

Augmentative and Alternative Communication Solutions for Individuals with Progressive Diseases

Part 1

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About Us

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 - Shepherd Center, Atlanta, Georgia
- **Krista Mullen, MS CCC-SLP-** Speech Language Pathologist (SLP)
 - Georgia Tools for Life, Atlanta, Georgia



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- Private, not-for-profit hospital specializing in medical treatment, research and rehabilitation for people with spinal cord injury and brain injury
- Established in 1975
- 152-bed facility
- Inpatient Spinal Cord Injury Rehab, Inpatient Brain Injury Rehab, Treatment for Pain and Neuromuscular diseases, Multiple Sclerosis Institute, Pain Institute, Day Program rehab, outpatient rehab, outpatient clinics



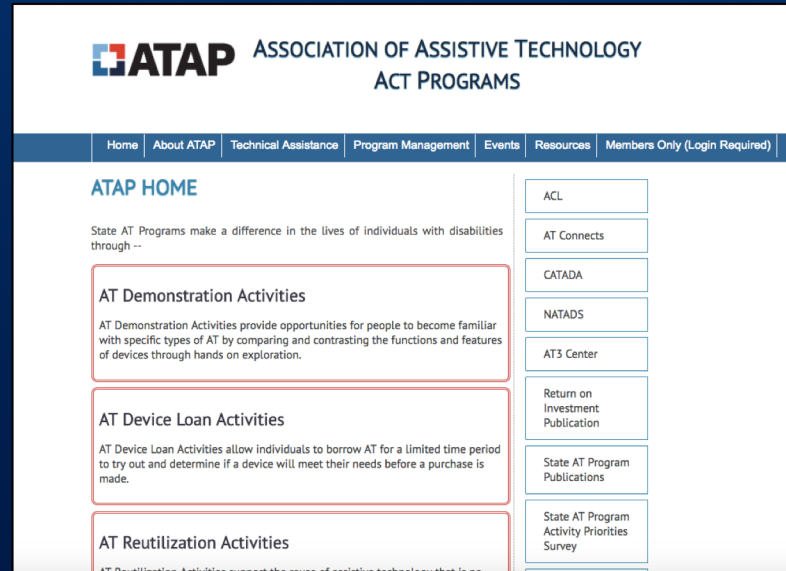
Tools For Life

- Georgia Tools for Life is a program designed to help Georgians with disabilities gain access to and the acquisition of assistive technology devices and assistive technology services so they can live, learn, work, and play independently in the communities of their choice.



Get to Know Your AT Act Program

Association of Assistive Technology Act Programs – www.ataporg.org



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Progressive Diseases

- Amyotrophic lateral sclerosis (ALS) is a group of rare neurological diseases that mainly involve the nerve cells (neurons) responsible for controlling voluntary muscle movement. Voluntary muscles produce movements like chewing, walking, and talking. The disease is progressive, meaning the symptoms get worse over time.
- Primary lateral sclerosis (PLS) is a rare neuromuscular disease with slowly progressive weakness in voluntary muscle movement. PLS belongs to a group of disorders known as motor neuron diseases. PLS affects the upper motor neurons (also called corticospinal neurons) in the arms, legs, and face. It occurs when nerve cells in the motor regions of the cerebral cortex (the thin layer of cells covering the brain which is responsible for most higher level mental functions) gradually degenerate, causing movements to be slow and effortful. The disorder often affects the legs first, followed by the body, trunk, arms and hands, and, finally the bulbar muscles (muscles that control speech, swallowing, and chewing).

Progressive Diseases continued

- Multiple sclerosis (MS) can range from relatively benign to somewhat disabling to devastating, as communication between the brain and other parts of the body is disrupted. Most people experience their first symptoms of MS between the ages of 20 and 40; the initial symptom of MS is often blurred or double vision, red-green color distortion, or even blindness in one eye. Most MS patients experience muscle weakness in their extremities and difficulty with coordination and balance. These symptoms may be severe enough to impair walking or even standing. In the worst cases, MS can produce partial or complete paralysis.

More on Progressive Diseases

- The muscular dystrophies (MD) are a group of more than 30 genetic diseases characterized by progressive weakness and degeneration of the skeletal muscles that control movement. Some forms of MD are seen in infancy or childhood, while others may not appear until middle age or later. The disorders differ in terms of the distribution and extent of muscle weakness (some forms of MD also affect cardiac muscle), age of onset, rate of progression, and pattern of inheritance.
- Spinal Muscular Atrophy (SMA) Types I, II, and III belong to a group of hereditary diseases that cause weakness and wasting of the voluntary muscles in the arms and legs of infants and children.

Terminology

- **Augmentative and alternative communication (AAC)** is an area of clinical practice that addresses the needs of individuals with significant and complex communication disorders characterized by impairments in speech-language production and/or comprehension, including spoken and written modes of communication.
- AAC uses a variety of techniques and tools, including picture communication boards, line drawings, speech-generating devices (SGDs), tangible objects, manual signs, gestures, and finger spelling, to help the individual express thoughts, wants and needs, feelings, and ideas.
- AAC is **augmentative** when used to supplement existing speech, and **alternative** when used in place of speech that is absent or not functional.
- **Speech Generating Device (SGD)** – A speech generating device is a piece of durable medical equipment.



