AAC Considerations in Advance of a Child's Upcoming Hospital Admission:

Preparing Early to Enhance Care

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Disclosure

No relevant financial or nonfinancial relationships exist

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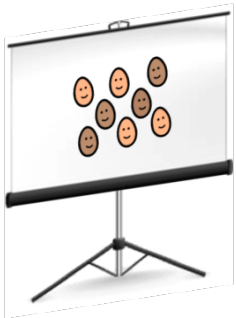

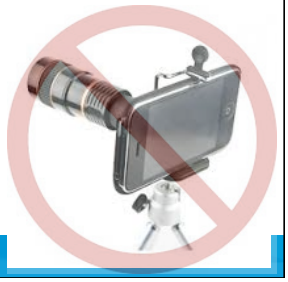

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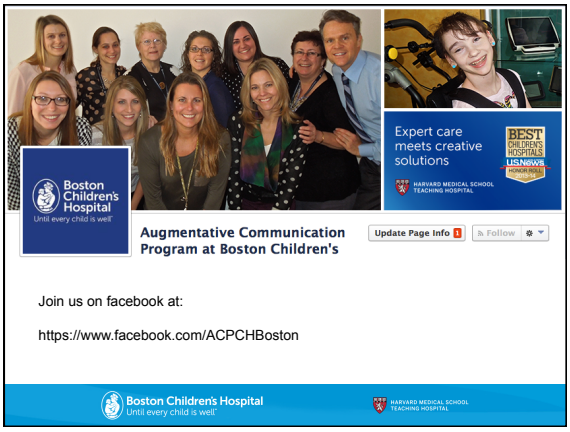

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Programs and History

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Preoperative Preparation: Why is this relevant?

- What we know:
  - Communication vulnerable patients are at risk for:
    - Medical errors
    - Adverse and sentinel events
    - Poor compliance
    - Lengthier hospitalization
    - Poor perception of quality care

    (Cohen et al., 2005; The Joint Commission, 2007; Andrulis et al., 2002; Flores et al., 2003)
  - Poor impact on patients, family, and staff

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Who does communication vulnerability impact?

Patient:

- Loss of control, sense of self, ability to participate in own care (Garrett et al., 2007)
- Inability to speak is closely linked to: insecurity, panic, worry, fear, anger, stress, and sleep disturbances (Happ et al., 2004)
- Feelings of low mood can lead to withdrawal from family and care givers. This impacts participation in care and recovery (Magnus and Turkington, 2005)

Family

- Afraid child will not be able to communicate wants and needs or call out for them
- Distress over temporary loss of child's personality (Costello, 2000)

Staff

- Delivery of nursing care
- Nurses don't have time to "figure out" patient's communication attempts
- May lead to limiting communication attempts beyond what is essential (Costello, 2000 and Garrett et al., 2007)

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Why Prepare?

- Access to AAC enhances patient care
- Patients admitted to the ICU are at high risk for communication vulnerability
- Research supports communication enhancement closely linked to patient satisfaction and safety
  - Happ (2004) and Patak et al. (2006)
    - Patients with access to communication:
      - Receive less sedation
      - Are transitioned quicker
      - Have increased satisfaction with health care
      - Feel more in control…and generally do better…

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Three Types of Preoperative Patients

1. No notable baseline communication vulnerabilities but will due to medical event or treatment

2. Baseline communication vulnerabilities who do not currently use AAC

3. AAC users who may require modifications and enhancements based on anticipated medical/surgical condition

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Baseline Communication Vulnerabilities

- Cerebral Palsy
- Duchene Muscular Dystrophy
- SMA Types I, II, III
- Autism Spectrum Disorder
- CHARGE syndrome
- Congenital deafness
- Developmental Delay
- Speech-language delay
- Trisomy 21
- Previous neurological injury
- DiGeorge Syndrome (Velocardiofacial Syndrome; 22q11.2 deletion)
- Intellectual disability
- Selective mutism
- Motor impairment that reduces ability to access the standard nurse-call system
- Child does not speak language of the environment
- Other

