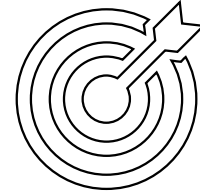# AAC Assessment Considerations in Degenerative Disease

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Learning Objectives

Participants will be able to:

1. Summarize the types of impairments that may arise from progressive neurologic conditions

2. Describe key components of an AAC assessment for patients with progressive neurologic conditions

3. Develop a dynamic AAC system that can be adapted as an individual's needs change over time

OVERVIEW AND GENERAL CONSIDERATIONS

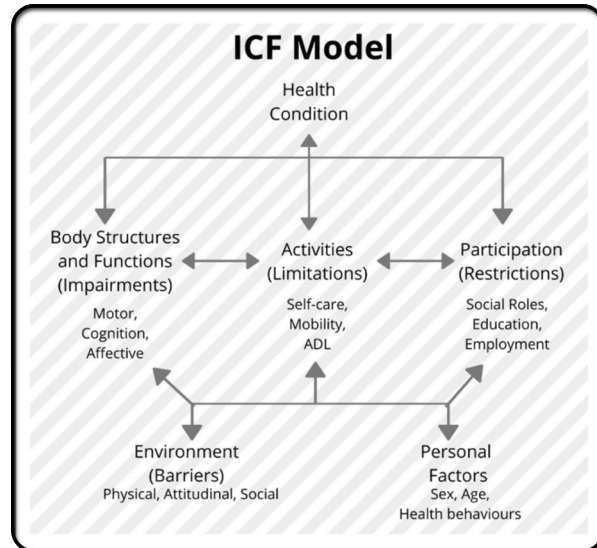# Neurodegenerative Conditions: A Brief Overview

- Acquired physical impairments
  - Primary focus for this presentation
  - Impairments resulting from neurologic disease that cause motor speech disorders
  - Examples: ALS, MS, Parkinson's disease, progressive supranuclear palsy, hereditary ataxias, multi-system atrophy, Huntington's disease
- Acquired cognitive-communication impairments
  - Conditions that progressively interfere with learning, memory, communication, and other cognitive functions
  - Examples: Alzheimer's disease, frontotemporal dementia, Lewy body dementia, primary progressive aphasia

Special Considerations in Degenerative Disease

- Progressive loss of function across body systems
  - e.g., body movements, eye movements, speech, breathing
  - Changes may occur in language, cognitive function, and behavior
  - Implications for AAC access, positioning needs, need for partner support
- Importance of counseling and shared decision-making
  - Addressing grief / coping with loss of function
  - Partnering with patients, families/caregivers, and other professionals
- Timing of AAC evaluation / intervention
- Selecting and funding an AAC system when functional decline is expected

WHO-ICF Model

- International Classification of Functioning, Disability, and Health

- Provides a standard language and framework for the description of health and functioning

- Neurodegenerative disease does not only result in physical impairments; it also can impact activities and participation in meaningful social roles

- Environment and personal factors can be barriers or facilitators of success with AAC

ICF Model

Health Condition

Body Structures and Functions (Impairments)
Motor, Cognition, Affective

Activities (Limitations)
Self-care, Mobility, ADL

Participation (Restrictions)
Social Roles, Education, Employment

Environment (Barriers)
Physical, Attitudinal, Social

Personal Factors
Sex, Age, Health behaviours

Steve's AAC Story - Tobii Dynavox I-Series+ with Eye Tracking

https://youtu.be/04Rhnt4J2b4?si=xMUo-uqoUfFcFW_t

Components of an AAC Assessment

- Timely referral for AAC assessment
    - *Can you refer too early? Too late?*
- Identify participation patterns / communication needs
- Assess current and anticipated capabilities
    - *Motor, cognitive, speech, language, visual, hearing*
- Assess potential constraints affecting AAC decisions
    - *Social support, attitudes / acceptance, funding / insurance*
- Trial and select AAC options (high tech, light tech, no tech)

"WE CAN'T CHANGE SOMEONE'S MEDICAL DIAGNOSIS. BUT WE CAN SUPPORT PEOPLE TO MAINTAIN DIGNITY, CONTROL AND SOCIAL CONNECTEDNESS WHILE EXPRESSING THEIR TRUE SELVES AND REMAINING ACTIVE MEMBERS OF THE WORLD AROUND THEM."