Referral Process

- Order for Appointment
 - Ex: ST Evaluation and Treatment for speech generating device
 - This order is for the evaluation, not the equipment
- Last clinic notes
- Must have face-to-face visit with MD within last 6 months for Medicare and some private insurance companies



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Initial interview and Background

- Common questions for interview
- Progression
- Feeding
- Breathing machines
- Caregivers
- Mobility
- Long Term planning



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Counseling

- Patients are at various stages of diseases when they come to you. Consider emotions and grieving.
- Where are they in their life cycle
- Future considerations
- Planning for medical and financial needs
- Be aware of end of life discussion



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Assessments and Considerations

- Standardized passages- Grandfather Passage or Rainbow Passage
- Sustained phonation
- Breath support
- Upper Extremity mobility
- Head and Neck Control
- Insurance/Funding
- Current Technology
- Comfort with Technology
- Cognition
- Family Support



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Adult Communication Checklist

ALS Functional Communication Scale

Communication Ability	Short Term Goals	Baseline G9174	Projected G9175	Achieved Today G9176
1. Alerting/Emergency	1. Patient (and caregiver) can demonstrate/describe the method by which patient can alert others, not in his/her immediate environment, to a need or emergency.	- / +	- / +	- / +
2. Communication Strategies	2. Patient (and caregiver) demonstrate patient and partner strategies (via speech or SGD) that improve communication success, efficiency, speed and reduce fatigue.	- / +	- / +	- / +
3. Non-Voiced (Low Tech) Communication	3. Patient demonstrates the ability to communicate novel messages via spelling or combining words using low tech AAC method.	- / +	- / +	- / +
4. Speech Generation	4. Patient demonstrates the ability to communicate a novel message with a voice (speech or SGD).	- / +	- / +	- / +
5. Communicate with those at a Distance	5. Patient demonstrates abilities to use all the methods s/he requires to communicate with partners at a distance .	- / +	- / +	- / +
6. Independently Set-Up and Customize AAC Systems	6. Patient (and caregiver) demonstrate the ability to independently use, set up and customize low and/or high tech augmentative communication equipment.	- / +	- / +	- / +
7. Prepared for Future Changes	7. Patient (and caregiver) can describe one or more pro-active strategies designed to prepare for typical changes associated with ALS in speech and/or access.	- / +	- / +	- / +
Total Functional Communication Score	Severity Modifiers 7/7 CH 6/7 CI 5/7 CJ 4/7 CK 3/7 CL 2/7 CM 0-1/7 CN	___ / 7 C ___	___ / 7 C ___	___ / 7 C ___

Developed by Amy Roman, C.S., CCC-SLP, 2014

ALS Communication Scale -- amyandpals.com/als-communication-scale



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Features of Device

Interview patient to find out the importance of:

- Communication – Face to Face and at a distance (Skype etc)
- Internet access
- Email
- Text messaging
- Environmental Control
- Music
- Photos
- Word Processing
- Games
- E-reader
- Phone Calls



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Dedicated Device vs Open Device

- Dedicated Speech Generating Device
- Open Speech Generating Device
- How to “open” a dedicated device



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Feature Matching

- Consider the individual you are evaluating, the technology and tools available, and what tasks the individual will be participating in.
- The Individual: cognition, medication, support, vision, Interest, motivation, emotions, support, financial resources positioning and Movement (UE and LE)
- The Technology: Technology: Ease of use, number of taps required to complete a task, support and training needed, support and training available, cost, cognitive load, components needed
- The Tasks: work, leisure, school, environmental control, computer access, ability to break down to small tasks.

Trials of Speech Generating Devices

Assess the patient's ability to:

- Utilize access options (direct selection, switch, head mouse, eye gaze)
- Calibrate
- Navigate
- Spell
- Use Word Prediction
- Store Phrases
- Retrieve Phrases
- Speed of Selections



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Vocabulary on SGD

- Work with caregivers family and patient.
- Core words. Single words. Preprogrammed phrases. Stories about self and family.
- AAC vocabulary from Temple University
- AAC vocabulary from University of Nebraska
- Ideas for vocabulary from Boston Children's Hospital

*See resource page for links



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Report Writing and Paperwork Process

- Medicare requires trials of multiple comparable devices
 - [ASHA Information on Medicare Speech-Generating Devices](#)
 - [Medicare Coverage Policy on Speech-Generating Devices](#)



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Funding

- Role of the representative from companies
- Tech support/Training
- Alternative Funding Sources



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Come Back for Part 2

- Non-Funded Solutions for communication and computer access
- Preparing for a device with message banking and voice banking
- Alternate Funding Sources and Loaner programs

Questions?

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References

- Cook, Albert and Miller Polger, Janice. (2015). *Assistive Technologies: Principles and Practices, 4e*
- <https://www.ninds.nih.gov/>
- <https://www.asha.org/SLP/healthcare/Medicare-Speech-Generating-Devices-Information/>
- <http://aac-rerc.psu.edu/>



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Resources

- AAC Vocabulary from Temple University –
<https://disabilities.temple.edu/aacvocabulary/e4all.shtmlhttps://disabilities.temple.edu/aacvocabulary/e4all.shtml>
- AAC Vocabulary from University of Nebraska –
<https://cehs.unl.edu/aac/aac-messaging-and-vocabulary/>
- AAC Vocabulary from Boston Children's Hospital –
http://www.childrenshospital.org/~media/centers-and-services/programs/a_e/als-program/message-bank-and-legacy-message-definitions-and-vocab-2017.ashx?la=en



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Resources, continued

- ASHA Information on Medicare Speech-Generating Devices –
<https://www.asha.org/SLP/healthcare/Medicare-Speech-Generating-Devices-Information/>
- Medicare Coverage Policy on Speech-Generating Devices –
https://www.asha.org/practice/reimbursement/medicare/sgd_policy/
- ALS Communication Scale, (n.d.), retrieved March 8, 2018 –
<http://amyandpals.com/als-communication-scale/>



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