Anticipated Medical Conditions:

- Any form of invasive ventilation
- Tracheostomy
- Non-invasive ventilation (BiPap, CPap)
  - Includes full-time, day-time only, night-time only
- Oro-facial surgery
- Brain tumor resection or biopsy
- Other neuro-surgical procedures
- Complex dental procedures
- Baseline motor impairment
- Anticipated motor impairment
- Degenerative neurological or neuromuscular disease
- Other

As the primary SLP, you know the child best!

- YOU understand child's speech and language skills
- YOU understand child's communication style and preferences
- YOU are already familiar with child's use and access to tools and strategies
- YOU might have access to materials and tools
- YOU are fun, stress-free, and informed

Focus on communication enhancement strategies in a *low stress* environment

Benefits of Early Preparation

- 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

The Pre-Operative Visit

Gathering Information

- Typically 1 day to weeks or months prior to admission date
- Child & Family meet team members
- Physical exam and tests

Expected Outcomes

- Length of admission
- Length of ICU stay
- Anticipation of respiratory needs
  - Intubation/ventilation?
  - Transition to non-invasive ventilation?
- Motor weakness?
- Sedatives/other drugs?
- Positioning needs?
  - i.e. Lay supine for 48 hours post-op
- Surgical incisions or relevant sensory information

Who can you call?

- Family
  - Information gathered during pre-op visit
  - Prior hospital experiences
- Connect with the hospital team
  - **SLP**
    - Is there an inpatient SLP?
    - Does the hospital have an outpatient clinic?
  - ***Child Life Specialist***
    - Virtually every pediatric hospital has one (or many!)
    - Coping, distraction, medical play, self-expression activities, and preparation
    - Great resource for gathering information, outcomes, and patient experience
  - **Social Worker**
    - Helps families with range of psychosocial issues, coping, and resources
    - Often department or unit specific
  - **Medical Team**

Quick Aside: Are you an inpatient SLP??

- **Contact your preoperative clinic/s**
- **Coordinate consultation time**
  (Even 5 minutes!)
- **Coordinate with family via email/phone if face-to-face not possible**

Phases of Communication Vulnerability

Understanding the patient experience relative to communication vulnerability and recovery

Phase I: Emerging from sedation

- Yes/no/I don't know board
- Adapted nurse call system
- Simple voice-output communication aid (VOCA) to gain attention
- Also – developmentally young/emergent communicators and 'control'

Phase II: Increased wakefulness

- Additional vocabulary
- Simple picture board
- Alphabet board:
  - QWERTY
  - ABC
- Body/positioning board
- General comfort board
- Customized communication board
- Voice amplification
- Multi-message voice output devices
- Digitally recorded messages

Phase III: Need for broader communication access

- Broader range of vocabulary
- More sophisticated page sets
- Generative communication with alphabet
- Word/grammar prediction
- Internet access

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Feature-Matching Assessment:

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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Assessment Domains:

1. Cognition
   - Alertness/awareness expectations
   - Baseline status
2. Communication and Language Skills
   - Use of symbols, text, and communication displays
3. Sensory
   - Vision
   - Hearing
   - Anticipated swelling/incision sites
4. Speech production
5. Motor skill
   - Alternative access strategies
6. Vocabulary selection
7. Environmental assessment
8. Communication Partners
9. Team members

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Assessment Considerations

Strengths and Needs

- Consider your student's strengths
- Conduct a feature-matching assessment to determine best new strategies and tools
- Update or modify current systems to include hospital related messages

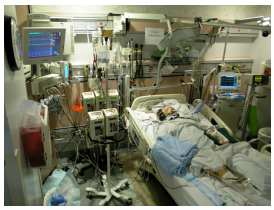
Assessment Considerations

- Access* – *How will the child access their existing or new communication system?*
  - Baseline skills and needs
  - Anticipated effects or surgery or medical event (i.e. IV boards, incision sites, halo traction)
  - Anticipated environmental considerations (i.e. lay supine 48 hrs post op, nurse-call wall adapter)

*May change throughout the continuum of care and recovery!