–JOHN COSTELLO, MA, CCC-SLP

DIRECTOR, JAY S. FISHMAN ALS AUGMENTATIVE COMMUNICATION PROGRAM, BOSTON CHILDREN'S HOSPITAL

Counseling

"The role of the SLP in the counseling process includes interactions related to emotional reactions, thoughts, feelings, and behaviors that result from living with the communication disorder." (ASHA, 2016)

"SLPs often feel uncomfortable about the counseling role, and consequently tend to avoid it... This occurs even though most of the counseling opportunities in speech–language pathology relate to coping with lives that have been changed by a communication disorder, not to psychopathology." (Holland, 2007)

Counseling

Good counseling can…

- Improve the therapeutic relationship
- Decrease feelings of isolation
- Promote acceptance and change
- Empower patients and families
- Support AAC acceptance and use

Counseling theories: *humanistic approach, cognitive-behavioral therapy, family systems theory, multicultural theory, dialectics, integrative approaches*

Counseling Techniques

- Content counseling (Education)
  - Demonstrates our expertise; establishes our credibility; can decrease feelings of powerlessness in patients/families
  - *"Information overload can be very harmful because the increased confusion leads to increased feelings of inadequacy and anxiety, which tends to reduce client self-esteem"* (Luterman, 2008, p.63)
- Affect counseling
  - Listening, empathizing, allowing emotions to come forward
- Motivational Interviewing (Miller & Rollnick, 2013)
  - *"MI is a collaborative, goal-oriented style of communication with particular attention to the language of change. It is designed to strengthen personal motivation for and commitment to a specific goal by eliciting and exploring the person's own reasons for change within an atmosphere of acceptance and compassion."* (Miller & Rollnick, 2013, p. 29)

Link: https://motivationalinterviewing.org

Counseling Tips

- Focus on building a partnership rather than being the "expert"
- Focus on the patient's goals, not yours!
- Meet the patient where they are while planning for the future
    - Acknowledge emotions and grief that come with an anticipated loss of function
    - Listen actively, reflect back, and find solutions jointly
    - Patients and families may feel overwhelmed. It's okay to start small.
    - The process typically is not linear
    - The patient is in control; we are offering support and resources

WHAT ABOUT "BUY-IN"?

- Resistance to AAC is common
- Discuss realistic expectations
- Don't focus solely on impairments
    - AAC / AT can allow patient to participate in meaningful activities and in social roles / settings even as function changes
    - AAC / AT can help with access to and control over the environment
    - Maintaining one's voice, dignity, social connectedness
- Trialing a device or other supports can help with buy-in
- Involve family / caregivers early
- Start small, the patient/family may need to see benefit from some simple supports before they are open to more novel and costly interventions

Multimodal communication

- Motor speech intervention – optimize / preserve speech
  - Environmental strategies
  - Speech production strategies
- No tech strategies – gestures, facial expressions, etc.
- Voice amplification
- Letter and topic cueing
- Low-tech communication boards, flip books, wallet cards, etc
- Partner-assisted scanning or spelling
- Text-to-speech software
- Speech generating devices

Letter / alphabet supplementation involves identification of the first letter of each word by the speaker, by pointing on an alphabet board as the word is spoken. Typically, intelligibility of connected speech is improved by about 25% and intelligibility of single words by about 10% with alphabet supplementation (Hanson, Yorkston, & Beukelman, 2004).

