AAC and Pediatric Tracheostomy in Acute Care:

When Speech isn't an Option, Communication is Possible

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Focus for today…

Augmentative and alternative communication strategies for children with tracheostomies who are non-speaking OR have a reduced ability to use spoken language secondary to a tracheostomy.

*Speaking valve/leak speech for spoken language is IDEAL when POSSIBLE

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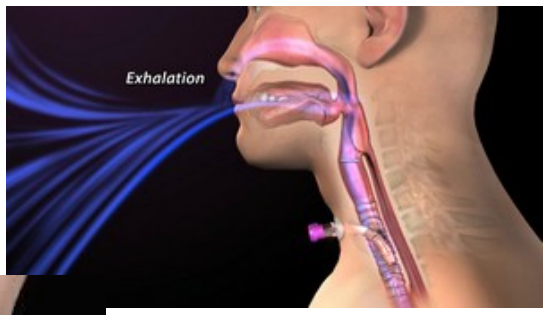
Background: Bedside AAC at BCH

- ICU and Acute Care floors
- 1.0 FTE inpatient AAC bedside service delivery
- Preoperative and Postoperative interventions
- Separate SLP communication and feeding teams

Background: Bedside AAC at BCH

- 581 patients in Tracheostomy Database
  - 384 active
  - 110 decanulated
  - 87 deceased
- ~50 tracheostomies/year
- ~10-15 inpatients w/ tracheostomies/day
- Multi-disciplinaryTracheostomy Clinic

Quick Review: Tracheostomy



Inflated Cuff

Deflated Cuff/cuffless trach w/ SV

http://passy-muir.com

When is a Speaking Valve NOT Appropriate?

Typically:

- Patient not awake
- Presence of upper airway obstruction or anatomical interference
- High end-expiratory pressure (EEP) (ideal: <10cmH2O)
- Copious secretions
- Severe aspiration risk
- Chronic, severe pulmonary disease
- Severe medical instability
- Inability to tolerate cuff deflation
- Inadequate air leak
  - Tube size vs. patient size

Utrachkij, J. et al, 2005)

Pediatric Patients at BCH w/ AAC Needs:

- Often difficult decision to undergo pediatric tracheostomy
- Careful medical and respiratory management
  - Long-term ventilation
- Complex medical needs
  - Preliminary GTC data

- Often:
  - Severe medical instability
  - Chronic respiratory insufficiency
    - Bridge to lung transplant
    - Inability to extubate
  - Inability to tolerate cuff deflation

Who?

- Children requiring
  - Short term strategies
  - Long term strategies

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Who?

- Children with short term AAC needs
  - All patients ~1 week post-op
  - Short term ventilation needs with anticipated speaking valve tolerance

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Who?

- Children with long term AAC needs
  - Long term ventilation needs
  - No air leak; long term
  - 8 vs. 24 hr communicators
    - i.e. Night time ventilation