Environmental Considerations

- How will implementation of tools, materials, and/or strategies affect cares and vice versa?
  - Space
  - Placement
  - Positioning
  - Physical Therapy
  - Impact of medication
    - Eye gaze
    - Blurry vision
    - Generalized weakness
    - Physical restraints
  - Signage!



Message Banking

- Patient focused
- Can think preemptively about temporary non-speaking condition
- Child participates in vocabulary selection
- Record child's voice when possible
  (there's an app for that)
- Vocabulary to reflect child's personality, humor, interests, etc.

Communicative Functions: What to consider?

- 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

Remember the 3 phases

Vocabulary Selection

- Medical
- Comfort
- Environmental needs
- People (family, friends, medical staff)
- Leisure
- Social
- Emotional
- Personal/Individualized, "Very You"
- Regulation – i.e. Opt out messages

Example vocabulary by category at end of slides!

Partner Training

Working with your student and their families

- Greatly improves implementation and carryover of AAC
- Demonstration, education, and use
- Posting bedside signage
- Partner-assisted communication
- Supporting implementation
- Educating hospital staff

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BRING YOUR VOICE!

If a patient already uses AAC tools/materials, encourage him/her and families to bring communication systems to the pre-operative appointment and upcoming hospital admission!

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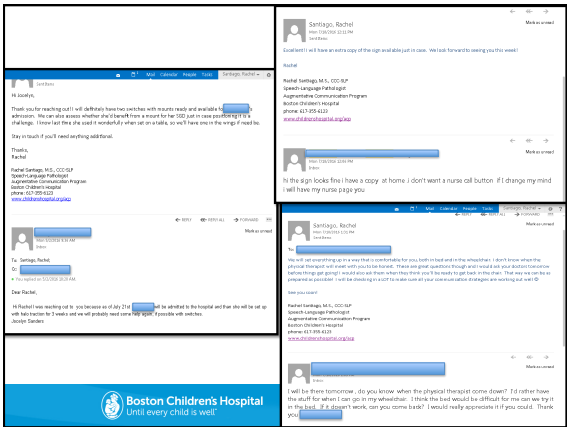

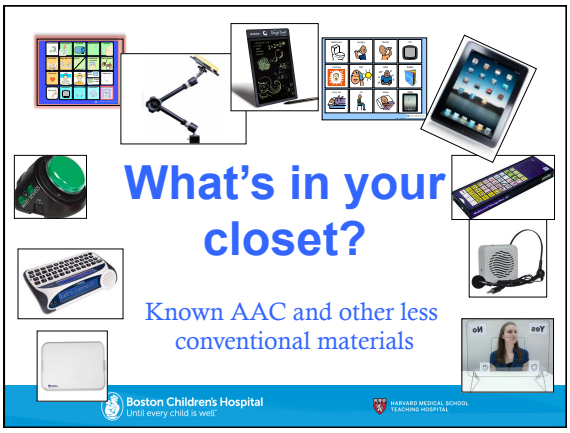

Tools, Equipment, and Strategies:

- Bedside Signage
- Ways to gain attention (in room, nurse-call system)
- Communication Boards (PCS, photographs, text/typing)
- Visual schedules, first-then boards, cue cards
- Writing tools
- Typing tools & text-to-speech (dedicated, low-tech, mobile-tech)
- Speech-generating device (mid-tech, high-tech)
- Mounting equipment & physical access strategies
- Voice amplifiers

- And much, much, MUCH more!

Example tools and strategies at end of slides!

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THANK YOU!

