ALS and Communication Devices

ALS Education Day – September 27, 2019

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Disclosure

- Financial support in the form of an honorarium has been provided by Mitsubishi Tanabe Pharma Canada, Inc.
- No other conflicts of interest.

Learning objectives

- 1. Identify when the use of augmentative and alternative communication (AAC) may be appropriate for patients with ALS.
- 2. List options for low-tech and high-tech AAC methods and devices.
- 3. Describe basic criteria for choosing high-tech AAC devices.

Communication changes in ALS

- Speech changes
  - Mixed flaccid-spastic dysarthria
- Respiratory changes
  - Low voice volume and shorter sentence length
- Cognitive changes
  - FTD and executive dysfunction
- Pseudobulbar affect
  - Emotional lability

(Duffy, 2005)

Stages of speech decline in ALS

- Speech
  - 4: Normal speech
  - 3: Detectable speech disturbance
  - 2: Intelligible with repeating
  - 1: Speech combined with nonvocal communication
  - 0: Loss of useful speech

- Rate of progression varies

ALSFRS (Cedarbaum et al., 1999)

Impact of communication changes in ALS

Question:

- How do you think progressive speech changes would impact you? List at least 3 ways.

Impact of communication changes in ALS

- Grief
- Social life
- Loss of identity

Role play

Approach to communication in ALS

- Maximize natural speech when possible
- Use alternative and augmentative communication methods (AAC) as needed
- Mix of both
  - Goal: To maintain functional communication for quality of life.

Examples of compensatory strategies to maximize natural speech

- Environmental
  - Quiet setting
  - Face to face
- Behavioural
  - Fewer words per utterance
  - Exaggerate articulation
  - Repeat as needed
- Partner-assisted
  - Yes/no questions (closed)
  - Providing choices based on context
  - Suggesting alternative communication methods as needed

(Yorkston, Miller, & Strand, 1995)

When is AAC appropriate for someone with ALS?

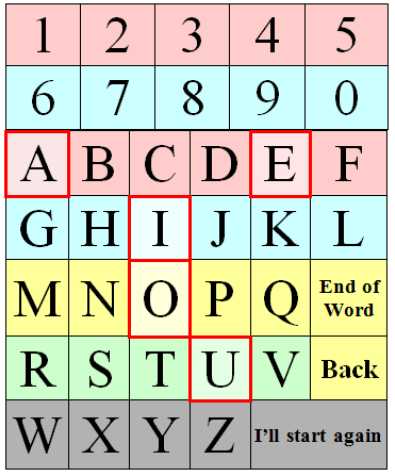
- Speech
  - 4: Normal speech
  - 3: Detectable speech disturbance
  - 2: Intelligible with repeating
  - 1: Speech combined with nonvocal communication
  - 0: Loss of useful speech

ALSFRS (Cedarbaum et al., 1999)

Low-tech AAC options

- Writing
  - pen/paper
  - LCD writing tablet
- Alphabet board
  - supplementation
  - partner-assisted scanning
- Communication board

- Augmentative
  - Voice amplifier



High-tech AAC in ALS

- Speech generating devices (SGD) using mostly text-based functions or applications
  - Dedicated communication devices
  - Everyday electronic devices (e.g. smartphone, tablet) are often compatible with text-to-speech apps
  - Message or voice banking

(www.tobiidynavox.com)

Potential barriers to using high-tech AAC

- Digital illiteracy
- Physical barriers
- Cognitive-linguistic deficits
- Languages used

Multidisciplinary assessment is often required to customize AAC

- Differing and evolving needs in people with ALS
  - Adapted access methods depending on physical needs: stylus, switches, head pointer, eye-gaze, etc.
  - Positioning, portability
  - Customization
- Training for people with ALS and caregivers
- Tech support

Programs dedicated to AAC in Quebec

- Specialized programs offering multidisciplinary assessment, adapted access, customization, training, tech support, etc.
  - Access to communication technology programs
    - Referral to a program based on region (postal code)
- Lending program for communication devices
  - PMATCOM
- Other resources for support and information for people with ALS: ALS Society of Quebec, Canada

Message or Voice banking

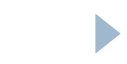
- Message banking
  - Pre-recorded messages to be used on a SGD
    - Pros: your natural voice (intonation, personality, emotion)
    - Barriers: limited number of messages
- Voice banking
  - ±1600 recordings are compiled to create a synthetic voice to be used on a SGD; works best if done in early stages
    - Pros: personalization, novel message production
    - Barriers: time-consuming, costly, synthetic-sounding
- Other options
  - Use someone's voice who sounds similar to you

(Hobson & McDermott, 2016)

Brain-computer interface: the future of AAC?

- EEG signals used to control a cursor or make a selection (e.g. typing)
- Not yet feasible for widespread use
  - Accuracy of selection
  - Practicality for daily use

(Hobson & McDermott, 2016)



Role play with AAC

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