Preserving Legacy: A Guide to Message Banking

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www.childrenshospital.org/acp

Begin with  
THANK YOU  
to many extraordinary people with ALS

Patient photo/video blocked
Notice the term
‘Message banking’
NOT
‘Voice Banking’

Children’s Hospital Boston
History of ‘Voice’ Banking

1994: CHB founded a model of AAC service delivery in the ICU including preoperative ‘voice banking’.

Patient photo/video blocked
Parent perspective on hearing daughter’s voice

Patient photo/video blocked

1998 Incorporated 'Voice' banking to support children living with life limiting illness/at end of life

Patient photo/video blocked

General model for ‘voice banking’

- Patient directed focus
- Patients are asked to imagine nonspeaking condition or reflect on previous experience
  ***many had previous experience
- Patient and family members ‘free flow’ selection
Vocabulary Selection part II

- Encourage vocabulary that focuses on representing individual personality, personal interests, personal humor or phrases particular to the individual

- No message was ‘rejected’ by the clinician

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

Categories of banked messages
(analysed of messages banked by 50 patients age 4 – 27 years)

- Personal needs
- Social
- Control
- Positioning
- Statements/directives
- Questions
- Emotions/Feelings
- Leisure/entertainment
- Sarcasm
- Clarifications
- Comfort
- Medical
2006
CHB Augmentative Communication Program asked by local ALS provider to see PALS.

2009
• Pilot program launched under grant for fast-forwarding SGD assessments
• Through fast-forward, Initial PALS referrals for high-tech SGD candidates seen by J. Gosnell
• Referrals diversified to head/neck cancer patients post-op
• Suggested our pediatric pre-op model could be applied

Sidebar:
Let’s examine terminology

The term ‘voice banking’ has continued to be used since we introduced it in the early 90’s
BUT
technology has changed!
With research and advanced technology, the term **Voice Banking** is now used to define a more sophisticated strategy.

ModelTalker
http://www.modeltalker.com/

The ModelTalker system was developed by the Norcom 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 Nemsos Biomedical Research.

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

![Synthetic Samples of Personal Voices](http://www.modeltalker.com/comparison.html)
ALS forum: post dated 10:06  retrieved: Nov 6, 2011

"So I finally finished recording the inventory of phrases.
I have about 1600 phrases and I would think you would need to dedicate a good 2 weeks of 1 or 2 hours a day.

But it is worth it. From those recorded phrases the Speech Research Laboratory at U. of Durham Hospital for Children and the University of Delaware synthesized a voice based on my recorded phrases. While it is not my real voice - it sounds better than any other voice synthesized I’ve heard such as the one Stephen Hawking used - and best of all it sounds like ME.

Sure I can write anything (even if the words were not in my recorded vocabulary) and it will be converted into speech using my voice.

I was almost in tears when I first heard it and I can’t express what it means to know that, whatever happens to me, I will be able to communicate with my own voice.

The whole process and software are FREE and just requires some time commitment on your part.

I am forever indebted to everyone at the Speech Research Laboratory at U. of Durham Hospital for Children and the University of Delaware

I would urge all PALS to do this now before it is too late."


DANGERS OF MEESOL TALKER:
Don’t let my voice - Lisa Modetaker is one of the most amazing programs out there. It is such a comfort knowing that even after I’ve lost the ability to speak I will still be able to talk using a synthesized version of my voice. All for free. I owe the developers of Modetaker a huge debt of gratitude.

As it becomes more and more difficult for me to speak, I’ve started practicing with the program instead and I’ve uncovered an insidious side to Modetaker.

Now every time I have a disagreement with my wife - she takes the computer, types in the response she wants me to hear, presses "read" - and with a "click" the argument washes away.

"Of course dear, I’d much rather watch taped episodes of Oprah instead of the Superbowl."

"By all means, go right ahead and re-decorate the house in pink."

"You’re quite right dear. Angela is a little bit haggard."

And the problem is I’m usually swayed by such an eloquent and knowledgable sounding voice.

But I have to find some way to password protect the program after I taught my nephew (who has Down Syndrome) to type in "I want a monkey and need the one too."


Custom voice created by Scottish company ‘Cereproc’
http://www.cereproc.com/en/home
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. The ModelTalker is one such project from the University of Delaware Speech Research Lab and their business partner AgoraNet.

The website is:
http://www.modeltalker.com/
(AgoraNet is the business partner for the speech research lab ModelTalker project)
**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 these words to create unique messages, although the output will sound more staccato than your natural speaking.

