The ALS Association – Ohio Chapters

Central & Southern Ohio Chapter

Northern Ohio Chapter
The ALS Association Central & Southern Ohio Chapter was formed in 1983 and serves 56 counties.

The Chapter...

- Provides services to the ALS community
- Advocates for ALS patients and families
- Promotes awareness of ALS
- Support research
- Raises funds for chapter programs
Serving the ALS Community

- ALS Information
  - Patients
  - Healthcare Professionals
- ALS Clinic Partners
- Support Groups
- Monthly Patient/Family Newsletter
- Nurse & Social Worker Consultation
- Equipment Loan Program
- Lending Library
- ALS Resources for Children & Teens
- Bereavement Program
Amyotrophic Lateral Sclerosis

Progressive Neurodegenerative Disease

- Catastrophic
- Unpredictable
- Terminal

- Affects upper & lower motor neurons
  - Brain
  - Brain Stem
  - Spinal Cord

- Sensory neurons not affected
What Are the Symptoms?

- impaired speech
- difficulty swallowing or choking
- drooling
- shortness of breath

**Bulbar Onset** – 15%

- stumbling
- difficulty walking
- falls
- loss of function/dexterity

**Limb Onset** – 85%

All ALS Cases
PROGNOSIS

ALS is a Terminal Illness
• 50% of patients die within 3 years
• 20% live 5 years
• 10% live 10 years.

Bulbar Onset 1 to 2 years
Limb Onset 2 to 4 years
How Does ALS Progress?

ALS is probably well along in its course before the individual recognizes the first symptoms.

<table>
<thead>
<tr>
<th>Year</th>
<th>Batting Avg.</th>
<th>RBI</th>
<th>HR</th>
<th>Hits</th>
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<td>1937</td>
<td>.351</td>
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<td>1938</td>
<td>.295</td>
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<td>170</td>
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</table>
Lou Gehrig - 1939 Season

Spring, 1939

Batting Avg. .143
RBI 1
HR 0

- Decreased coordination & speed
- June – Diagnosed with ALS
- Lou Gehrig 1903-1941
Disease Progression – Limb Onset

2003

2010
Disease Progression – Bulbar Onset

2007

2009
ALS Management

• Slow Disease Progression
  • Rilutek
  • Nutritional Support
  • Respiratory care

• Manage Symptoms
  • Physical
  • Emotional
ALS – Treatment Options

SYMPTOM MANAGEMENT

Palliative?

Life-Sustaining?
Case 1: Limb Onset

- 76 year old right handed male
- Social history: Lives with wife in 2 story home with walk-in shower on second floor, half bath on first floor. Retired; enjoys fishing, reading, active church member

- June 2012
  - Began noticing right leg weakness (foot drop) and right arm weakness but attributed to right hip and shoulder injury
- July 2013
  - MRI brain, MRI c-spine, multiple EMGs to confirm diagnosis
  - Diagnosed at neurology clinic and referred to ALS clinic for f/u
• August, 2013
  – Weight 217 lbs
  – FVC 81% of predicted. Uses CPAP at night for history of OSA
  – Motor exam: noted atrophy in right bicep, tricep, bilateral hand intrinsics. No speech, swallowing, respiratory deficits

• Physical Therapy Recommendations
  – Spasticity management: stretching, discussed Baclofen side effects
  – Energy conservation
  – Equipment: wheeled walker, transport W/C, seat assist, gait belt, bed cane
  – Outpatient PT for transfer training, equipment
  – Home modifications: first floor set up, ramp
  – Refer W/C clinic
• Occupational Therapy Recommendations
  – Right UE weakness limiting ADL abilities
  – Transfer bench/shower chair
  – Outpatient OT to more thoroughly address needs
    • Leg lifter and bed cane for bed mobility
    • EZ lift for sit to stand transfers
    • Sock aid
    • Built up silverware
    • Button hook
  – Patient stopped driving on his own accord due to safety needs; otherwise would have benefited from a driver’s evaluation to determine modifications and/or ability for continued participation
The ALS Association – Care Services

**Assess:**
- Determine knowledge of ALS disease process, understanding of life changes ahead.
- Consider availability of resources such as VA, church community, transportation options, extended family assistance.

