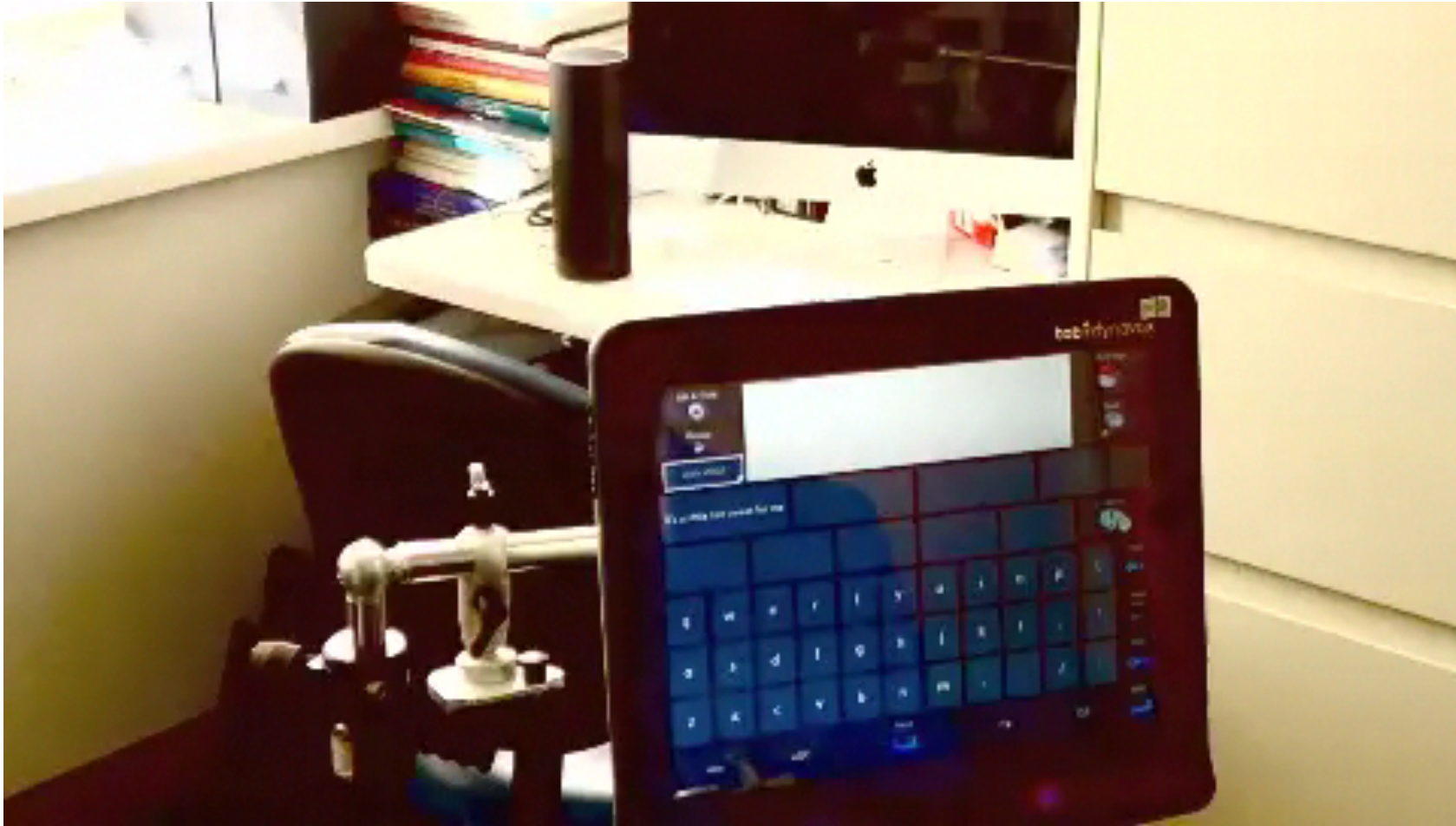
- Direct selection (unaided)
- Direct selection (aided)
  - headmouse
  - eye tracking
    - dwell, switch, blink
- Scanning
  - Single switch
  - Two switch
  - Use of switch interface for technologies
  - Software vs. tech access options within tech (accessibility features)

