Communicating with ALS: Keeping the Conversation Going

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• Define communication
• Identify communication challenges often experienced with ALS
• Identify terms
• Identify examples of No Tech, Low Tech, and High Tech AAC
• Discuss role of SLP & communication partner
• Q & A
Communication

- Exchange of thoughts, messages, or information through speech, signals, writing, or behavior
- Foundation of all human relationships
- Communication is multi-modal ~ we use more than one mode to communicate (speech, facial expressions, gestures, writing, technology)
- We communicate to request information, protest, gain attention, comment/state opinions, gather information, express feelings, share information/stories
Speech Changes in ALS

- Changes in speech are common with ALS and progress over time.
- ALS damages/destroys the nerve cells that control muscle movement.
- Weakness or tightness in the muscles which are responsible for speech production cause dysarthria (slow, slurred speech).
- Reduced breath support is caused by weakened lung muscles and may decrease the volume of an individual’s speech and limit their ability to produce longer sentences.
Communication Challenges

Physical Symptoms
- Decreased speech intelligibility (dysarthria)
- Reduced breath support to produce speech
- Loss of speech
- Some are ventilator-dependent

Psychological Impact
- Grief
- Feelings of frustration
- Feelings of social isolation
- Dependent on others to interpret thoughts or feelings
Terms Defined

Dysarthria ~ condition in which the muscles used for speech are weak resulting in slow or slurred speech that can be difficult to understand

SLP ~ Speech Language Pathologist ~ specialist who evaluates and treats individuals with speech, language, cognitive-communication, and swallowing disorders

AAC ~ Augmentative and Alternative Communication

SGD ~ Speech Generating Device

Message/Voice Banking ~ process of creating digital recordings or a customized digital voice to be imported/installed on an SGD

Alternative Access ~ using an alternative area of the body, specialized technology, and/or modifications to access low and high-tech AAC systems
What is Augmentative & Alternative Communication (AAC)?

AAC is any device, system or method that improves a person’s ability to communicate effectively and participate in the world around them.

Approximately 80% of individuals with ALS will eventually use AAC to supplement or replace speech.
Why is AAC important?

All persons, regardless of the extent or severity of their disabilities, have a basic right to affect, through communication, the conditions of their own existence.

- American Speech and Hearing Association
ALS Stages of Intervention
(Yorkston, Miller, & Strand, 1995)

➢ Stage 1: No detectable speech disorder
➢ Stage 2: Obvious speech disorder with intelligible speech
➢ Stage 3: Reduction in speech intelligibility
➢ Stage 4: Residual natural speech and AAC
➢ Stage 5: Loss of useful speech
Stage 1: No detectible speech disorder

Plan of action/strategies . . .
• Meet with SLP to measure baseline speech rate
• General AAC education
• Message/Voice banking ~ SLP can make recommendations and provide assistance
  o http://projectrevoice.org/
Stage 2: Obvious speech disorder with intelligible speech

- Characterized by speech differences that are noted by unfamiliar listeners

- Plan of action/strategies . . .
  - Make an appointment with SLP to document changes in speech rate and to develop strategies to help improve communication challenges.
  - Minimize environmental interference (TV volume, noisy restaurants, dimly lit rooms)
  - Be aware of your fatigue level and plan activities/conversations accordingly
  - If speech is clear, but volume is decreased, discuss voice amplification options with your SLP
Stage 3: Reduction in speech intelligibility

- Characterized by a decrease in speech intelligibility, a decrease in speaking rate, and an increase in communication breakdowns

- Plan of action/strategies . . .
  - Continue to discuss strategies with your SLP for improving speech intelligibility or volume (reducing number of words spoken on a single breath, voice amplification systems)
  - Develop strategies your communication partner can use to assist you in being understood
  - AAC evaluation
  - Use low and high tech AAC systems for specific needs (telephone, unfamiliar listeners) as well as to resolve communication breakdowns
Stage 4: Residual natural speech and AAC

➢ Characterized by AAC transitioning from secondary source of communication to primary source

➢ Plan of action/strategies . . .
  • Low and high tech AAC systems customized for specific needs
  • Adjustments to SGD access method may be necessary
Stage 5: Loss of useful speech

➢ Characterized by lack of functional/intelligible speech

➢ Plan of action/strategies . . .
  • Low and high-tech AAC primary mode for most communicative interactions
  • Ventilators may be used for respiratory support
Loss of speech ≠ inability to communicate
Different Forms of AAC

➢ No Tech Systems ~ those systems that do not require an external tool and include facial expressions, gestures, vocalizations, sign language

➢ Low Tech Systems ~ those systems that do not need batteries, electricity, or electronics and include pen & paper, communication boards/books, and eye gaze boards

➢ High Tech Systems ~ those systems that require electricity and produce speech including SGDs, computers, and tablets loaded with speaking software.
Low Tech AAC

- Typically simple, inexpensive, and easy to learn
- Include paper-based communication boards, LCD/dry erase writing boards, eye-gaze boards
- Essential part of a complete communication system and often used as a back up to a high tech device
- Can be accessed in a variety of ways (pointing, gestures, eye movements)
- No voice output
High Tech AAC

- Often referred to as SGDs ~ can range from simple keyboarding devices to fully functioning computers
- Considered durable medical equipment and are often funded by Medicare, Medicaid, and most private insurance
- Typically require more training and support
- Most can be accessed in multiple ways including using your hands, switch scanning, head mouse, or eye gaze
Other Options

• Desktop computers, laptops, and tablets can be used as communication devices with voice output
• Additional hardware and software may be necessary
• Not covered by most insurance plans
• Most do not come with support/training (some manufacturers offer purchased trainings)
Help please!

Role of SLP . . .
• Educates patients and families regarding changes in speech and swallowing
• Provides ongoing monitoring of changes in speech and strategies to improve communication
• Reviews AAC options, performs AAC evaluation, and helps customize appropriate augmentative communication (AAC) systems

Role of Communication Partner . . .
• Shares the responsibility for communication
• Assists with the development and implementation of AAC supports
• Helps control the environment to promote successful communication
• Offers persistence when communication breakdowns occur
Final Thoughts . . .

➢ Be proactive vs. reactive ~ connect with an SLP as soon as possible to customize a personalized plan of action

➢ Consider message banking/voice banking sooner rather than later . . . You will be glad you did!

➢ You are not alone! Use your resources . . . SLP, local ALSA chapter staff, support groups, websites:
  ◦ http://amyandpals.com/
  ◦ http://www.childrenshospital.org/Centers-And-Services/Programs/A-E/als-augmentative-communication-program
Questions ???