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
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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

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Communication is the thread that connects us all
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
1994: CHB founded a model of AAC service delivery in the ICU including preoperative 'voice banking'.

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!

<table>
<thead>
<tr>
<th>Michael</th>
<th>Mom</th>
<th>Friends</th>
<th>Well</th>
<th>Scream</th>
<th>PAIN medicine</th>
<th>Bathroom</th>
<th>When am I going?</th>
<th>Ask a nurse</th>
<th>How am I doing?</th>
</tr>
</thead>
<tbody>
<tr>
<td>Annie</td>
<td>Thank you</td>
<td>SUCKS!</td>
<td>?</td>
<td></td>
<td>Nurse</td>
<td>Dressing</td>
<td>Soak</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>YES</td>
<td>NO</td>
<td>OK</td>
<td></td>
<td>Uncomfortable</td>
<td>Handsome</td>
<td>Writing</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Boston Children's Hospital

Until every child is well

HARVARD MEDICAL SCHOOL
TEACHING HOSPITAL
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, Amalika, and Peggy,

I just want to thank you for everything you did for my mother, 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. I think 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 telling people I had met an angel. I still do that'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)
Begin with THANK YOU to many extraordinary people with ALS
Patient videos
Opening statement:

“My goal is to waste your time”
Second statement:

“You are stuck with us”
## AAC/Speech Pathology Protocol of Assessment Considerations

<table>
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<tr>
<th>Category</th>
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<td>Speech strategies</td>
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<td>Partner training</td>
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<td>Amplification while using BiPAP</td>
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<td>Call system for emergency and attention</td>
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<td>Quick access encoding strategies (non-electronic)</td>
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<td>Electronic encoding</td>
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<td>Quick access encoding strategies (non-encoding)</td>
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<td>Writing strategies</td>
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<td>Message Banking</td>
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<td>Speech Generating Device assessment</td>
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<td>Speech Generating Device trial for Practice Based Evidence</td>
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<tr>
<td>Training, implementation/integration</td>
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Resources located at our new website. Will be live by end of December 2016.
SPEECH STRATEGIES
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
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

<table>
<thead>
<tr>
<th>People</th>
<th>Food</th>
<th>Emotions</th>
</tr>
</thead>
<tbody>
<tr>
<td>Places</td>
<td>Colors</td>
<td>Questions</td>
</tr>
<tr>
<td>Animals</td>
<td>Entertainment</td>
<td>Body</td>
</tr>
<tr>
<td>School</td>
<td>Home</td>
<td>Community</td>
</tr>
</tbody>
</table>
Identification/explanation card for car

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: __________________________
http://alsworldwide.org

**ALS worldwide**

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: 

---

**Important Personal Information**

Emergency Contact Name

Emergency Contact Phone Number

Medications in use, etc.

---

**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 -
Many patients now ask about medications and we ALWAYS refer them back to their physician.
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.
PARTNER TRAINING
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.
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.

Boston Children’s Hospital
ALS Augmentative Communication Program © 2016
Holly's advice (recorded early in the day when speech was easier to produce)

Patient videos
Holly's advice on predicting (recorded early in the day when speech was easier to produce)

Patient videos
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
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
Amplification while using bi-pap

Assessment of transdermal microphone options
Patient videos
EMERGENCY CALL
Call system(s)/switch control
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
Phone app for emergency requiring no speech
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 devices 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.

December 2014
QUICK ACCESS ENCODING (NON-ELECTRONIC)
Quick Access **Encoding**

- 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
Introducing partner assisted
Patient videos
Partner assist scan
Review of ‘body board’
Etran
Video courtesy of ALS association
(Iowa Chapter YouTube)
ELECTRONIC ENCODING
Electronic encoding

• Minimize working memory demands for communicator and partner
• Provide a visual script/reminder of message progress
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)
Quick Access (non-electronic continued)

• Personal tabbed flip chart
• Alphacore displays or others with direct selection by:
  – Hand
  – Stylus
  – Safe laser
You have to keep looking at my face and DON'T Guess Please!