# Language organization for Environmental Control

Amazon Alexa activated by synthetic speech and responding appropriately



# Amazon Echo and page set organization





# Speech Generating Device Assessment and trial(s) continued

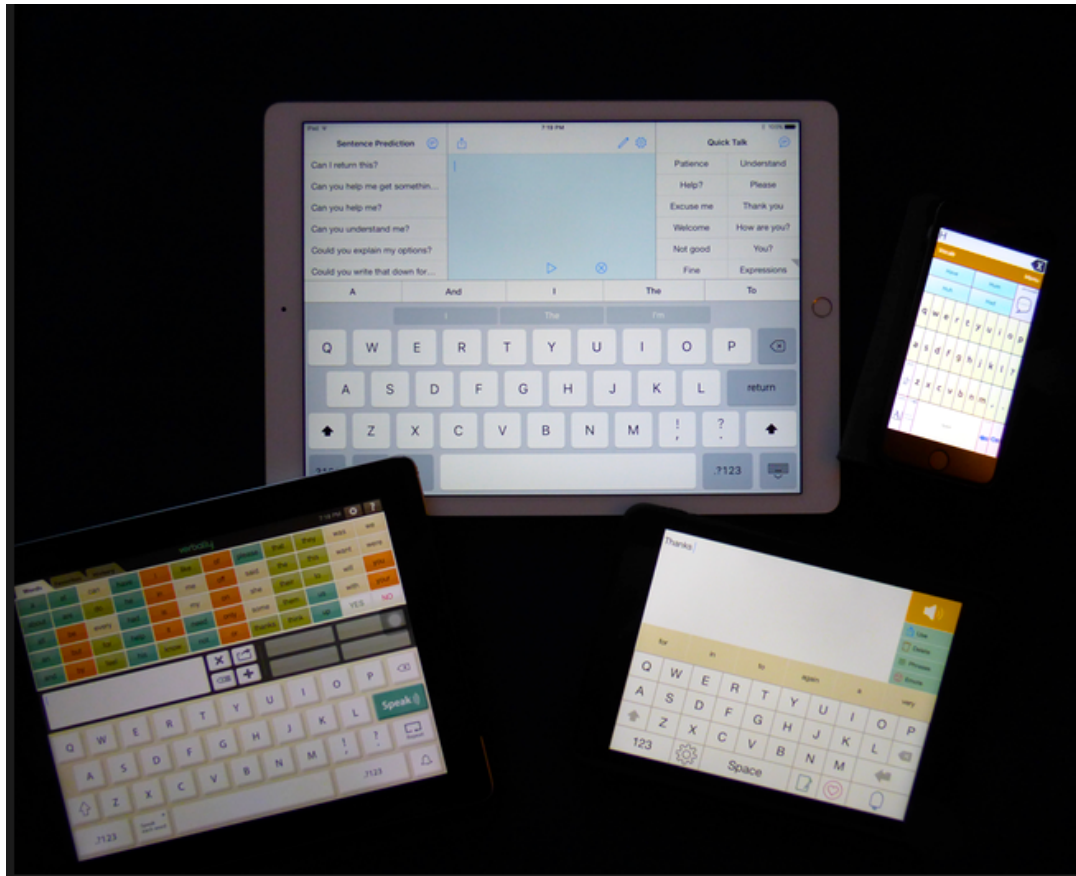
## Integration features:

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

## Other:

- Language
- Text
- Symbols
- Synthesizer (and integration with environment such as 'Alexa')





Text-to-Speech (TTS) Apps Comparison Chart (as of February 13, 2014) Boston Children's Hospital

	ProloquoText	Predictable	ClaroCom Pro	Assistive Express	Verbally
Developer	AssistiveWare	Therapy Box Limited	Claro Software Limited	assistiveapps	Intuity
Website	www.assistiveware.com	http://therapy-box.co.uk/	www.claro-apps.com	www.assistiveapps.com	www.verballyapp.com
Price	\$129.99	\$159.99	\$13.99	\$24.99	Free. Upgrade to Verbally Premium for \$99.99
Platforms	iPad, iPhone, iPod Touch (iOS 6.0 or later)	iPad, iPhone/iPod Touch, Android	iPad, iPhone, iPod Touch (iOS 3.0 or later)	iPad, iPhone, iPod Touch (iOS 6.0 or later)	iPad (iOS 3.2 or higher)
Efficiency features	Phrase storage by category & history; Quick talk phrases	Phrase storage by category & history; 1-button to save phrase	Phrase storage by category & history; 1-button to save phrase; Fillable prompt phrases (e.g., "Can I order ___")	Phrase & history storage; list view (no organization framework)	Core word and phrases grid (cannot customize); with Premium upgrade can edit and store phrases by category & view history
Speech customization	Can adjust rate, pitch, pronunciation	Can adjust rate, pitch, "emote" options (e.g., yawn, kiss, whistle, etc.)	Can adjust rate	Can adjust rate	Premium version- can customize rate and pitch
Voices	89 voices options (21 US English)	4 US English options, 3 UK English options, 2 Australian options	Male and female Nuance Vocalizer voices installed; option for UK, Australia, India, Ireland, Scotland, South Africa, & UK (in-app purchase)	Male, female, & boy (high quality Acapela)	Free- Male & female low quality; Premium- Male, female & child US voices & male & female UK, high quality (Acapela) voices
Languages	13 including Spanish, French, German, Dutch and new bilingual American Spanish	US or UK English only	English only	English only	US or UK English with Premium
Prediction	Yes- word and phrase	Yes- word and phrase	Yes- word and phrase	Yes- word and phrase	Yes- word and phrase, can also import contacts for improved prediction
Speak options	Speak by letter, word, sentence, and/or paragraph	Speak by word or sentence; Pronunciation editor	Speak by word or sentence	Speak by letter, word, or phrase	Speak by word or phrase
Built-in scanning	No	Yes; screen as switch and compatible with Therapy Box & Ri Cooper	No	No	No
Abbreviation Expansion	Yes	No	No	No	No
Share options	Email, AirDrop for messages, Twitter, & Facebook	Email, Facebook, Twitter, Air Print, Send SMS on Devices with 3G capability	Email, iMessage, Facebook, Twitter	Email per website *new sharing to Facebook, Twitter, and iMessage	Email
Other access methods		Button hold delay options, input via handwriting			"Steady Hands" feature- allows touch and drag
Privacy features	Private use disables logging history	Speak' or 'Publish' option (publish inverts texts for the partner to read for private conversations)	Rotate 180° to display large message (instead of scroll to output)	No	No
Backup options	Backup via Dropbox or iTunes sharing	Backup via Dropbox or iTunes sharing	No	No	No
Appearance options	Quick 'blocks' customization, Many style options (e.g., font size, type, background color, etc.)	Can adjust message window color and font size & buttons appearing on keyboard (e.g., WritePad Key, Bell Key, etc.)	Many options for font type, size, background color, etc.	Font size adjustable- small, medium, large	3 keyboard orientations (horizontal QWERTY, right or left handed ABCD)