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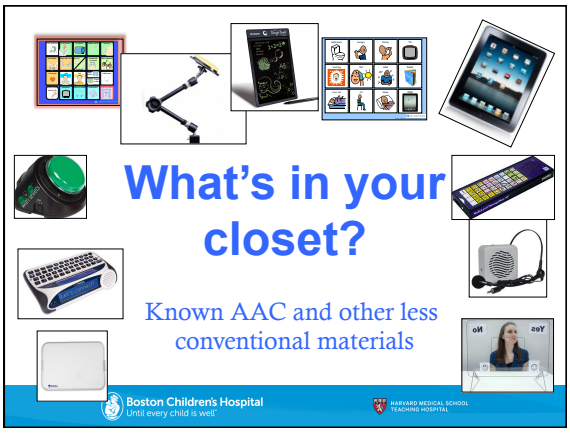
What's in your closet?
Known AAC and other less conventional materials
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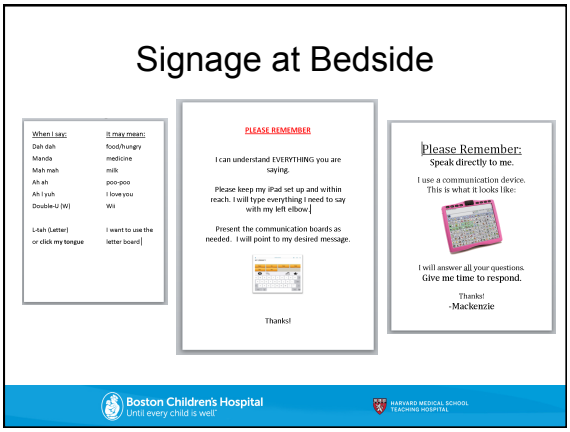
Signage at Bedside
When I say:
It may mean:
Dah dah
food/hungry
Manda
medicine
Mah mah
milk
Ah ah
poo-poo
Ah I yuh
I love you
Double-U (W)
Wii
L-tah (Letter)
or click my tongue
I want to use the letter board
PLEASE REMEMBER
I can understand EVERYTHING you are saying.
Please keep my iPad set up and within reach. I will type everything I need to say with my left elbow.
Present the communication boards as needed. I will point to my desired message.
Thanks!
Please Remember:
Speak directly to me.
I use a communication device. This is what it looks like:
I will answer all your questions. Give me time to respond.
Thanks!
-Mackenzie
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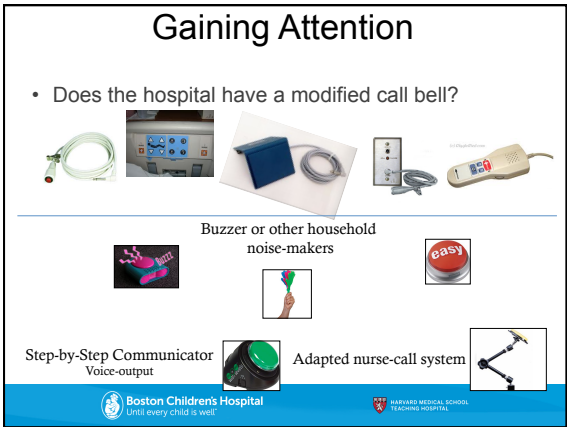
Gaining Attention
Does the hospital have a modified call bell?
Buzzer or other household noise-makers
Step-by-Step Communicator
Voice-output
Adapted nurse-call system
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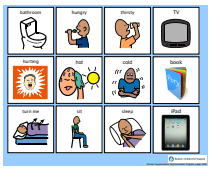
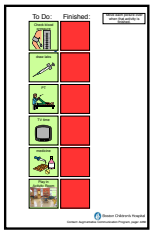
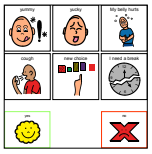
Communication Boards

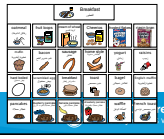
- Access:
  - Direct selection?
  - Partner assisted scanning?
  - Eye gaze?