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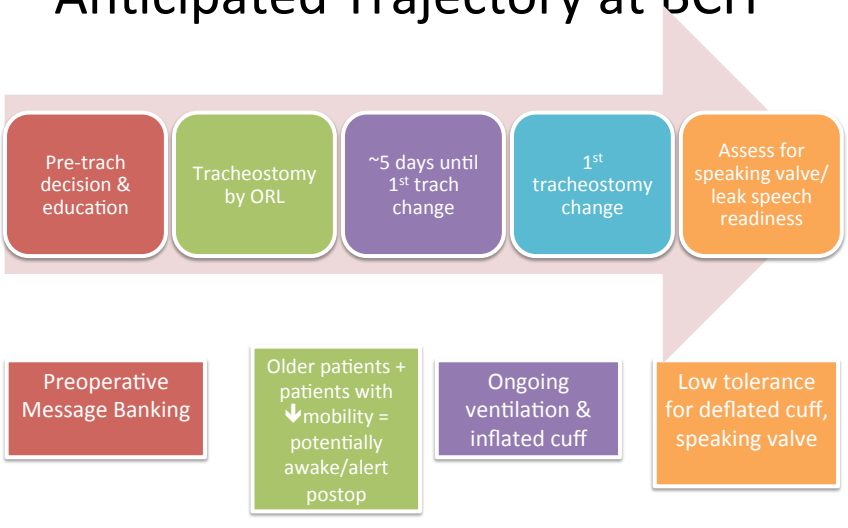
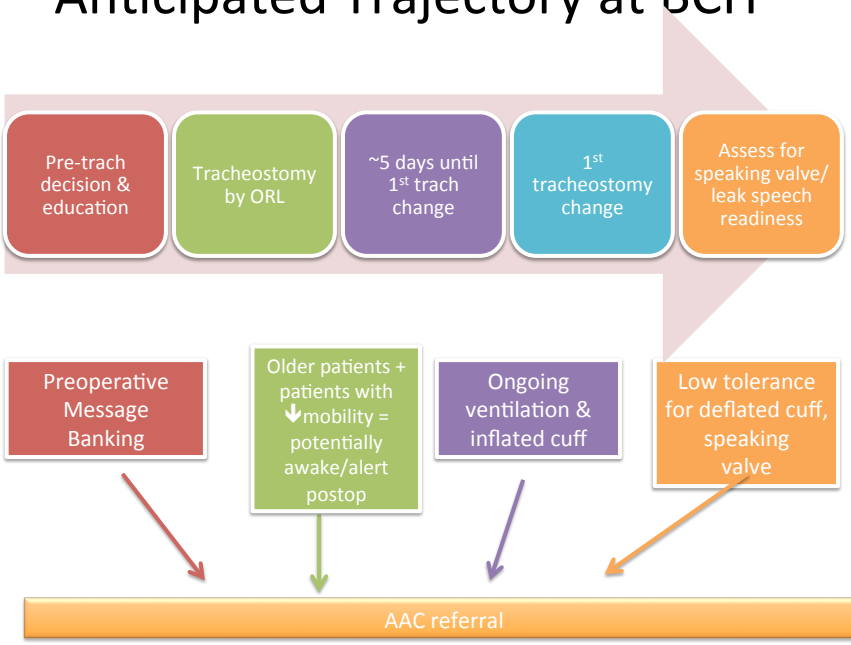
Anticipated Trajectory at BCH

Anticipated Trajectory at BCH



Anticipated Trajectory at BCH



When is referral for AAC appropriate?

INPATIENT:

Patient Status:	Intervention:
WILL undergo tracheostomy: 1. Patient speaks at baseline	***WILL undergo tracheostomy:*** 1. Preoperative message banking; set up communication system
2. Patient does not speak at baseline	2. Identify supports/strategies to enhance patient-provider communication.
Trach at baseline 3. Tolerates deflated cuff/speaking valve but requires mechanical ventilation	***Trach at baseline*** 3. Identify supports/strategies to enhance patient-provider communication until able to tolerate deflated cuff/speaking valve.
4. Does not tolerate deflated cuff/speaking valve at baseline	4. -Support use of existing augmentative and alternative communication (AAC) supports/strategies. -Identify new AAC supports/strategies

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Feature Matching Process

Systematic process by which a person's strengths, abilities, and needs are matched to available tools and strategies

- Shane and Costello, 1994

Think about **baseline** *and* **anticipated** strengths, abilities, and needs

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Domains of Assessment

1. Cognition
   - Alertness/awareness expectations
   - Baseline status
2. Speech and Language Skills
   - Use of speech, symbols, text, and communication displays
3. Sensory
   - Vision
   - Hearing
   - Anticipated swelling/incision sites
4. Respiratory Status
5. Gestures
6. Sign Language
7. Literacy
8. Vocabulary selection
9. Medical Status
10. Motor Skills
11. Team members & Communication Partners

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AAC Tools and Strategies

- Unaided:
  - Natural forms of communication (including gestures and facial expressions) as well as manual signs and American Sign Language (ASL).
- Aided:
  - Communication that requires some form of external support (including line drawings, pictures, printed words, speech-generating device, etc.)

www.asha.org

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Unaided Strategies

May include:

- Sign language
- Gestures
- Body language
- Facial expressions
- Vocalizations

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Aided Strategies

May incorporate:

- Objects
- Pictures
- Writing
- Typing

May be high-tech, mid-tech, or low-tech

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Phases of AAC need in the **Acute Care Setting**

1. Preoperative
2. Emerging sedation
   - Example: bridge to lung transplant and early rehab needs
3. Increased wakefulness
4. Broader communication needs
5. Long term communication needs → Rehab & Outpatient