- BED
- BIPAP
- URGENT
- OTHER
- CANT BREATHE
- CHANGE POSITION
- MOUTH DRY - WATER
- TV and LIGHTS OUT
- CHAPSTICK
- PAIN
- NECK
- PEE
- VICKS
- NOSE - SALINE
- NOSE - Q-tip
- SMALL TOWEL
- BEHIND NECK
- PILLOW TOO HIGH/ TOO LOW

- IN BED
- COMFORT
- TRANSFER AND POSITION
- WHEELCHAIR
- COMPUTER
- BATHROOM

back to categories
START OVER
GET ALPHABET BOARD
CALL JOAN
Creating a customized flip chart for PARTNER ASSISTED SCANNING

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
<table>
<thead>
<tr>
<th>ROW 1</th>
<th>ROW 2</th>
</tr>
</thead>
<tbody>
<tr>
<td>I CAN’T BREATHE</td>
<td>NEED NURSE</td>
</tr>
<tr>
<td>ORAL SUCTION</td>
<td>I AM IN PAIN</td>
</tr>
<tr>
<td>DEEP SUCTION</td>
<td>NEED PAIN MEDS</td>
</tr>
<tr>
<td>ADJUST MY TUBING</td>
<td>FEEDING TUBE HURTS:</td>
</tr>
<tr>
<td>TRACH FROM CHIN</td>
<td>CLEAN AROUND IT</td>
</tr>
<tr>
<td>EMPTY WATER IN</td>
<td>CALL JOHN CALL MELISSA</td>
</tr>
<tr>
<td>TRACHE TUBE</td>
<td></td>
</tr>
<tr>
<td>REMOVE GAUZE FROM</td>
<td></td>
</tr>
<tr>
<td>TRACHE</td>
<td></td>
</tr>
<tr>
<td>PUT TRACHE UP HIGHER</td>
<td>I’M HUNGRY</td>
</tr>
<tr>
<td>PUT AIR IN BALLOON</td>
<td>I HAVE A STOMACH</td>
</tr>
<tr>
<td>DISCOMFORT WITH P-SWITCH</td>
<td>ACHES</td>
</tr>
<tr>
<td>PUT PILLOWS:</td>
<td>NO BOWEL MOVEMENT</td>
</tr>
<tr>
<td>UNDER MY LEGS</td>
<td>LACTULOSE FOR</td>
</tr>
<tr>
<td>UNDER MY ARMS</td>
<td>Constipation</td>
</tr>
<tr>
<td>OR FIX MY ARMS</td>
<td></td>
</tr>
<tr>
<td>PUT LEGS CLOSER</td>
<td>PLEASE OPEN WINDOW</td>
</tr>
<tr>
<td>I HAVE A HEADACHE</td>
<td>PLEASE CLOSE WINDOW</td>
</tr>
<tr>
<td>TYLENOL PLEASE</td>
<td></td>
</tr>
<tr>
<td>CLEAN MY NOSE</td>
<td>PLEASE OPEN CURTAIN</td>
</tr>
<tr>
<td>SWAB</td>
<td>PLEASE CLOSE CURTAIN</td>
</tr>
<tr>
<td>CATHERETER SITE HURTS</td>
<td></td>
</tr>
<tr>
<td>CLEAN MY MOUTH</td>
<td>PLEASE REMOVE HAIR</td>
</tr>
<tr>
<td>NEED TO BE CHANGED</td>
<td>FROM MY FACE</td>
</tr>
<tr>
<td>WIPE MY EYES</td>
<td>I NEED EARDROPS</td>
</tr>
<tr>
<td>ZOFRAN PLEASE</td>
<td>I’M NAUSEOUS</td>
</tr>
<tr>
<td>TURN FEEDING OFF</td>
<td></td>
</tr>
<tr>
<td>WASH MY FACE</td>
<td></td>
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http://lowtechsolutions.org

Amy Roman and Margaret Cotts
Holly

Tech is not the answer - needing ALL the tools

Patient videos
WRITING
Boogie Board

- Used to write messages
- Can use fingernail
- Lightweight
**To Do:**
- Grocery store
- Soccer @ 4:00
- Mow the grass
- Call Jill
- Send thank you's
Patient videos
Writing strategies

• Notepad
• Notebook
• Boogie board
• Ipad/android – note apps
  – Finger
  – Rubber tipped stylus
  – Jot stylus
  – Apple pen
MESSAGE BANKING
“Our voice is our ACOUSTICAL fingerprint”
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.
DEFINITIONS:

**Voice Banking** is a process of recording a large inventory of frequently used messages that are used to create a synthetic voice that approximates one's natural voice.