Communication Partner Training

- Communicative interactions are impacted for both the person with a degenerative condition and for communication partners
- Lack of communication partner training can increase feelings of frustration for both partners
    - Can impact self-esteem, dignity, social connectedness
- Increased need for communication partner support is anticipated over disease progression
    - Early education + training is key to success
- Hear people with ALS share their opinions on communication partners predicting their messages during communicative exchanges

Link: https://www.childrenshospital.org/programs/als-augmentative-communication-program/protocol-assessment-considerations/partner-training/partner-training-videos

High-tech AAC Options / Companies

- Tobii Dynavox
- PRC-Saltillo
- Forbes AAC
- Smartbox
- Talk to Me Technologies
- Eyegaze Inc.

https://nwacs.info/aacat-companies

Note: This is not an exhaustive list

CONDITION-SPECIFIC CONSIDERATIONS

Amyotrophic Lateral Sclerosis (ALS)

- A degenerative disease that impacts motor neurons of the brain & spinal cord
- Prevalence: 5 cases per 100,000 people in the United States
- Mean age of onset: 56 years of age
- Prognosis: Mean survival time is 2-5 years from symptom onset
- Initial symptoms typically include weakness, most commonly of the arms or legs, however, initial symptoms may also consist of dysarthria, dysphagia, and/or respiratory weakness
- Approximately 80-95% of people with ALS are unable to speak by the time of their deaths
- Timely introduction of AAC plays a critical role in communication and quality of life over the course of the disease

Communication Impairments in ALS

- Motor speech: Mixed flaccid-spastic dysarthria
  - UMN and LMN signs/symptoms
  - Respiratory weakness
- Cognitive – communication: Possible cognitive / behavioral changes
  - 6.5% experience frontotemporal dementia and 4% experience mild cognitive impairment
  - ~30% experience a behavioral impairment (ranging from mild to severe)
  - Behavioral impairment may manifest as apathy, irritability, inflexibility, poor frustration tolerance, and emotional indifference
  - These factors do not preclude AAC implementation, however they may impact evaluation and treatment decisions. Cognitive and behavioral changes may impact the individual's acceptance, learning, and use of an AAC system.
  - Language: Language impairments may occasionally be associated with ALS, although they are not a hallmark of the disease

ALS & AAC Acceptance

Ball et al. (2004)

- 90% of participants immediately accepted AAC

- 6% accepted AAC after a delay

- 4% rejected AAC

    - Primarily due to cognitive limitations / co-occurring dementia

- None of the participants discontinued use of AAC

- Many participants no longer used their SGDs and rather relied on dependent communication strategies

Delayed acceptance themes ($n = 3$)		
Family resistance	$n = 2$	
	I can understand everything I need to I can take care of my spouse's needs just fine!	
Physician resistance	$n = 2$	
	You don't need to bother with that, you are going to die soon, anyway. You need to go home and put your affairs in order.	
Persons with ALS resistance	$n = 3$	
	I am NOT disabled! My speech isn't affected yet and probably won't be. I simply don't need or want that.	
Rejection themes ($n = 2$)		
Cognitive impairment	Cognitive limitations were viewed as the primary reason for rejection (Persons with ALS exhibited prefrontal-type dementia sometimes associated with ALS that results in resistance to new things, inflexibility of thought, and changes in personality).	

AAC Assessment / Intervention for ALS

Three-phase intervention model (Ball, Beukelman, & Bardach, 2007)
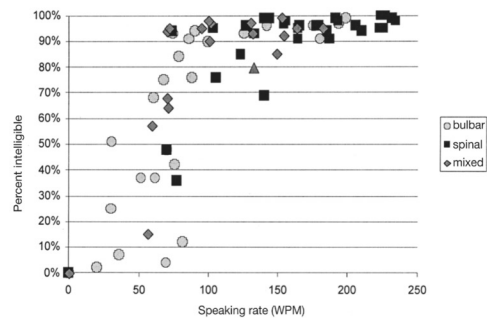
- Early Phase: Monitor, Prepare, & Support
    Time period between ALS diagnosis and referral for AAC assessment
- Middle Phase: Assess, Recommend, & Implement
    Time period from AAC referral through selection, purchase, and initial instruction in AAC use
- Late Phase: Adapt & Accommodate
    Time period between initial AAC instruction and the individual's death