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Phases of AAC Need: Pre-Tracheostomy

Benefits of early preparation (IF POSSIBLE)

- The hospital admission is stressful enough
- Postoperative status → misunderstanding, confusion, waxing and waning mental status
- Patients can participate in selection of tools and messages during less acute and stressful time
- Patient can record own voice if able
- Time to familiarize → easier and more functional use
- Sense of control in own care and preservation of personality

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Phases of AAC Need: Pre-Tracheostomy

- Understand expected outcomes → Influences assessment
  - Length of admission
  - Length of ICU stay
  - Anticipation of respiratory support needs
    - Trajectory of ventilation requirements?
  - Motor weakness?
  - Sedatives/other drugs?
  - Positioning needs?
  - Surgical incisions and other relevant sensory information

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Phases of AAC Need: Pre-Tracheostomy

- Hospital Narratives and Social Stories™
- Design varies based on language skill and use of visuals
  - Photographs
  - Picture-communication symbols
  - Symbol supported text
  - No visuals
- Outline expected details and outcomes of the procedure

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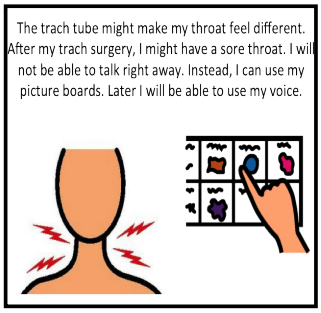

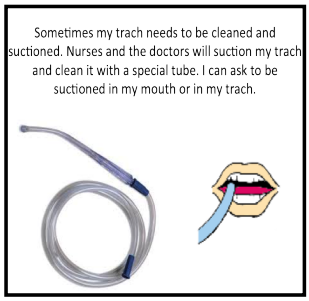

If sedated or otherwise unable to participate in preoperative message banking, preparation is STILL beneficial!

Consult family members, nurses, multi-disciplinary team members

Phases of AAC Need: Emerging from Sedation

- High likelihood of reduced phonation for ~5 days
- Sedatives → generalized weakness; temporary vision deficits, confusion or delirium

- Possible Interventions:
  - Yes/no/I don't know communication board
  - Adapted nurse call system
  - Simple voice-output communication aid (VOCA) to gain attention

  - Also – developmentally young/emergent communi and 'control'

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Phases of AAC Need: Increased Wakefulness

- Possible Interventions:
  - ALL PRIOR SUPPORTS
  - Additional vocabulary
  - Simple picture board
  - Alphabet board:
    - QWERTY
    - ABC
  - Body/positioning board
  - General comfort board
  - Customized communication board
  - Multi-message voice output devices
  - Digitally recorded messages

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Phases of AAC Need: Broader Communicatic

- Possible Interventions:
  - ALL PRIOR SUPPORTS
  - Broader range of vocabulary
  - More sophisticated page sets
  - Generative communication with alphabet
  - Word/grammar prediction
  - Internet access

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Message Considerations: Acute Care & Beyond

- Gaining attention
  - Call for help
- Medical Needs
  - discuss *and* understand
- Social interaction
- Making choices & indicating preferences
- Feeling in control
- Asking questions
- Communicate to regulate the task
  - Opt in/out
  - Take a break
- Commenting
- Personality
- BEYOND…

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When does AAC become a long term need?

Not yet able to tolerate:

- Deflated cuff
- Inadequate air leak (tube size?)
- Alternative source of vibration:
  - Electrolarynx
- Speaking valve

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Presence of:

- Baseline or new onset speech/language production difficulties
  - Dysarthria
  - Apraxia
  - Aphasia
- Vocal cord paresis or paralysis
- Anatomical or structural deficits
- Baseline cognitive skills
- Baseline language skills
- 8 hr vs. 24 hr AAC users
  - i.e. night time ventilation requirements

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Communication Boards

- Picture-symbols and/or photographs
- Paired written labels
- Access:
  - Direct selection?
  - Partner assisted scanning?