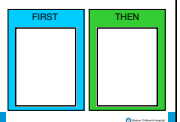
Communication Enhancement: Other Visuals











Writing

- Dry erase boards
  - No training required

- BoogieBoard
  - Used to write messages
  - Can use fingernail
  - Lightweight
  - Often motivating
  - BestBuy, Amazon.com, Toys R' Us, Staples (~$22.99)

Speech-Generating Devices Mid-tech

- Digitized voice
  - Direct selection?
  - Multiple levels?
  - Auditory/visual scanning?
- Examples:
  - MessageMate 40
  - GoTalk
  - QuickTalker
  - Smart Scanner
  - Tech/Talk
  - Apps:
    - SoundingBoard
    - GoTalk Now

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Speech-Generating Devices High-tech

- Digitized or Synthesized voice
- Access:
  - Physical direct selection
  - Eye gaze
  - Single or multi-switch scanning
- Mounting:
  - Rolling mount
  - Bedside mount
  - Wheelchair mount
  - Check with hospital team to ensure mounting capabilities!

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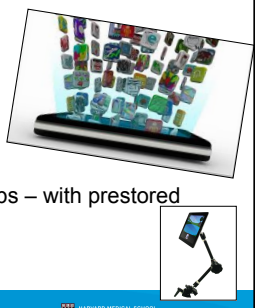
Speech-Generating Devices Mobile-tech

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



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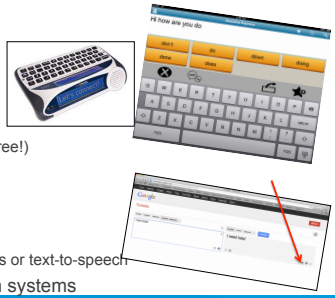
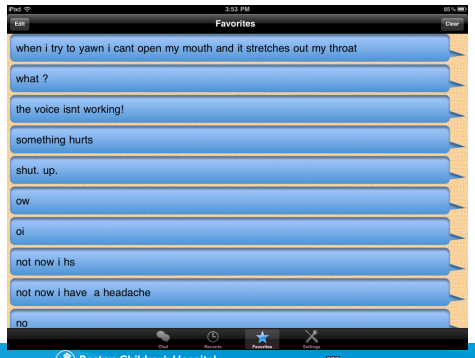
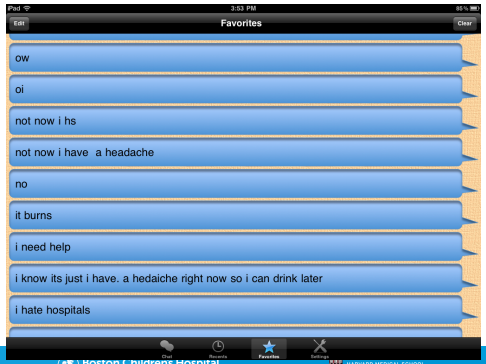
Text-to-Speech

- Dedicated systems:
  - Lightwriter
  - Dynawrite
- Apps:
  - AssistiveExpress
  - Predictable
  - NeoJulie / NeoPaul (Free!)
  - Verbally
- Laptop:
  - Software
  - GoogleTranslate
    Non-English speakers or text-to-speech
- Within communication systems



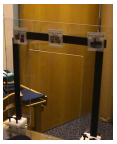




Physical Access

Bedside mount

Angled switch



Eye gaze frame

Sip and Puff Switch

Rolling mount – Eye Gaze SGD over the bed

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Hospital Narratives

- Social Stories™ - Carol Gray
- Design varies based on language skill and use of visuals
  - Photographs
  - Picture-communication symbols
  - Symbol supported text
  - No visuals
- Outline expected details of the hospital admission, procedures, bedside cares, and more.
- **Call the Child Life Specialist or Social Worker** to gather information related to admission for inclusion in narrative.