Done successfully, this allows 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.speech.delaval.edu/speech/ModelTalker.html

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

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 "re-trieve" 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 selection 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.
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/ACPCHBoston/
Patient videos
Gene – waiting for 'temporary' weakness to clear in voice

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)
### Message Bank

**Search**

<table>
<thead>
<tr>
<th>Title</th>
<th>Text</th>
<th>Confidence</th>
<th>Recording</th>
<th>Tags</th>
</tr>
</thead>
<tbody>
<tr>
<td>good-husband</td>
<td>You're a good husband</td>
<td></td>
<td>0:02</td>
<td>compliment, polite</td>
</tr>
<tr>
<td>less-eat</td>
<td>Let's get something to eat</td>
<td></td>
<td>0:02</td>
<td>request</td>
</tr>
<tr>
<td>0804782</td>
<td>What do you have to drink?</td>
<td></td>
<td>0:02</td>
<td>polite, question</td>
</tr>
</tbody>
</table>
BETA GOING LIVE BY First week of December!!!!
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.
Upload multiple messages to the message bank from your Zoom H1 recorder.
Selected messages are queued for upload.
<table>
<thead>
<tr>
<th>Title</th>
<th>Text</th>
<th>Confidence</th>
<th>Rec</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZOOM0019</td>
<td>%hesitation world leaders I'm</td>
<td>68%</td>
<td></td>
<td></td>
</tr>
<tr>
<td></td>
<td>tracking AAC</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0016</td>
<td>hostilities to baby</td>
<td>61%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0018</td>
<td>this marshmallow is good</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0017</td>
<td>thank you for making that for me</td>
<td>100%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0010</td>
<td>I think that is correct</td>
<td>99%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0012</td>
<td>do you want to go out for a beer</td>
<td>97%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0011</td>
<td>I wish you wouldn't do that</td>
<td>94%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>i-can't wait</td>
<td>I can't wait</td>
<td>99%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>can-you-keep-a-secret</td>
<td>can you keep a secret</td>
<td>97%</td>
<td></td>
<td></td>
</tr>
<tr>
<td>did you close the dog door</td>
<td>did you close the dog door }</td>
<td>74%</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>
Users can fix errors

Users listen to messages
<table>
<thead>
<tr>
<th>Title</th>
<th>Text</th>
<th>Score</th>
<th>Recording</th>
<th>Tags</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZOOM0019</td>
<td>%HESITATION word tracking AAC</td>
<td>70%</td>
<td>0.05</td>
<td>+</td>
</tr>
<tr>
<td></td>
<td>Reviewed messages show acceptance</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>ZOOM0016</td>
<td>Hasta la vista, baby!</td>
<td>100%</td>
<td>0.02</td>
<td>+</td>
</tr>
<tr>
<td>ZOOM0018</td>
<td>this marshmallow is good</td>
<td>100%</td>
<td>0.03</td>
<td>+</td>
</tr>
<tr>
<td>ZOOM0017</td>
<td>thank you for making that for me</td>
<td>100%</td>
<td>0.02</td>
<td>+</td>
</tr>
</tbody>
</table>
Tag messages with one or more categories.
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

Select multiple messages to download text for offline proofing.
Select multiple messages to tag many at once.
Select multiple messages to download a set
Select multiple messages to delete a set

### Message Bank

<table>
<thead>
<tr>
<th>Show 20</th>
<th>Show All</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
</tr>
</tbody>
</table>

Showing 1 - 20 of 33 results

<table>
<thead>
<tr>
<th>ID</th>
<th>Message</th>
<th>Confidence</th>
<th>Time</th>
</tr>
</thead>
<tbody>
<tr>
<td>ZOOM0019</td>
<td>%HESITATION world leaders I'm tracking AAC</td>
<td>68%</td>
<td>0.05 s</td>
</tr>
<tr>
<td>ZOOM0016</td>
<td>Hasta la vista, baby!</td>
<td>82%</td>
<td>0.02 s</td>
</tr>
<tr>
<td>ZOOM0018</td>
<td>this marshmallow is good</td>
<td>100%</td>
<td>0.03 s</td>
</tr>
<tr>
<td>ZOOM0017</td>
<td>thank you for making that for me</td>
<td>100%</td>
<td>0.02 s</td>
</tr>
</tbody>
</table>
Patient videos
Patient videos
Patient videos
Need to bank more, body is changing

Has been banking messages in
many formats for children

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
Strategies that change with you

27 days later

Patient videos
Patient videos
Kim's husband commenting on hearing his wife's recordings

Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
Patient videos
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
Patient videos
Patient videos
Patient videos
VOICE BANKING
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
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.