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**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: historically, typical strategy used**

- Acquire high quality microphone
- Create a list of appropriate message
- Use a recording software on your computer such as sound recorder
- Try to record message that sound as natural as possible
Outcomes?
- Patients report it’s ‘hard’ to know what to record
- “I can’t figure out what I am going to want to say”
- Some prioritize and record specific messages to loved ones (terms of endearment, appreciation to loved ones)
- Is tedious and artificial so is a ‘chore’ to accomplish
- Informal survey of colleagues nationally reveals banking of 10 – 20 messages on average with some instances of about 100

Message Banking:

*We can do better!*

*My dilemma*
Email referral: March 04, 2011
Friday @ 7:10 PM

“John, I want to send a patient to you next week for voice banking - he is a 56 y.o. heading into surgery 3.22 for a likely total glossectomy/total laryngectomy. Surgeon does not know if he needs to take the whole tongue but he likely will. The patient is calling Monday to schedule this. His name is: John XX. Let me know what you need - The MD is faxing a referral to you”.

What would make this process easier and more functional?

• Record any time and on the spot
• Have each recording be a .wav file
  – Highest quality so we have flexibility of all platforms at highest quality
• Easily download to a computer and determine communication platform later

On-line search for ‘handheld .wav file audio recorder’

• Kept finding ‘zoom’ products

• Wanted to be certain so called the US distributor:
  Samson Technologies Corp.
  45 Gilpin Avenue, Hauppauge, NY 11788

• Described my exact mission and was directed to Zoom H1 which I purchased from Amazon and received next day delivery
On-line search of “handheld .wav file audio recorder”

Zoom H1 Paik Portable Digital Recorder With Accessories Bundle and Headphones
Price: $199.99

Demonstration of .wav file creation

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

Note:
Going to stay focused on today’s topic

Clearly, the broader topic of AAC, alternative access strategies and Feature Matching must be addressed with each patient as early as possible
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

Strategies/categories identified by patients

- Follow text
- Specific requests
- Self care
- Medical needs
- Personal space
- Refusal

Susan

Patient photo/video blocked
**Legacy Messages:**

...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 ‘talking’ for them.

**Core Vocabulary** refers to messages and words that are frequently used by many individuals across many contexts. This vocabulary typically consists of "functor" words such as "is, was, he, she" and common nouns and primary verbs (e.g. person, like, want). (Beukelman & Mirenda, 1992).

**Fringe Vocabulary** is vocabulary specific or unique to a person or to one activity or topic (Beukelman & Mirenda, 1998).

**Categories of messages banked (initial analysis)**

- Personal messages/noises/sounds that are uniquely meaningful
- Appreciation
- Conversational modifiers
- Family routines
- Initiation of social activity
- Explanation of condition
- Expletives
- Personally relevant locations
- Social – time of day related
Categories of messages banked
(initial analysis)

- Sports/cheers
- Conversational starters
- Conversational enders
- Compassion toward others
- Complaints
- Personal info (biographical)
- Personal state

Categories of messages banked
(initial analysis)

- Messages to children
  - Daily routine
  - Pride
  - Tender moments
  - Discipline
  - Future
- Requesting assistance
- Phone conversation
- References to future
- Humor and Sarcasm
- Social questions

Early referral of PALS

- Determining goals and motivations
- Voice vs Message banking
- Bank now, select platform later
- Vocabulary and counseling
- Tools and options to consider (based on patient’s interest)
  - Simple/low tech
  - iDevice options
  - Dedicated/integrated SGD

Patient photo/video blocked

Paul, age 52
diagnosis: ALS ten months prior to first visit

Patient photo/video blocked
Categories

- Greetings
- Need ‘food/drink’
- Need ‘medical’
- Need ‘personal’
- Advice to boys
- Apologies
- Appointments
- Communication with doctors
- Phone calls to friends
- Car related messages
- Change of location/position in the house
- Social initiation “do you wanna…”
- Environmental needs/control
- Encouragement to others
- General social
- Gratitude
- To family ‘be there for each other’
- Silly intonations
- Statements about medical status
- Special occasions
- Sports
- Thanks and love to others
- Thanks (general)

Meaghan, age 11
dx: Juvenile Huntington’s Disease
Message Bank on iPad

What Platform??

There are MANY but here are a few possibilities
Today
www.childrenshospital.org/acp

In mid-August
http://www.patientprovidercommunication.org