**Learn:**
- Provide ALS educational information (Patient/Family Resource Guide, Living with ALS booklets, Living a Fuller Life with ALS, Every Step of the Journey)
- Familiarize patient/caregiver with ALS management issues (emphasize nutrition and respiratory care)
- Introduce National ALS Registry

**Support:**
- Provide clinical trial/research options
- Introduce Chapter services including support group/monthly newsletter/access to care services staff, equipment loan program
Case 2 - Bulbar Onset with FTD

- 49 y/o right handed woman
- PMH: Smoker, endometriosis, Grave’s disease

- April 2012
  - Started noticing speech changes - “my speech sounds like I’m drunk”

- September 2012
  - Diagnosed with bulbar onset ALS. EMG reveals extensive denervation in left UE and sparse denervation left LE
  - Gait normal
• March 2013
  – Swallowing difficulties, noticeable dysarthria, fasciculations, bilateral UE weakness, dyspnea with difficulty lying flat.
  – Excessive crying (acute depressive disorder vs pseudobulbar affect)
  – Gait and LE strength normal
  – Weight: 119 lbs, FVC 40%
  – Address communication options
  – Discussion re: PEG.

• June 2013
  – Weight 112 lbs
  – Profound dysarthria
  – Feeding tube placed while hospitalized for pneumonia,
  – Some left lower facial weakness.
  – FVC, unable to perform valid test
September 2013

- Weight 109 lbs.
- Oriented to person and place, but delayed recall. Unable to add a serial 7’s, even when writing out numbers.
- Speech unintelligible. Uses dry erase board and gestural communication. Tongue atrophy and fasciculations.
- Showing signs of FTD including decline in short term memory, orientation, poor insight.
- Overnight pulse oximeter reveals significant desaturations. Bi-Pap is recommended.
- Using suction device and cough assist vest, but recent episode of pneumonia.
- Ambulates slowly, independently. Requires maximum assistance for dressing.
The ALS Association – Care Services

Assess:
• Evaluate caregiver burden
• Discuss advance directives
• Establish position regarding ongoing disease management, hospice

Learn:
• Discuss reasons for and implications of weight loss.
• Introduce PEG.
• Provide information on disease progression, FTD
• Investigate opportunities for caregiver support

Support:
• Promote support group participation
• Provide communication picture board
• Stress home safety measures
Important Decisions Facing Patients and Their Families

• How to tell the family
• When to stop working
• When to apply for Social Security Disability
• When and whether to change living arrangements
• Activity of daily living needs
• Dealing with mobility issues – driving, power wheelchair, transportation, home environment
• Feeding Tube option
• Choosing appropriate communication devices
• Non-Invasive Ventilation (Bi-Pap, Trilogy)
• Diaphragm Pacing
• Invasive Ventilation
The Faces of ALS
Mary Pat - RN - age 60
Onset – hand weakness
Diagnosis – 11/2011
Brian - age 63
Onset – limb onset
Diagnosis – 11/1995 (age 48)
Roger – College Professor - age 70
Onset – lower extremity weakness
Diagnosed – 6/2003
Lori – Sales Manager – age 49
Onset – hand cramping
Diagnosis – 2/2004 (age 39)
Greg – conveyor belt installer - age 52
Onset – hand weakness, cramping
Diagnosis – 11/2005 (age 43)
Bill – Minister - age 66
Onset – fatigue with walking
Diagnosed – 8/2010
GOALS

The ALS Association

Working Together to Meet Patient Needs

- Disease Management
- Decision Making
- Caregiver/Family Support
- Coordination of Care

Treatment Team
Meet the Care Services Team

Peggy Clary, RN
Leigh Reed, RN

Yvonne Dressman, LSW

Wilma Beckner, RN
Support Group
ALS Awareness
Equipment Needs
ALS Information
Chapter Care Services

- ALS Information
  - Patients
  - Healthcare Professionals
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