Communication Management Guidelines for Amoytrophic Lateral Sclerosis Patients
ALS Center at Penn

I. Research

A. Individuals with ALS (and other progressive neuromuscular diseases) present the greatest challenge regarding communication issues. Approximately 75% of all people diagnosed with ALS will need some form of communication assistance. (1) While progression of speech disturbance varies in each person with ALS, most people will experience a severe communication disorder during the last few months of life. In a retrospective study of 100 hospice patients with ALS, 28% were anarthric (unable to speak) and 47% were severely dysarthric (slurred speech) at the time of their deaths. Only 25% could speak understandably during the terminal stage of the illness. (2)

II. Physical Symptoms—Dysarthria

A. Individuals with ALS will often present with dysarthria which is defined by Hedge as " a group of motor speech disorders resulting from disturbed muscular control of the speech mechanism due to damage of the peripheral or central nervous system; oral communication problems due to weakness, incoordination, or paralysis of speech musculature; physiologic characteristics include abnormal or disturbed strength, speed, range, steadiness, tone, and accuracy of muscle movements; communication characteristics include disturbed pitch, loudness, voice quality, resonance, respiratory support for speech, prosody and articulation." The act of speaking is an extremely fine motor activity. Therefore, when the muscles that allow us to articulate are weakened, uncoordinated, or rigid speech can sound slurred. ALS patients present with spastic, flaccid or a mixed spastic-flaccid dysarthria. (3)

III. Psychological Impact of Loss of Communication

A. Communication disorders are accompanied by strong feelings; this is true for both the client and the family of the client. (4)
B. People with disabilities like ALS, will vary in how they adjust to and cope with illness and the loss of communication as the disease progresses. (5)
C. Communication is so basic to humanness that when it is blocked or distorted, the people involved become emotionally upset. (6) The ability for humans to speak and use language with what distinguishes us from all other species. (7)
    i. There is deep pain in having a communication disorder, and in most cases we as professionals cannot do or say anything that will take the pain away. (8)
        11. The pain needs to be acknowledged for what it is—a normal reaction to a terrible situation (9)
    ii. There are many emotions regarding the loss of communication: grief, inadequacy, anger, guilt, vulnerability, and confusion. (10)
    iii. Depending on the client's emotional state, they may need assistance with communication but may be unwilling to accept it.
        11. It is a client's prerogative to accept help and if they decline, professionals should counsel the family on what their communication choices are and how to prevent communication breakdowns.
        12. Use of a communication system is often perceived as "giving in" to the disease and reflects a constant reminder of what the person has lost. Acceptance of AAC is a process that may take weeks or months. (11)

IV. Compensatory Strategies and Environmental Changes

A. Establish the type of communication environment that is comfortable for the patient with ALS as the speaker. He/she may find that they feel more comfortable having the listener finish their

sentences so as to take the burden of conversation off of themselves. Conversely the speaker may want to finish what he/she has to say themselves. This can take the pressure to understand/be understood off both the listener and the speaker.

B. Have the person with ALS slow down and over articulate. The act of producing sounds requires rapid movement of the lips and tongue. When the muscles are impaired, speech becomes slurred and words tend to sound as if they are running together. Therefore, people with ALS have to think of producing *every* sound in the word. This will help to improve accuracy of the sounds while slowing down the rate of speech.

C. Have the person with ALS and their family limit the amount of distractions in the room for both speaker and the listener. Sit face to face with the listener in a well lit room. This will help the listener read nonverbal cues that can aid in intelligibility.

D. When communicating with a person with ALS, as the listener, repeat the words you understood. Typically, the listener will comprehend the first few words of the utterance but as the speaker becomes more fatigued, they tend to miss the end of the phrases/sentences. Therefore it does not make sense to have the speaker repeat what they have already said as they are only going to become fatigued. This strategy also helps to reduce the amount of overuse of the muscles for speaking and conserve energy. (12)

III. Use of Augmentative/Alternative Communication

A. Given the progressive nature of ALS, compensatory strategies like over-articulating or slowing down speech may, over time, lose effectiveness. It is then that the use of AAC may be most effective and appropriate to allow for functional communication. The term "Augmentative/Alternative Communication" (AAC) refers to any mode of communication other than speech. AAC, in its simplest form, can be gestures, eye blinks or communication boards with letters or symbols. In its more advanced state, electronic communication devices or computers allow the user to have voice output, send email, and surf the web. (13)