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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 wish 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



# Ion Clipster blue tooth speaker



~~\$21.23~~ \$49.99 **Prime**  
Get it by **Wednesday, Nov 19**  
More Buying Choices  
**\$16.25 new** (30 offers)



**ION Clipster Ultra-Portable Bluetooth Speaker with Built-In Clip (Orange)**  
by ION Audio  
~~\$14.99~~ \$49.99 **Prime**  
Get it by **Wednesday, Nov 19**  
More Buying Choices  
**\$14.99 new** (14 offers)



**ION Clipster Ultra-Portable Bluetooth Speaker with Built-In Clip (Blue)**  
by ION Audio  
~~\$24.99~~ \$49.99 **Prime**  
Only 10 left in stock - order soon.  
More Buying Choices  
**\$12.67 new** (57 offers)  
**\$17.66 used** (4 offers)



**ION Clipster Ultra-Portable Bluetooth Speaker with Built-In Clip (Green)**  
by ION Audio  
~~\$19.99~~ \$49.99 **Prime**  
Get it by **Wednesday, Nov 19**  
More Buying Choices  
**\$16.99 new** (10 offers)  
**\$14.69 used** (1 offer)



**ION Clipster Ultra-Portable Bluetooth Speaker with Built-In Clip (Black)**  
by ION Audio  
~~\$22.33~~ \$49.99 **Prime**  
Get it by **Thursday, Nov 20**  
More Buying Choices

Patient videos

# Mounting/positioning



# 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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# Occupational Therapy/ Assistive Technology

- ❖ Access Consideration
  - ❖ **Activity Goal**
  - ❖ Access site
  - ❖ Access method
  - ❖ Access settings
  - ❖ Real life use
  - ❖ Preparing for the next access site





**How the customer explained it.**



**How the project leader understood it.**



**How the analyst designed it.**



**How the programmer wrote it.**



**What the customer really wanted.**



# Activity Goal

- ❖ OT related – includes activities of daily living (non-communication, non-computer)
- ❖ Communication –
  - ❖ Relay quick messages – wants/needs
  - ❖ Relay novel messages
  - ❖ Participate in conversation
  - ❖ People with ALS have a lifetime of fast, sophisticated, multimodal communications



# Activity Goal

## ❖ Computer –

- ❖ Email
- ❖ Facebook
- ❖ Word Processing
- ❖ Spreadsheet (often work-related)
- ❖ Internet
- ❖ Games
- ❖ Movies/videos/music
- ❖ Reading

## ❖ Smart phone or iPad

- ❖ Phone
- ❖ Text
- ❖ Email
- ❖ Games
- ❖ Music
- ❖ Reading



# The activity goal drives the process.

## Other important considerations:

- ❖ Technology availability
  - ❖ Computer at home? PC? Mac?
  - ❖ Casual user or computer whiz?
  - ❖ Somebody nearby to troubleshoot?
  
- ❖ Motor Control available
  - ❖ Hands? Head? Foot?
  
- ❖ Speech available
  - ❖ Intelligible?
  - ❖ Breath Support?
  - ❖ Fatiguing?



# HIGH TECH

## Low Tech vs.



# Physical Access Control Site assessment

- ❖ 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
- ❖ the range and control of movement
- ❖ the amount of training and practice required to use
- ❖ the short and long-term costs/benefits of using access method





“He cannot use a computer. We have tried everything. He can’t use his hands.”



“I have ceded to the disease and now I type with one hand.”

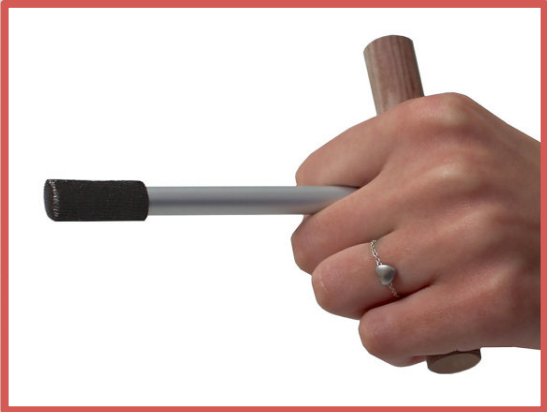
NO. You are not giving into to the disease. You are outsmarting the disease and getting the job done another way.