Communication Boards

- Eye gaze communication board
- Eye gaze letter frame
- E-tran system

Speech-Generating Devices Low-tech; Mid-tech

- Digitized voice
  - Direct selection?
  - Multiple levels?
  - Auditory/visual scanning?
- Examples:
  - Step-by-Step
  - Big Mack/Little Mack
  - Italk 2
  - MessageMate 40
  - GoTalk
  - QuickTalker
  - Smart Scanner
  - Tech/Talk

Digital Recording Tool
i.e. MessageMate

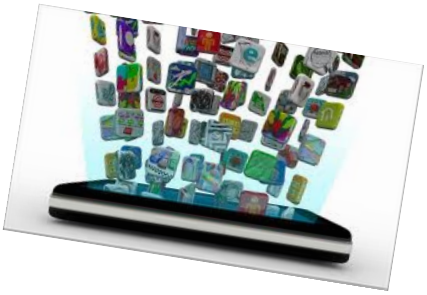
- Speech generating device
- Digitized voice
- Up to 40 messages
- Access: direct selection or switch scanning
- Can be mounted for optimal acces

Speech-Generating Devices
High-tech

- Digitized or Synthesized voice
- Access:
  - Direct selection
  - Eye gaze
  - Single or multi-switch scanning
- Mounting:
  - Rolling mount
  - Bedside mount
  - Wheelchair mou
  - Tabletop mounts

Mounting personal equipment at bedside

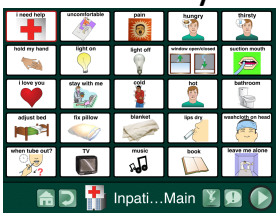
Speech-Generating Devices Mobile-tech



- Customizable AAC apps
- Picture-symbol
- Text-to-speech
- Full-communication apps
- Medical Communication apps – with prestored messages

Communication Applications

- Picture Symbols

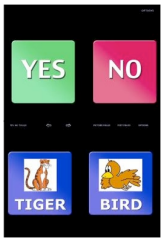


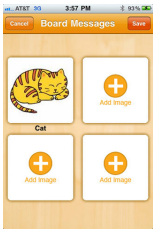
GoTalk NOW

TouchChat

Proloquo2Go

Answers HD-YesNo





SoundingBoard

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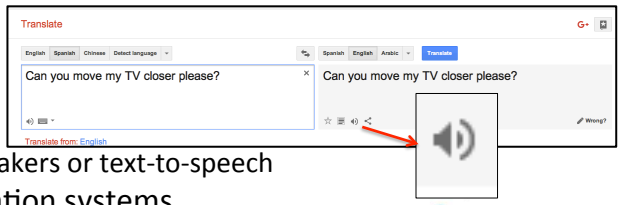
Text-to-Speech

- Dedicated systems:
  - i.e.:
    - Lightwriter
    - Dynawrite
- Apps:
  - AssistiveExpress
  - Predictable
  - Proloquo4Text
  - Verbally
  - And more!
- Laptop:
  - Software
  - GoogleTranslate
    Non-English speakers or text-to-speech
- Within communication systems



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CASE STUDY

CASE STUDY:
Hadley

- Baseline:
  - 15 y.o.
  - Glasses
  - Hearing aid; left ear
  - Hx of progressive cervico-medullary region pilocytic astrocytoma s/p resection and prolonged chemotherapy
  - Medical complications s/p brain tumor including:
    - Vocal cord paralysis
    - Swallow dysfunction
    - Laryngomalacia
    - Right hemiparesis

CASE STUDY:
Hadley

- Date of admission:
  - Increased work of breath (WOB) at Jimmy Fund Clinic
  - Limp and unresponsive
  - Acute respiratory decompensation
  - Intubated; transferred to ICU

CASE STUDY:
Hadley

Emerging from Sedation

Patient Presentation:

- Intubated; awake throughout day
- Drowsy; moderate sedation
- Nodding to simple questions
- Per report – tried typing on own iPad
  - Bilateral IV boards
  - Significant discoordination
- Baseline anxiety + related to intubated state
- Unable to extubate