B. AAC has two meanings--augmentative communication systems are used by people who already have some speech but are either unintelligible or have limited abilities to use their speech. In such cases, other modes of communication are used to support, or supplement what the person is able to say verbally. Alternative communication is the term used when a person has no speech and must completely rely on another method to make all of his ideas, wants, or needs known. (14)

C. AAC options available to a person with ALS include no technology like writing on paper or a dry erase board, using "low" technology like laminated letterboards or picture boards that allow the user to spell messages on or points to a picture, or using "high" technology like communication devices or computers that offer some form of voice output. (15)

V. Physical Symptoms—Low Vocal Volume without Dysarthria secondary to reduced vital capacity

A. Use of voice amplification

i. For individuals with ALS who can not project their voice due to respiratory compromise, use of voice amplification can reduce fatigue and increase the volume of their voice.

ii. Amplification systems are available commercially through specialty companies like Luminaud (www.luminaud.com) or can be purchased at a local electronics store like Radio Shack. (microphone and speaker)

V. Communication Options

A. No Tech

a. Establish a yes/no/maybe system. Always have a "maybe" because the way the question is phrased may be incorrect or needs clarification.

i. Use of eye blinks (one blink = yes, two blinks = no)

ii. Turning eye movement (right = yes, left = no)

iii. Giving "targets". Listener holds out right arm/hand at a 90 degree angle and asks patient to look at their hand. Hold left arm out for yes, right arm for no, and hands over head for maybe.

B. Low Tech

a. Writing via use of pen and paper, whiteboard, MagnaDoodles, etc….

b. Letterboard or Picture Board.

i. Alphabet board or personal patient picture board (depending on patient's cognitive status). These boards can be used with the patient pointing to the appropriate letter or if the patient does not have hand function, the listener using "partner assisted scanning". ***The speaker does not need hand function to utilize a letterboard.*** (16), (17), (18), (19), (20)

c. Chart based encoding

i. Chart-based techniques which have and index of codes and their corresponding phrase or request. (21)

ii. Patient and family create a chart of the most often patient request. Have an established system for the patient to indicate yes—whether an eye blink, grunt, small thumb movement, etc….(22)

1. Chart is placed on the wall of the room and if the patient has something to say, caregiver asks "is it a number?". If yes, caregiver recites number until the patient gives the signal and now caregiver knows what patient wants.

d. Laser Pointer in combination with a letterboard

i. Laser pointers can be utilized by individual with ALS in combination with a letterboard or words, phrases, or letters on a piece of posterboard. The speaker projects the red dot on the letter, phrase, or word they want. (23), (24)

1. There are laser pointers that stay on all the time. Most laser pointers that are available in office supplies stores require the user to press down a button. However, there are laser pointers that are used for hunting rifles that once turned on, will stay on all day. An example of a specialized laser pointer can be found at www.cabelas.com

2. Laser pointers can be used by someone with hand function or head function. They can be placed on a terry cloth headband on the head and the user simply moves their head around to point the dot at phrases, words or letters. A video example of a person with ALS using a laser pointer and letterboard to communicate can be found on You Tube at http://www.youtube.com/watch?v=AooDQOzdOyE and http://www.youtube.com/watch?v=s0jlCq9QaM4

ii. Megabee

1. MegaBee™ is easy-to-use and rapidly deployed, providing convenient, frequent means of communication with the care giver, thus providing a much enhanced lifestyle for the user. It does not require calibration and accommodates changes in head position or movement of the tablet. It requires very little training and is learned in minutes. Megabee is an electronic tablet that uses eye movement and blinking

as the method to select letters or phrases, which are then displayed on its screen. (25)

C. High Tech
    a. Use of Smartphones
        i. Combining voice output apps (example Speak It, Small for Aphasia, Locabulary, Proloquo2Go) that are available for the iPhone, Blackberry, and Droid phones. This access is only available for those that have hand and finger function. (26), (27)
    b. Personal Computers with voice output software
        i. Use of a client's existing computer downloaded with free or low cost software. (28)
        ii. If a client can no longer use their hands, personal computers can be accessed via the use of a headmouse. This is where the user operates the computer through head movements that are tracked by a receiver on top of the computer monitor. (29), (30)
    c. Speech Generating Devices (SGD)
        i. ***Electronic SGD's are not covered under a hospice benefit***. These devices would need to be ordered prior to a patient signing on to hospice because they are very expensive--$5,000-$15,000) Examples of SGD's: VMax from Dynavox, ECO from Prentke Romich, Freedom 2000 from Words+, Lightwriter from Tobii/ATI. (31)
        ii. The above SGD's can be accessed several ways—through the use of a patient's hands or head or by placement of a switch wherever they have consistent muscle movement. For access information, contact the local vendor of the SGD.
    d. Electronic Eye Gaze
        i. SGD's similar to the above but have an attachment to them that tracks a users eye movement. The patient needs to have functional eye movement in order to operate electronic eye gaze systems. These systems are very expensive (upwards of $10,00) and need to be ordered prior to a client signing on to hospice. (32), (33), (34)