AAC Assessment / Intervention for ALS

Early phase: Monitor, Prepare, & Support

- The individual has functional natural speech for daily communication needs

- Speech performance should be monitored to detect changes ins **speech rate** and **intelligibility**

  - Objective measures should be used for accuracy, such as the Sentence Intelligibility Test or timed reading of a standard passage

  - AAC assessment is recommended when speaking rate approaches 125wpm (typical = 140-160 wpm), OR when intelligibility drops below 90% regardless of speaking rate

Relationship between speaking rate & intelligibility in ALS (Ball et al., 2002)

AAC Assessment / Intervention for ALS

Early Phase: Monitor, Prepare, & Support

- Cognitive & behavioral function should be screened
  - ALS Cognitive Behavioral Scale (ALS-CBS)
- Support AAC options, e.g., voice banking, message banking
- Timely AAC assessment / referral to an AAC team
- Assist in implementation of AAC supports to preserve communicative effectiveness through natural speech as long as possible
  - Voice amplification, apps, video or audio recordings for loved ones, compensatory speech strategies
- Educate and partner with the individual / family about AAC-related decisions

Voice Banking / Message Banking

- Voice banking
  - The process of recording the individual's speech to create a synthetic voice that approximates their natural voice
  - Allows the user to continue to produce novel messages over time in a voice that sounds like theirs
  - Requires **4-6 hours** of recording time, which often needs to be broken up into smaller pieces due to fatigue
- Message banking
  - The process of recording personally selected messages in your own voice and inflection that can be uploaded to an AAC device and played at a later time
- "Double Dipping" *(developed by John Costello at BCH)*
  - Allows you to use your message banked messages to create a synthetic voice with Acapela

Voice Banking / Message Banking

- Several voice / message banking platforms are available
  - Acapela MyOwnVoice DNN
  - Model Talker
  - VocalID
  - The Voice Keeper
  - Cereproc Cerevoice Me
  - My Message Banking (from Boston Children's Hospital and Tobii Dynavox)
- Acapela and Model Talker are covered by the Team Gleason Foundation

AAC Assessment / Intervention for ALS

Middle Phase: Assess, Recommend, & Implement

- Time period from AAC referral through selection, purchase, and initial instruction in AAC use
- Identify participation patterns and communication needs
- Assess current and anticipated capabilities – motor, cognitive, speech, language, visual, hearing
- Assess potential constraints affecting AAC decisions – social support, attitudes/acceptance, funding
- Select high and low tech AAC options
- Help develop operational competence
- Provide facilitator support

AAC Assessment / Intervention for ALS

Late Phase: Adapt and Accommodate

- Time period between initial AAC instruction and the individual's death
- AAC system modifications are necessary due to changes in communication needs, physical capabilities, and living situations
- Factors to consider during your AAC assessment and during ongoing management:
    - Multimodal communication options
    - Access
    - Positioning
    - Effort and fatigue
    - Strategies for co-construction of messages with communication partners

AAC & ALS – RESOURCES

Assessment tools:
- ALS Functional Communication Scale
- ALS Functional Rating Scale – Revised
- Communication Needs Questionnaire (ALS)
- ALS Cognitive Behavioral Screen (ALS-CBS)

Voice / message banking:
- ALS Association Guide to Voice Banking Services (with comparison table of different services)
- Free and open access message banking: https://mymessagebanking.com
- Ideas for types of messages to record: Message Banking, Voice Banking, and Legacy Messages

Additional Resources:
- Team Gleason Foundation

Free message banking – joint project between Boston Children's Hospital and Tobii Dynavox. Free system use, message storage, and message downloading