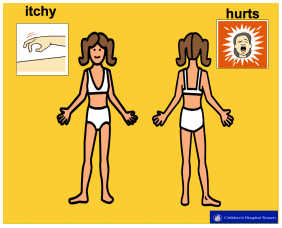
HADLEY:
Emerging from Sedation

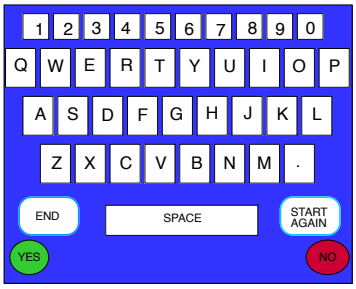
Domains of Assessment:	Observations:
Cognition	Awake and alert Moderate sedation
Sensory	Glasses donned upon request Hearing aid not at bedside; functional hearing regardless
Language Comprehension	Answering Q's appropriately w/ head nods
Motor Access	Bilateral IV boards on hands/wrists; position restriction d/t intubation
Speech Production	Non-speaking d/t oral intubation
Vocabulary Selection	Able to participate by answering simple questions and pres. of template vocabulary; basic wants/needs, comfort/medical, attention
Environmental Considerations	Noise: minor Lights: on Frequent bedside RN cares
Communication Partners	Parents, RN, providers

CASE STUDY:
Hadley

- Interventions:
  - Encouraged glasses + hearing aid (at home)
  - Reduced size of bilateral IV boards to accommodate direct selection
  - Lights on, as able
  - Noise reduced, as able
  - Gain attention: Step-by-Step communicator; mom recorded voice
  - Express wants/needs: Template ICU communication boards

CASE STUDY:
Hadley





CASE STUDY:
Hadley

Increased Wakefulness → Need for Broader Communication Access (*same day*)

Patient Presentation:

- Awake throughout day
- Mild sedation; very alert
- Increased strength
- Accessing all materials appropriately
- Baseline anxiety + related to intubated state
- NEW PLAN: tracheostomy d/t inability to extubate safely

HADLEY:

Increased Wakefulness → Broader Comm. Needs

Domains of Assessment:	Observations:
Cognition	Awake and alert Mild sedation
Sensory	Glasses donned Hearing aid not at bedside; functional hearing regardless
Language Comprehension	Answering Q's appropriately w/ head nods Accessing prev. provided materials well
Motor Access	Downsized IV board on left (dominant) hand
Speech Production	Non-speaking d/t oral intubation
Vocabulary Selection	Able to participate by answering simple questions and demo of template vocabulary - Need for generative communication + beyond comfort/medical
Environmental Considerations	Noise: minor Lights: on Frequent bedside RN cares
Communication Partners	Parents, RN, providers, sibling

CASE STUDY:

Hadley

- Interventions:
  - Encouraged glasses + hearing aid (at home)
  - Reduced size of bilateral IV boards to accommodate direct selection
  - Lights on, as able
  - Noise reduced, as able
  - Gain attention: Step-by-Step communicator; mom recorded voice
  - Express wants/needs: Ongoing access to communication boards + customized board and modifications
  - Generative Communication:
    - iPad w/ application: Assistive Express
    - Secured iPad mount to left bedrail
    - During RN cares = low-tech strategies

CASE STUDY:

Haley

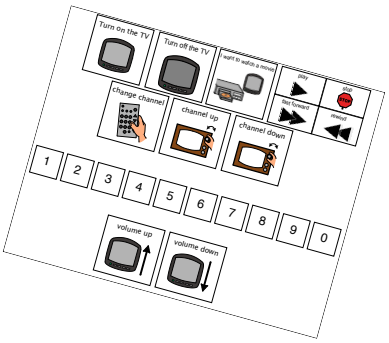
Pre-trach: Introduced iPad w/ Assistive Express

- Participated in preoperative discussion about tracheostomy
- Accessed during conversations and pre-op prep with psychologist, MDs
  - "Can it be pink?"
  - Thoughtful questions about trajectory of need and expectations
- Saved messages into Favorites List
  - Helpful for post-op
- Utilized word prediction

CASE STUDY:

Hadley

Post-trach: Customized and modified communication boards:



CASE STUDY:

Hadley
Broad Communication Needs

Patient Presentation:

- Anxious, sad about having trach; feeling "stuck"
- Communicating "well" per RN – access to communication boards + ABC supports [Assistive Express and QWERTY board]
- Further participation in customizing communication boards
- Using humor to engage:
  - "Welcome to Entertaining You in the ICU"
  - "My brother's gonna think I'm an alien!"
  - "I like to move-it move-it"