D. Locked In Syndrome
    a. Two different variations that may affect a person with ALS
        i. Locked-in syndrome (LIS), also know as ventral pontine syndrome, refers to severl motor impairment in which an individual is conscious but is quadriplegic. Voluntary movement is limited to eye movements or perhaps eye blinks. (35)
            1. Those with LIS *may* be able to use a letter or picture board via partner assisted scanning, use a communication device with a switch, or use an electronic eye gaze system

        ii. Total Locked-in syndrome
            1. Total locked-in syndrome is characterized by tetraplegia, anarthria and paralysis of eye motility (36)
                a. There are no commercially available devices that will assist a person with TLS with communication

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3. Brownlee A, Palovcak M, The Role of Augmentative Communication Devices in the Medical Management of ALS. Journal of NeuroRehabilitation, Volume 22, Number 2, 2007, 445-447.

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5. Gray D, Quatrano L, Lieberman M, Designing and Using Assistive Technology-The Human Perspective, Baltimore, MD: Paul H. Brooks 1998, 100.

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12. Cook A, Hussey S. Augmentative and alternative communication systems. Assistive Technologies, Principles and Practice. Second Edition ed. St. Louis: Mosby, 2002, 285-286, 287.

13. Beukelman D, Mirenda P. Introduction. In: Augmentative and Alternative Communication, Management of Severe Communication Disorders in Children and Adults. Second ed. Baltimore, MD: Paul H. Brooks, 1998, 4-5.

14. Kazandjian M. Communication intervention. First ed. San Diego, CA: Singular, 1997, 15-16; 17; 18; 19; 20; 21; 22.

15. Beukelman D, Garrett K, Yorkson K, Augmentative Communication Strategies for Adults with Acute or Chronic Medical Conditions, First ed., Paul H. Brooks, Baltimore, MD, 2007, 299-300.

16. Examples of letterboards

17..The National ALS Association offers a free kit of letterboards to any interested hospice. Contact Alisa Brownlee at abrownlee@alsa-national.org to receive a kit.

18. Pre-made letterboards are available from AliMed at http://www.alimed.com/Alimed/product/The-Critical-Communicator,14192,339.html. These boards come in a variety of languages including English, French, Spanish, German, Italian, Arabic, Korean, Greek, Chinese, Hindi, Polish, Indonesian, Farsi, Hebrew, Turkish, Romanian, Vietnamese, Hungarian, Hmong/Laotian, Russian, Japanese, Tagalog/Filipino.

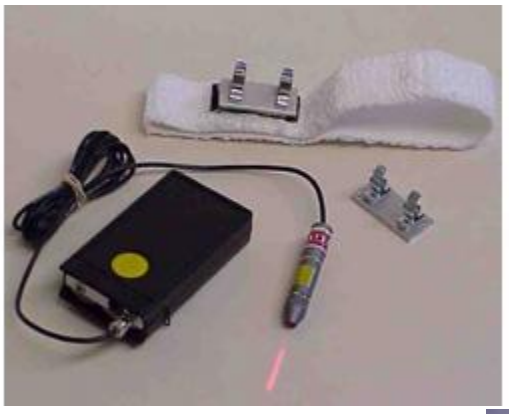
19. You Tube Videos on Use of Letterboards
1. http://www.youtube.com/watch?v=Y2UiP1DAej4
2. Partner assisted scanning with a letterboard: http://www.youtube.com/watch?v=pLb6-Oi3uR0

20. Communication vocabulary to make your own communication board:
http://www.temple.edu/instituteondisabilities/aacvocabulary/HEALTH_FULL.shtml

21.Cook A, Hussey S. Augmentative and alternative communication systems. Assistive Technologies, Principles and Practice. Second Edition ed. St. Louis: Mosby, 2002, 487.