# Direct Selection

- ❖ Touch screen (iPad for example)
  - ❖ Not pressure sensitive – capacitive
  - ❖ Skin (not fingernail), capacitive tip stylus
  - ❖ Timing matters – longer touch results in different action
  - ❖ One point of contact
  - ❖ Cannot drag across the screen
  - ❖ Reposition to be near body, add stylus





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# Computer Access



# Direct Selection Keyboard

- ❖ Small keyboard
- ❖ Close to body
- ❖ Support arms/wrists
- ❖ Typing aid (pointer)
- ❖ Type with one hand
- ❖ Keyboard Adjustments – sticky keys and filter keys





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# Keyboard adjustments

## ❖ Sticky keys

- ❖ Allows the user to type keys in a row
- ❖ Designed for one-handed typing
- ❖ Great for poor coordination
- ❖ Press the shift key five times to turn on

## ❖ Filter Keys

- ❖ Adjusts for tremor or for holding the keys down too long
- ❖ Can add key click for auditory feedback
- ❖ April Fool's anyone?
- ❖ Hold the right shift key for 8 seconds to turn on



# Direct Selection: Mouse

- ❖ Problem – difficulty gripping the mouse, hard to move cursor across the screen, hard to hit the left mouse button, accidentally hitting the mouse buttons
- ❖ Solution – Trackball
  - ❖ Do not need to grip – can move the ball with any part of your hand
  - ❖ Trackball remains stationary – no reaching to move it
  - ❖ Buttons are separated from the mouse movement



- ❖ Problem – difficulty gripping the mouse, hard to move cursor across the screen, hard to hit the left mouse button, accidentally hitting the mouse buttons
- ❖ Solution – Hands-free Cursor control
  - ❖ Foot Mouse
  - ❖ Head Mouse

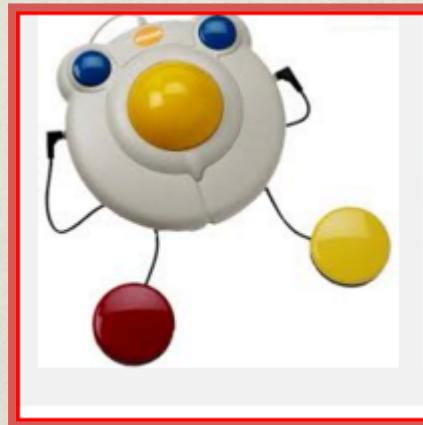


# Foot Mouse

- ❖ Foot time mouse



- ❖ Trackball



# Head Mice

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



# Head Mice

- ❖ All provide wireless cursor control
- ❖ All involve transmitter and receiver
- ❖ All require USB port (no Bluetooth yet)
- ❖ All require good head control
- ❖ Infrared devices require “line of sight”
- ❖ Quha Zono is gyroscopic – no line of sight required
  - ❖ Can be programed to be used on hand or foot

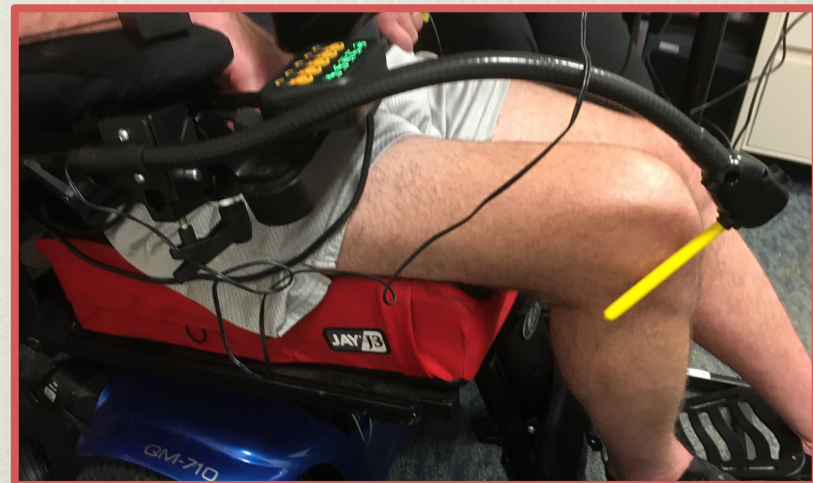


- ❖ Head movement provides cursor control – need to add clicking function



# How do I click?

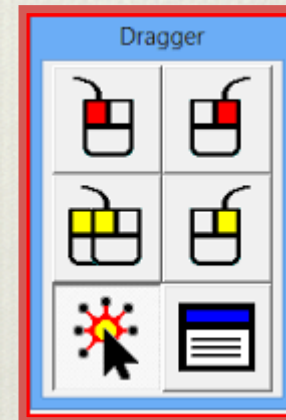
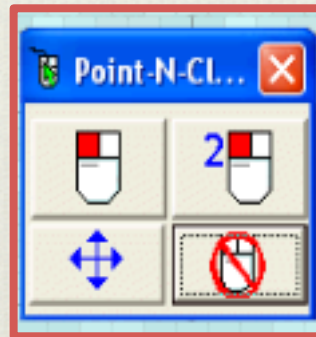
- ❖ Switch click
  - ❖ Any reliable switch site – except for the head.
  - ❖ Activates left click, double click, and drag