http://www.modeltalker.com/comparison.html
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: 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 1,600 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 is proud to offer you a unique chance to create your own text-to-speech voice. Traditionally, only a small handful of 'standard' voices are available, but this website will offer a computer voice that is unique to you, 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 voice sounds
- an amateur voice talent willing to show the world how nice your text-to-speech voice sounds
- a student, working on your first steps into the fascinating 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.
AssistiveWare Video July 2012
So, let's explain how to start.
<table>
<thead>
<tr>
<th>Language</th>
<th>Completion Percentage</th>
<th>Create my voice!</th>
</tr>
</thead>
<tbody>
<tr>
<td>English (US)</td>
<td>100.0%</td>
<td>Done</td>
</tr>
<tr>
<td>English (UK)</td>
<td>0.0%</td>
<td>Not enough recorded</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sentences</td>
</tr>
<tr>
<td>French (Canada)</td>
<td>0.0%</td>
<td>Not enough recorded</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sentences</td>
</tr>
<tr>
<td>North American Spanish</td>
<td>0.0%</td>
<td>Not enough recorded</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sentences</td>
</tr>
<tr>
<td>English (Australia)</td>
<td>0.0%</td>
<td>Not enough recorded</td>
</tr>
<tr>
<td></td>
<td></td>
<td>sentences</td>
</tr>
</tbody>
</table>

Language: **English (US)**

Text to pronounce:

Speed: %

Shaping: %

Go!
NEW! Update to MOV Recorder

My-own-voice is now available in a new, flexible version with ‘MOV recorder’
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
◆ Acapela project
◆ VOCALiD
SPEECH GENERATING DEVICE ASSESSMENT
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

![Image](https://via.placeholder.com/150)

<table>
<thead>
<tr>
<th>App Name</th>
<th>Platform Support</th>
<th>的语言</th>
<th>功能</th>
<th>优点</th>
<th>缺点</th>
</tr>
</thead>
<tbody>
<tr>
<td>Proloquo2Go</td>
<td>iOS, Android</td>
<td>English</td>
<td>语音转换</td>
<td>高质量, 真实感语音</td>
<td>高价, 需要订阅服务</td>
</tr>
<tr>
<td>Textalk</td>
<td>Windows, MacOS</td>
<td>English</td>
<td>语音转换</td>
<td>低成本, 简单使用</td>
<td>需要购买软件</td>
</tr>
<tr>
<td>Dragon NaturallySpeaking</td>
<td>Windows, MacOS</td>
<td>English</td>
<td>语音转换</td>
<td>自然语音, 可定制</td>
<td>经济性差, 需要学习使用</td>
</tr>
<tr>
<td>fluencySTT</td>
<td>iOS, Android</td>
<td>English</td>
<td>语音转换</td>
<td>高质量, 自然语音</td>
<td>高价, 需要订阅服务</td>
</tr>
<tr>
<td>ReadSpeaker</td>
<td>Windows, MacOS</td>
<td>English</td>
<td>语音转换</td>
<td>自然语音, 适应性强</td>
<td>需要购买软件</td>
</tr>
</tbody>
</table>

![Image](https://via.placeholder.com/150)

**Note:** As of February 15, 2023, Boston Children's Hospital
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
Patient videos
Mounting/positioning
Tele-treatment
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
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 explainened 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?
Low Tech vs. High Tech
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
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
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

*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, accidently 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 programmed 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
- “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
- 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”.

Boston Children’s Hospital
Until every child is well

Harvard Medical School
Teaching Hospital
“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.”
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
Back of your head.

"I have, at least, a well-polished, silver-plated coffee-pot in front of me," said he. "But, tell me, Watson, what do you make of our visitor's stick? Since we have been so unfortunate as to miss him and have no notion of his origin, this accidental souvenir becomes of importance. Let me hear you reconstruct the man by an examination of it."

"I think," said I, following as far as I could the methods of my companion, "that Dr. Mortimer is a successful, elderly medical man, well-esteemed since those who know him give him this mark of their appreciation."

"Good!" said Holmes. "Excellent!"

"I think also that the probability is in favour of his being a country practitioner who does a great deal of his visiting on foot."

"Why so?"

"Because this stick, though originally a very handsome one has been so knocked about that I can hardly imagine a town practitioner carrying it. The thick iron ferrule is worn down, so it is evident that he has done a great amount of walking with it."

"Perfectly sound!" said Holmes.

"And then again, there is the 'friends of the C.C.H.' I should guess that to be the Something Hunt, the local hunt to whose members he has possibly given some surgical assistance, and which has made him a small presentation in return."

"Really, Watson, you excel yourself," said Holmes, pushing back his chair and lighting a cigarette. "I am bound to say that in all the accounts..."
“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