22.Example of an encoding chart:
1. I am in pain
2. I need to be repositioned
3. I need a drink
4. I need my glasses
5. I need a tissue
6. I need my medication
7. I am cold
8. I am hot

23. Safe Laser Pointer by Zygo: (www.zygo-usa.com)



24.. Laser pointer mounted to a headset

25. Megabee (www. http://megabee.net) 

26. iPhones, iPads, and iTouches for Communication

27. Apps for iPhones/iTouches/iPads

- Software that enables an iPhone or iTouch to speak whatever the user types in (not covered under insurance)
- iPhones run about $200.00 with phone plan
- iTouches about $299.99 (new but you can get used on eBay)
    a. **Speak It!** Turns anything a user types into speech. Good voice synthesizer with very clear speech. $1.99 through iTunes.
    b. **Small Talk for Aphasia.** Designed for people with aphasia, Small Talk provides a vocabulary of pictures and videos that talk in a natural human voice. Fee on iTunes.
    c. **Speak! Text to Speech for iPhone and iTouch with Historic Quotes.** Type anything into the communication box and tap Say It, and the iPhone will repeat what the user has typed. Free on iTunes.
    d. **iSpeech**. Type anything into the communication box and tap Say It, and the iPhone will repeat what the user has typed. Free on iTunes.
    e. **Talk to Me**. Does the same as above but reads words as the user types them. $1.99 on iTunes.

f. **Locabulary** . Allows the user to communicate words, phrases, and sentences. It is a small, compact alternative to a larger AAC devices. Free on iTunes.

g. **Proloquo2Go: AAC in Your Pocket:** Proloquo2Go™ is a new product from AssistiveWare that provides a full-featured communication solution for people who have difficulty speaking. It brings natural sounding text-to-speech voices, up-to-date symbols, powerful automatic conjugations, a default vocabulary of over 7000 items, full expandability and extreme ease of use to the iPhone and iPod touch. $189.00 on iTunes.

28. Free and Low Cost Software available on the Internet.

Cost	Name of Software	Website	Non-English Language Available?	PC or Mac
FREE	CHIPSpeaking	www.chipspeaking.com	NO	PC
$30	CoolSpeech	www.bytecool.com	NO	PC
FREE	E-triloquist	www.etriloquist.com	YES	PC
$40	GhostReader	www.nextup.com	YES	Mac
FREE	MyFTC	http://www.oatsoft.org/Software/myftc-my-freedom-to-communicate	NO	PC
FREE	MyVoiceX	www.myvoiceX.info	NO	PC or Mac
FREE	Natural Reader	http://www.naturalreaders.com/download.htm	NO	PC
$100	NextUp Talker	www.talkforme.com	YES	PC
$300	Proloquo	http://www.assistiveware.com/proloquo.php	YES	Mac
FREE	PVoice	www.pvoice.org	YES	PC
FREE	ReadPlease	www.readplease.com	NO	PC
$30	TextOutloud	http://www.nextup.com/	NO	PC
$20-$100	TextSpeechPro	www.textspeechpro.com	NO	PC
$50	UniversalReader	www.ReadingMadeEasy.com	NO	PC
$80	UniversalReader IGT	www.ReadingMadeEasy.com	YES	PC

29. HeadMouse Systems
    a. Origin Instruments (http://www.orin.com/access/headmouse) $995.00
    b. Madentec (http://madentec.com/products/tracker-pro.php) $995.00
    c. Camera Mouse (www.cameramouse.com) FREE. (requires user have a webcam—about $20.00)

30. You Tube Video showing use of headmouse:
    a. http://www.youtube.com/watch?v=VKsIoZ9oa_Y
    b.http://www.youtube.com/watch?v=ZHZ9p3ydNBc&feature=PlayList&p=5BD0CF9D639DB3AB&playnext=1&playnext_from=PL&index=7

31. Speech Generating Device Manufacturers
    h. Dynavox (www.dynavoxtech.com)
    i. Prentke Romich (http://www.prentrom.com)
    j. Tobii/ATI (http://tobiiati.com)
    k. Words+ (www.words-plus.com)

32. Electronic Eye Gaze Units

33. Manufacturers of Electronic Eye Gaze Units:
    a. Dynavox (www.dynavoxtech.com)
    b. LC Technologies (http://www.eyegaze.com)
    c. Prentke Romich (http://www.prentrom.com
    d. Tobii/ATI (http://tobiiati.com)
    e. Quick Glance (http://www.eyetechds.com)

34. You Tube Video for Electronic Eye Gaze Devices
    a. http://www.youtube.com/watch?v=Oev92bys2qI
    b. http://www.youtube.com/watch?v=z8axxC65Qi4

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