# Switchless clicking

- ❖ Auto click dwell software
- ❖ Dragger
- ❖ Smart Click
- ❖ Point n Click



Set the dwell time  
Set the jitter box  
Have a pause button



# Mouse-only access On Screen Keyboard

- ❖ Windows onscreen
- ❖ Onscreen
- ❖ Softype
- ❖ Reach Interface Author

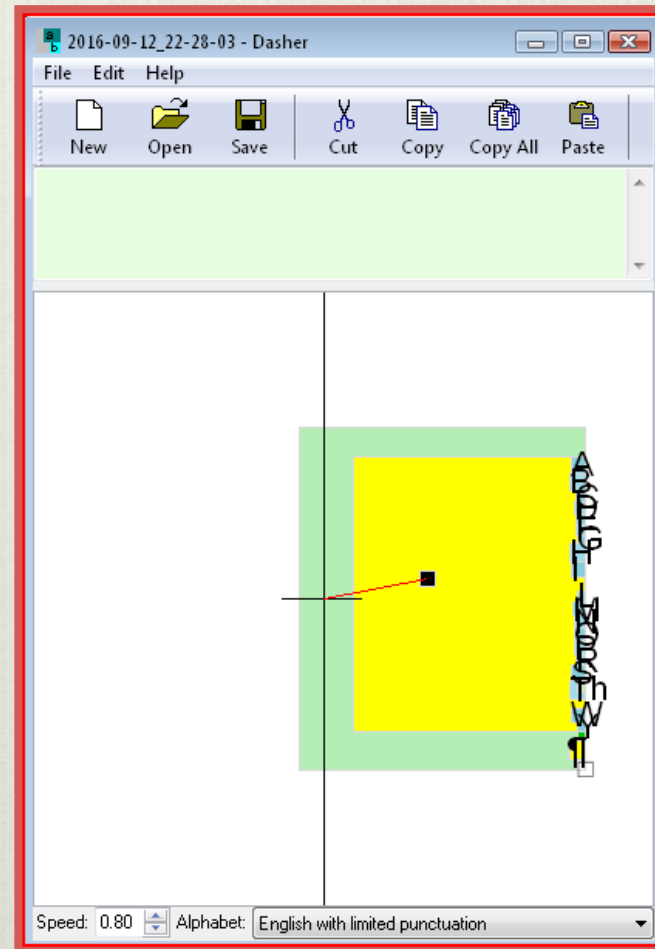


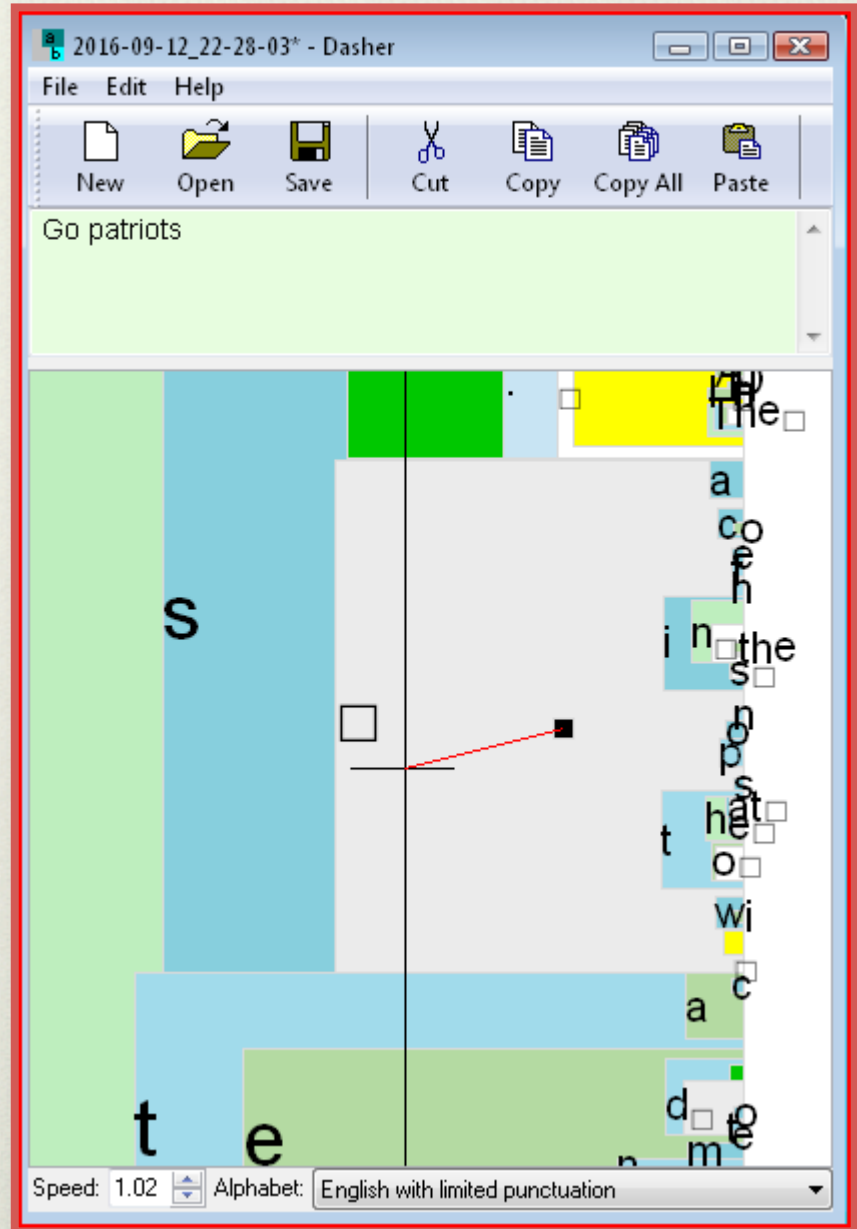
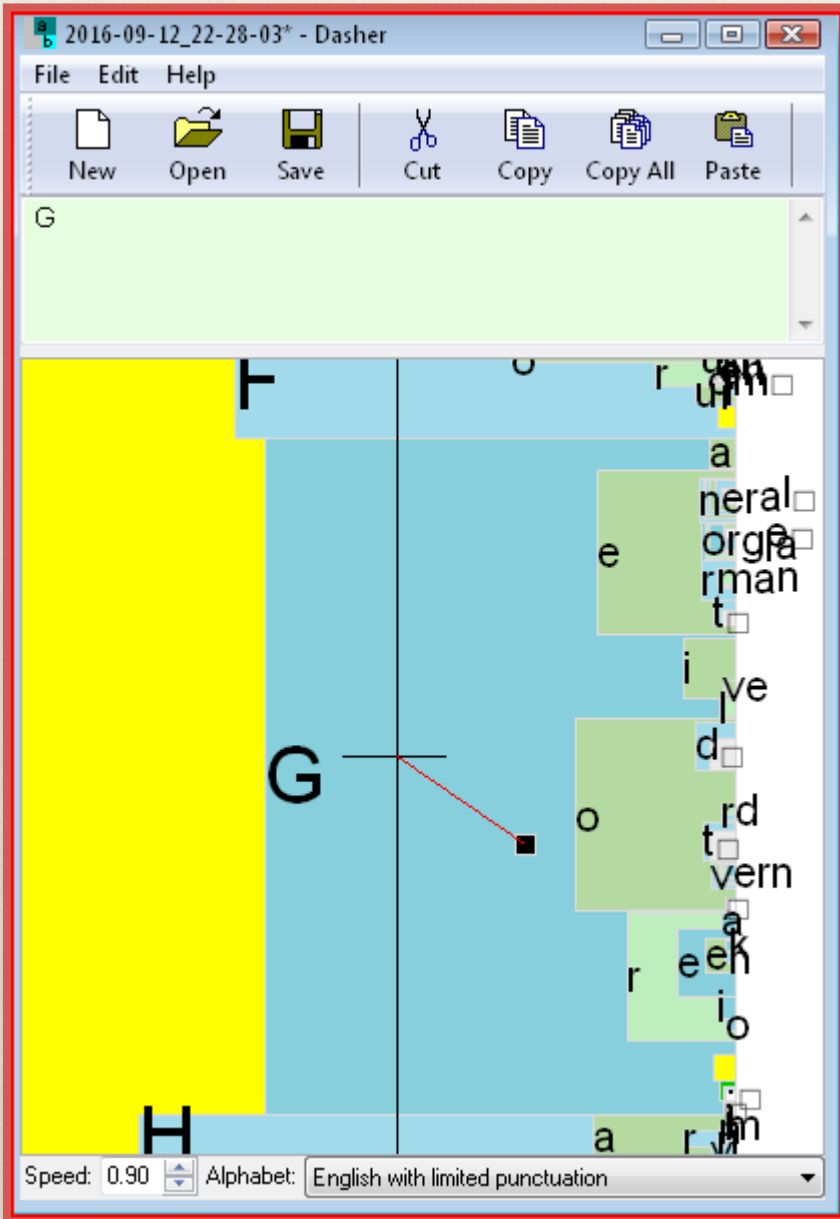
Features:  
Word prediction  
Size adjustments  
Built in dwell option  
Macro capability



# Video game style

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





# 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



# 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



- ❖ For people with limb onset ALS, voice recognition software allows them to remain connected to friends, family and the world. Voice recognition software may provide the means of remaining employed.
- ❖ Use of voice recognition software requires training and customization.
  - ❖ Adding vocabulary
  - ❖ Adding text macros
  - ❖ Adding command macros



“Living with ALS seems a bit like going into the witness protection program. Everything I have ever known about myself, how I look, how I act, how I interact with the world, is rapidly and radically changing. When I could no longer type with my hands, I knew I could give up writing entirely or use voice recognition software. I’m not a young woman. This took real work. Interestingly, I write more now than ever before.”