TEAM GLEASON
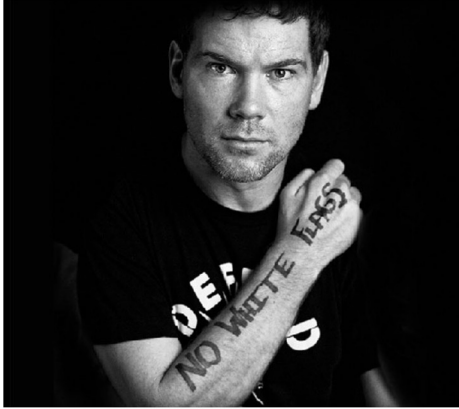
Team Gleason is committed to providing solutions for people living with ALS through leading edge technology, equipment, and services.

There is no universal "best" technology. Team Gleason recommends that each individual works with their care team to find the best solution for their unique situation.

Team Gleason's mission is to provide innovative technology and equipment to individuals living with ALS to help improve and empower their life experiences. With expertise in communication, home automation, and alternative mobility, Team Gleason aims to empower families to access and use the available technologies. This is done through a number of grants and program services including:

- Adventures
- Communication Device Copays and Loaners
- Support Services
- Seat Elevator Grants
- Voice Banking, Message Banking™ & 'Double Dipping'

Multiple Sclerosis (MS)

- An acquired, inflammatory, demyelinating disease of the CNS
- Prevalence: about 1 in 1,000 in the US
- Age of onset: 95% of cases begin between age 10 – 50 years, with a median onset age of 27 years.
    - MS is the most common neurological condition of young and middle-aged adults.
- Course & Prognosis: Variable disease course, average life expectancy is ~5-10 years shorter as compared to the general population
- Types of MS:
    - Relapsing-remitting MS
    - Primary progressive MS
    - Secondary progressive MS
- Symptoms vary based on the location of MS lesions
    - AAC interventions must be individualized
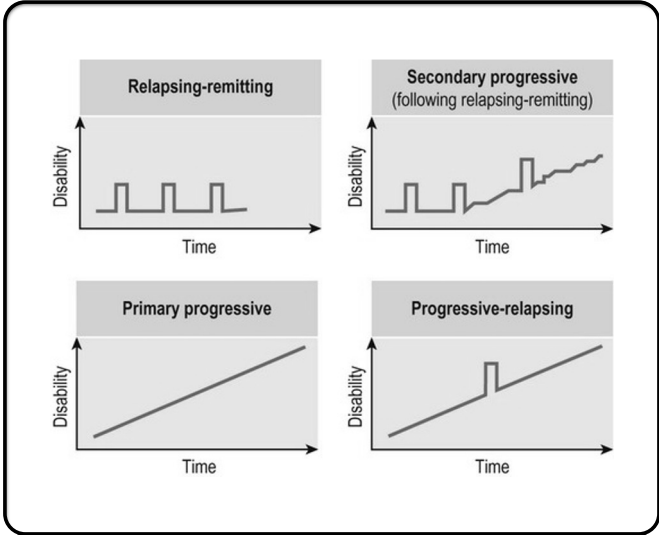
TYPES OF MS

Communication Impairments in MS

- Motor speech: Dysarthria is the most common communication impairment associated with MS
    - Mixed spastic-ataxic dysarthria is common
- Cognitive – communication: Impairments occur in ~34% to 65% of individuals with MS
- Language: Word-finding difficulties and reduced verbal fluency may occur

AAC Assessment / Intervention for MS

Early Phase: Use Assistive Technologies
- MS onset occurs earlier in life, so individuals may be in employed or enrolled in educational programs
- Screen readers, adaptive keyboards, memory/organizational supports, accessibility features

Middle Phase: Introduce Compensatory Support of Natural Speech
- Alphabet supplementation, photographic support, writing or spelling