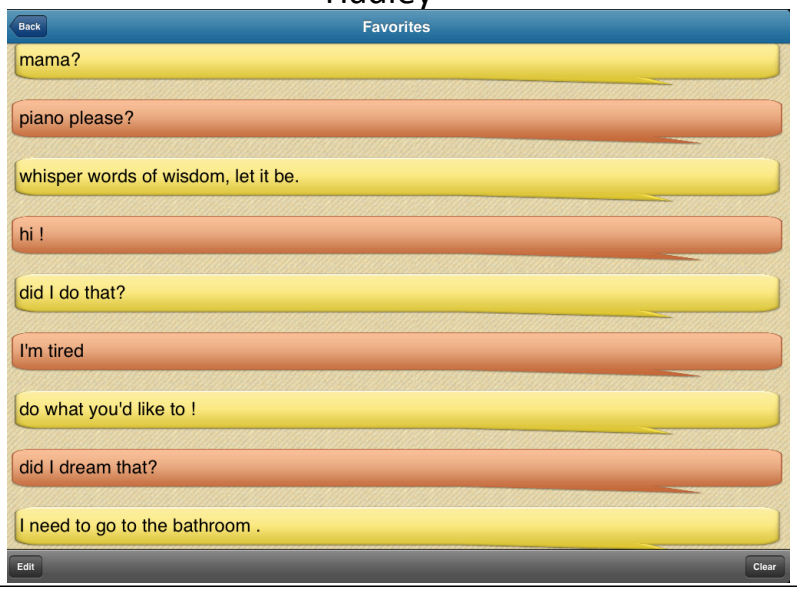
HADLEY:

Broad Communication Needs

Domains of Assessment:	Observations:
Cognition	Awake and alert Mild sedation
Sensory	Glasses donned Hearing aid not at bedside; functional hearing regardless
Language Comprehension	Engaged in conversations
Motor Access	During RN cares, will access low-tech materials. Otherwise text-to-speech
Speech Production	Non-speaking d/t tracheostomy until first trach change
Vocabulary Selection	- Participating in further customization of messages - Saved prestored messages to Assistive Express "Favorites List: - Humor!
Environmental Considerations	Noise: minor Lights: on iPad mount – bedrails, chair rails, tabletop
Communication Partners	Parents, RN, providers, sibling

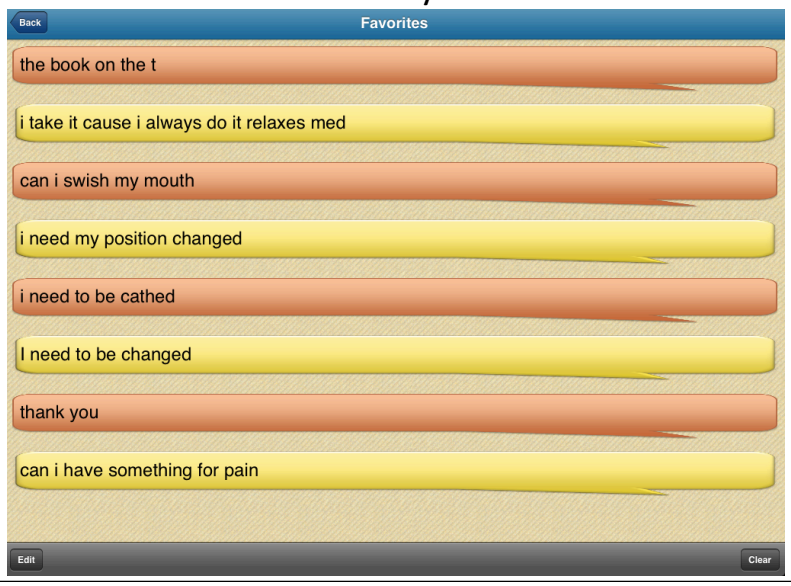
CASE STUDY:

Hadley



CASE STUDY:

Hadley



CASE STUDY:

Hadley

Broad Comm. Needs → Long Term Needs

Patient Presentation and Interventions:

- Transition to neurology unit
- Back to baseline
- Introduction of Speaking Valve
- Tolerating for ~30 min – 1 hour initially
- Continued access to AAC as needed

- Recs for ongoing speaking valve use
- Reviewed text-to-speech apps upon discharge as 'back-up'

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