Catherine Royce





# Voice mouse control

- ❖ Mouse Grid
- ❖ Move mouse up/down/right/left
  - ❖ Faster / Much Faster
  - ❖ Slower / Much Slower
  - ❖ Stop
- ❖ “Mouse click” / “Mouse double click”
- ❖ “Drag mouse up/down/right/left”



# Macros

- ❖ “Peggy’s email” = [Peggy.Dellea@Childrens.Harvard.edu](mailto:Peggy.Dellea@Childrens.Harvard.edu)
- ❖ “Visa Card Number” = 5808 330 2435 3319
- ❖ “Bank sign in page” = <https://www4.citizensbankonline.com/efs/servlet/efs/login.jsp>
- ❖ “Bank password” = Give\$Me\$Money\$



❖ “Check my email” =

❖ Alt + D

❖ `https://login.yahoo.com/config/login?.src=fpctx&.intl=us&.lang=en-US&.done=https%3A%2F%2Fwww.yahoo.com`

❖ Enter

❖ Wait

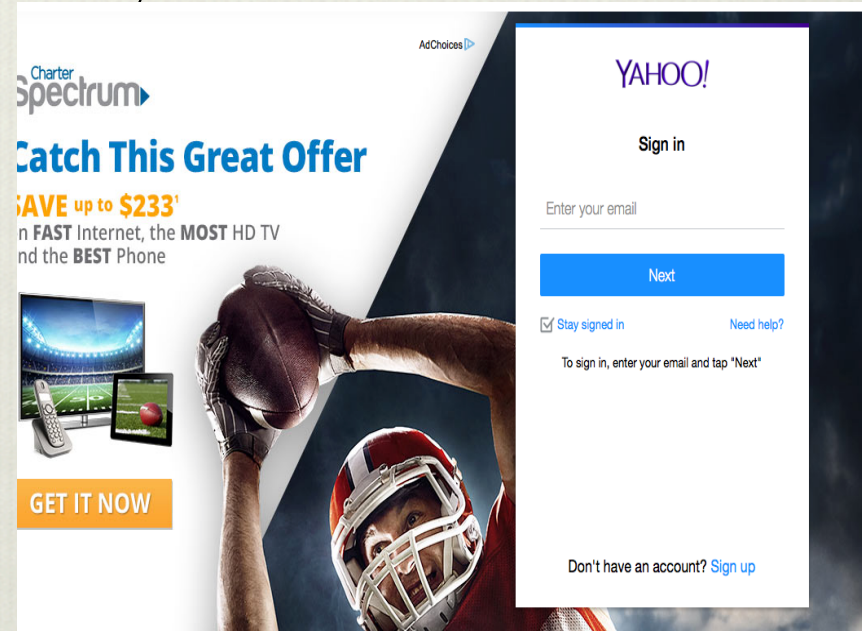
❖ `PeggyDelleaOT@yahoo.com`

❖ Enter

❖ Wait

❖ `MySecretPassword`

❖ Enter



*Yes – this can be done with individual voice commands/typing.  
But Catherine Royce once told me to “choose easy”.*



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- ❖ “Short Pier” =
- ❖ Ctrl + A
- ❖ Alt + O
- ❖ F
- ❖ Times New Roman
- ❖ Tab
- ❖ 8
- ❖ Enter
- ❖ Control + Enter



# Eye Gaze Interface – The eyes have it



# *Eye Gaze*

- ❖ Infrared Camera
- ❖ Position Position  
Position
- ❖ Enlarged Targets
- ❖ Blink, Dwell, or  
Switch clicking



# Problems

- ❖ Ptosis - camera needs to view the full pupil
- ❖ Cataracts
- ❖ Dry Eyes
- ❖ Head Movement
- ❖ Glasses and Contacts
- ❖ Pupils dilated or constricted
- ❖ Nystagmus
- ❖ Attentional deficits
- ❖ (Re) Positioning (position, position, position)



# Eye Gaze for Computer Interface

- ❖ Eye camera “bar” connects via USB
- ❖ Moves cursor across the screen
- ❖ Requires use of “gaze interaction” software





“Reading is  
huge.”



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# Access to books (hardcopy or digital)