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Vocabulary Selection: MEDICAL

- Something hurts
  - Body Parts
- Something is itchy
  - Body Parts
- I'm tired
- I feel better
- I feel worse
- I need my nurse
- I need to be suctioned
- I need medicine
  - Sleep
  - Pain
  - Nausea
- I'm going to throw up
- My IV
- My incision site
- My g-tube
- It burns
- *Respiratory:*
  - I can't breathe
  - It's hard for me to inhale/ exhale
  - I need to be bagged
  - Please follow my breathing
  - It's easier for me to breathe now
  - When is my chest PT?
  - The tube is bothering me.

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Vocabulary Selection: COMFORT

- I'm uncomfortable
- Please move my bed up/ down
- I need to turn over
- I want to sit in the chair
- I want to go to bed
- I'm hot
- I'm cold
- Fix my blanket
- Fix my pillows
- I need to be changed
- Cold cloth on head
- Brush my hair
- Brush my teeth
- I need Chapstick
- Ice pack
- Heating pad
- I can't sleep
- *More comfort needs:*

Vocabulary Selection: PERSONAL NEEDS

- I'm hungry
- I'm thirsty
- Swab my mouth
- Brush my teeth
- Brush my hair
- Get/fix glasses
  - My vision is blurry
- Get/fix hearing aids
- I need to go to the bathroom
- I need to be changed
- Rub/massage
- I need a break
- Give me a minute

Vocabulary Selection: ENVIRONMENTAL

- Open/close door
- Open/close window
- Turn lights on
- Turn lights off
- Don't pull my lines!
- Don't touch my IV!

Vocabulary Selection: POSITIONING

- Turn me over
- I want to lay on my __ side
- Move my bed up
- Move my bed down
- Move me up in bed
- Prop me up
- I want to lay down
- I want to sit up
- I want to sit in the armchair
- Turn my head
- Put a pillow under my __

Vocabulary Selection: LEISURE

- I want to go to the playroom
- I want to go for a walk
- Can I have a volunteer hang out with me?
- I want to watch TV
- I want to watch a movie
- I want to listen to music
- Volume up/down
- Change the:
  - Channel
  - Song
  - Movie
- I want to read a book
  - Read to me
- Let's play a game
  - Relevant messages (Your turn! I got you!)
- Think about:
  - Items child is bringing to the hospital
  - Special blanket/ stuffed animals
  - Phone
  - Tablet

Vocabulary Selection: SOCIAL-EMOTIONAL

- Hey!
- How are you?
- How is __?
- What's the scoop?
- Who are you?
- Thank you!
- Have a great day
- You may enter the bat cave.
- I'm feeling __
- Where is my mom/dad?
- Let's chat
- I love you
- Hold my hand
- Stay with me
- This sucks!
- That tastes awful!
- When can I go home?
- *Leave me alone / Come back later
- Let's Pray
- (Phone script)

Vocabulary Selection: QUESTIONS

- What are you doing?
- Who are you?
- Why are you here?
- What's going on?
- How am I doing?
- When is the tube coming out?
- When can I go home?
- When can I eat?
- When can I drink?
- Where is my mom/dad?
- What day/time is it?
- What did you say?
- Can you say that again?
- What's in the IV bag?
- What medications am I on?
- Will it hurt?
- *Procedure Specific:*
  - Why do I need a trach?
  - When can I use my speaking valve/deflate my cuff?
  - When will the Foley catheter come out?

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Vocabulary Selection: HUMOR, SARCASM, PERSONALITY

- Oh greeaaat!
- Hellooooooo?
- Ummm I'm trying!
- Hahahahaha!
- You've GOT to be kidding me!
- I *hate* bugs!
- Ugh, read the chart!
- Pick that up and clean it with a sterile wipe!
- It's peanut butter jelly time!
- Jokes
- Patience required beyond these doors (door sign)

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