Low Tech AAC

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The ALS Association’s mission is to lead the fight to cure and treat ALS through global, cutting-edge research, and to empower people with Lou Gehrig’s disease and their families to live fuller lives by providing them with compassionate care and support.
What is ALS?

- Amyotrophic Lateral Sclerosis; Lou Gehrig’s Disease
- Progressive, fatal neurodegenerative disorder
- Death of motor neurons cause progressive muscle weakness, atrophy and paralysis of the voluntary muscles
Epidemiology

- Annual Incidence of ALS is 2 per 100,000
- Each year 5,600 cases are diagnosed in U.S.
- 30,000-40,000 Americans may have the disease at any given time
- ALS Prevalence is 6-8 / 100,000
- Mean age of onset: 56 - 63 years
- Risk increases with age
Epidemiology

- Mortality rate is 2 per 100,000 annually
- Male/Female: 1.5/1 especially in younger onset cases
- Rare cases of diagnosis before age 20
- ALS is not contagious
Statistics

- Every 90 minutes someone is diagnosed with ALS and every 90 minutes someone dies of ALS
- 1 in every 50 families is affected by ALS
- 300,000 people alive today in the U.S. will develop and die with ALS
- Types: Sporadic (90%), Familial (10%)
- Approximately 50% of all ALS diagnoses in the United States are Veterans
Risk Factors Linked to ALS

- Aging
- Gender
- Genetics (10% of ALS is familial)
- Military service
- Other potential factors
  - Smoking
  - Viral infections
  - Exposure to environmental toxins
  - Head and Spinal Trauma
Life Expectancy

- Average: 2-5 years after diagnosis
- Slow progression: 15% to 25% with ALS live 10 years after they first notice initial symptoms
- Rapid progression: respiratory failure within a year which is unusual.
Types of Onset

- **Limb Onset (Upper or Lower)**
  - Fasiculations: twitching of muscles
  - Drop foot: tripping over carpet, etc.
  - Weak hand: often mistaken for carpal tunnel

- **Bulbar Onset**
  - Problems with speaking, chewing and swallowing

- **Respiratory Onset**
  - Problems with shortness of breath, sleep, fatigue

- **FTD**
  - Word finding, poor decision making, low impulse control
ALS Diagnosis

- No clinical or laboratory test to identify ALS.

- Diagnosis is generally made through a careful examination of medical history and neurological examination.
Differential diagnoses that can lead to ALS

- **PLS:** Primary Lateral Sclerosis
  - Upper Motor Neuron Only
- **PMA:** Progressive muscular atrophy
  - lower motor neuron only
  - **BAD:** Brachial Amyotrophic Displegia
- **PBP:** Progressive Bulbar Palsy
Treatment

• Symptom Management
  – Providing management of the patient’s symptoms rather than curing the disease
  – Quality of life
Principles of ALS Management

- High priority on patient self-determination or autonomy in the therapeutic relationship
- Patients and families need information that is timed appropriately and well in advance of major management crossroads.
- Health care professionals should address the full continuum of care for the ALS patient
- Advanced Directives should be introduced and reevaluated at least every 6 months
Psychosocial Impact

• Fatal Illness
  – Life expectancy is two to five years

• Quality of Life
  – Needs assistance with daily living skills/personal care
  – Ability to continue with employment and responsibilities
  – Remaining physically and emotionally independent

• Physical and Emotional Losses
  “I have to let go of who I am and who I will become.”
  – Such as mobility, communication, control
  – Role in family and spousal relationship
Psychosocial Impact

- Grieving
  - For/by the patient
  - For/by the family members
- Decisions
  - Healthcare
  - End of life: Peg Tube, Invasive Ventilation
  - Estate planning, providing for family
- Financial Impact
  - Average cost to an ALS patient is $200,000 per year, which includes cost of medicine, round-the-clock care, equipment and special devices, lost wages, etc.
Iowa Chapter
Care Services

- Home Visits
- Provide Information and Referrals
- Professional Education
- Provide Local Support Groups
- Provide Care Connections
- Volunteer Training

- Caregiver and Family Support
- Equipment Loan Program
- Communication & Assistive Device Program
- Respite Program
- Advocate for ALS Patients and their Families
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Support Groups

Cedar Rapids Support Group
1st Monday of each month
New Beginnings Church

Mason City Support Group
1st Tuesday of each month
Mercy West Clinic

Sioux City Support Group
1st Monday of each month
Opportunities Unlimited Community Room
Support Groups

Des Moines Support Group: Skype available
3rd Tuesday of each month
First Assembly of God Church, Des Moines

Des Moines Caregivers Support Group: Skype available
4th Tuesday of each month
First Assembly of God Church, Des Moines
• Oral motor exercises are not recommended given the nature of the disease
• Early referral for augmentative and alternative communication (AAC) evaluation and treatment
• Essential to educate PALS on all AAC options: no technology, low technology and high technology
• SLP needs to be familiar with the process of ALS, as ongoing modification of the AAC system(s) will be required as the person’s physical and communication limitations progress.

• Consider insurance benefit and funding source when assisting with high technology AAC device selection.
  – Eye Gaze System vs. Text to Speech System
• Introduce voice banking and messaging resources
  – Contact [krista@alsa-iowa.org](mailto:krista@alsa-iowa.org) for step by step voice banking guide
Communication

- No Technology
  - Non-verbals
  - Yes/No /Maybe System
    - Eyebrow raised = Yes
    - Eyebrows frown = No
    - Look away to the left = Maybe

- Low Technology
  - Partner Assisted Scanning
    - Free boards available from The ALS Association, Iowa Chapter

Partner Assisted Scanning Video
Communication

- **Low Technology**
  - Laser Pointer Device
    - Laser pointers and larger communication boards available from The ALS Association, Iowa Chapter Communication & Assistive Device Loan Closet
    - Lowtechsolutions.org
      - Laser Pointer Device Video
  - ETRAN Board or Eyelink Board
    - Available from The ALS Association, Iowa Chapter Communication & Assistive Device Loan Closet
      - Eyelink Communication Board Video
Communication

• Low Technology
  – Communication Boards: picture or letter
    • Free boards available from The ALS Association, Iowa Chapter
    • Create personalized free communication board with google images
    • Vidatak EZ communication board:
      http://www.vidatak.com/
    • Boardmaker: http://www.boardmakershare.com/
    • PogoBoards: http://www.pogoboards.com/
  – Alternative Pointer Option
    • http://amyandpals.com/
• **Low Technology**
  – Voice Amplifier
    • Available from The ALS Association, Iowa Chapter Communication & Assistive Device Loan Closet
  – Partner Assisted Communication Strategies
    • Speakbook.org
    • [Video Demo](#)
Communication

• Low Technology
  – Mega Bee: video demo
  – Writing Board
    • paper & pen
    • dry erase board
    • magna doodle
    • Boogie board, available from The ALS Association, Iowa Chapter Communication & Assistive Device Loan Closet
Communication Guide

Functional Movement Abilities

**Upper Extremity and Head Movement**
- Yes/No/Maybe System
- Partner assisted scanning w/ letter or picture board
- Writing
- Personal Computer with voice output
- Tablet with text to speech app

**No Upper Extremity Movement**
- Yes/No /Maybe System
- Partner assisted scanning and Communication Strategies
- ETRAN or Eyelink Board
- Head Mouse
- Laser Pointer Device
- Eye Gaze AAC

**Locked-In Syndrome**
- Yes/No/Maybe System
- Partner assisted scanning
- ETRAN or Eyelink
- Eye Gaze AAC
- Brain Computer Interface
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