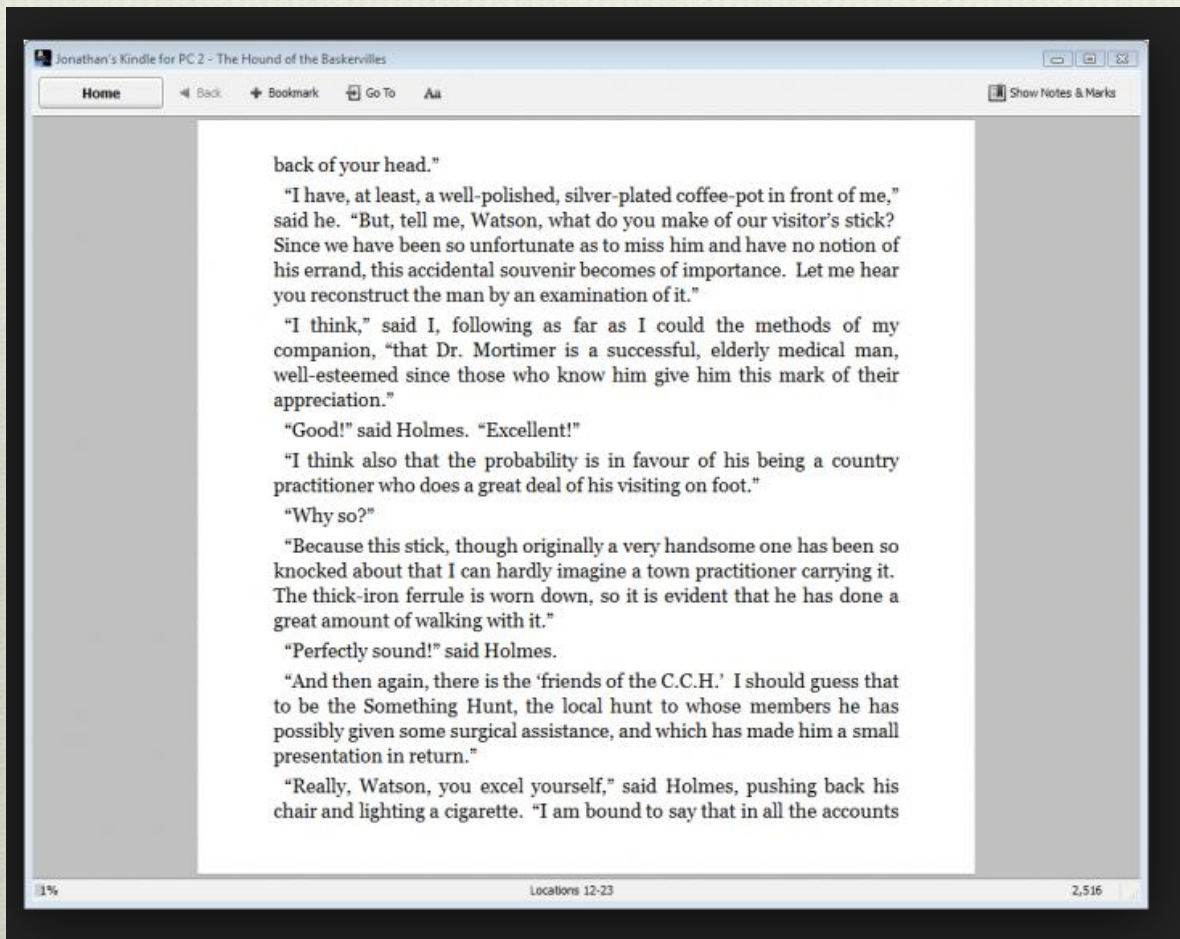
- ❖ Audio books
- ❖ Hardcopy books/ book holders
- ❖ Kindle/iBooks



# Kindle for the computer

- ❖ Free download (Amazon.com)
- ❖ Available for PC or Mac
- ❖ Out of copyright material is free
  - ❖ (free is good!)
- ❖ Simple program
  - ❖ Easy to adapt





Click to turn page:

- Mouse
- HeadMouse
- Switch-adapted mouse
- Dwell software
- Eye Gaze interface
- Switch programmed to the right arrow key
- “Press right arrow” command
- Custom voice command (e.g. “turn page”)



“The best thing about that session was seeing his face when he was using the Kindle software.”



“Shouldn’t he be doing this without the switch? He won’t be able to use the switch when the disease progresses.”



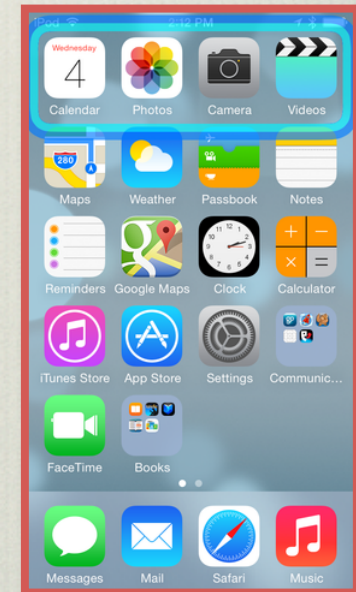
# Speech Generating Device Access

- ❖ Touch screen
- ❖ Stylus and stylus holders
- ❖ Keyboard
- ❖ Mouse
- ❖ Trackball
- ❖ Head tracking
- ❖ Adapted mouse
- ❖ Switch scanning
- ❖ Eyetracking access



# Phone Access

- ❖ Landline options – large buttons, speaker phone
- ❖ Speaker phone options
- ❖ Smartphone use
- ❖ Hands-free cell phone use
- ❖ Switch scanning on iPhone
- ❖ Siri/ OK Google
- ❖ 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



❖ Expensive

❖ Learning curve

❖ Need to be programmed



# Brain Computer Interface

- ❖ EEG signal – surface or implanted
- ❖ Map EEG response to what is happening
- ❖ Create a program to convert EEG response to action
  
- ❖ Braingate
- ❖ P300