Late Phase: Implement Communication Supports
- Establishing AAC access can be difficult due to vision problems, tremor, spasticity, ataxia
- Interventions must be highly individualized and must address participation patterns / communication needs, sensory/motor/cognitive/linguistic capabilities, and constraints related to MS characteristics

Alphabet supplementation involves identification of the first letter of each word by the speaker, by pointing on an alphabet board as the word is spoken. Typically, intelligibility of connected speech is improved by about 25% and intelligibility of single words by about 10% with alphabet supplementation

AAC Assessment / Intervention for MS

Access considerations

- Visual limitations - consider high contrast symbols, larger icons / fonts, eye patching or prism glasses to mitigate double vision (in collaboration with other providers), screen covers to reduce glare, auditory scanning systems

- Motor limitations - consider body positioning / supports, key guards, switch-based scanning systems, alternate keyboards

- Cognitive limitations – keep cognitive demands of AAC system learning / navigation in mind, incorporate cognitive supports and strategies to promote success

- Consider AAC systems that support multiple different access methods

- Need for interdisciplinary collaboration and adaptation of interventions as symptoms patterns change

DOCUMENTATION, INSURANCE, AND FUNDING

Insurance Coverage of AAC / SGDs

- High-tech devices and equipment (e.g., mounts) are mostly paid for by insurance
  - Cost burden to the patient will vary based on details of their insurance coverage
- Must demonstrate "medical necessity" – i.e., moderate to severe impairment
  - May be able to get coverage in earlier stages if you can show that there is a "crippling fatigue"
  - Be mindful about potential consequences of selecting an AAC system *too early*
  - Patient report measures to quantify functioning, for example:
    - Modified Fatigue Index Scale (MFIS)
    - Communication Participation Item Bank (CPIB)

Medicare / CMS guidelines

- Definition of SGD
    - provide an individual the ability to meet their "functional, speaking needs";
    - are primarily used for the purposes of generating speech;
    - include the capability to generate email, text or phone messages as "other covered features";
    - include other non-covered features at the expense of the Medicare patient.
- SGDs are DME, Medicare will only cover one SGD every four years (however, upgrades can be requested)
- Claims are submitted by the manufacturer / supplier – work closely with your device reps!

Medicare / CMS guidelines

- Documentation needs
    - SGD reimbursement requires SLP eval and face-to-face visit with physician demonstrating the beneficiary was evaluated / treated for a condition that supports the need for the SGD
    - Must show consideration for 3+ AAC systems and provide a rationale for the device / features that the patient requires
    - Must show that lower cost AAC systems have been trialed (e.g. no tech, low tech) and document why the patient can't meet their communication needs without an SGD
    - Document need for specific mounts / accessories
- Medicare typically covers 80% of device cost, remainder may be covered by other insurance, but patient may have out-of-pocket costs
- If Medicare denies coverage of a specific accessory or feature (e.g., eye gaze), you can request an upgrade of equipment

AAC-RERC Assessment/Application Protocol

AAC-RERC Medicare Checklist for SLPs

Sample report templates from AAC-RERC: http://aac-rerc.psu.edu/index.php/pages/show/id/21

Device vendors have report templates you can use!

Additional Funding Resources

- Device vendors have report templates available, and reps will help with the funding process, wording in reports, etc.
- Team Gleason Foundation for those diagnosed with ALS
- ALS Association will loan devices if the person with ALS is in the process of getting a device *(wait time is often 3-6 months to fund and acquire device)*
- Multiple Sclerosis Foundation Assistive Technology Program
- Telecommunication Equipment Distribution (TED) program of Washington
- Washington State Division of Vocational Rehabilitation Services includes Assistive Technology Services
- Private pay is an option for all or part of the AAC system cost
- NWACS AAC Funding Evening Seminar

TED: distributes specialized telecommunication equipment that enables WA residents to have independent use of the telephone, including iPads for those who are unable to speak for themselves

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RERC on AAC: https://rerc-aac.psu.edu