ALS ASSOCIATION

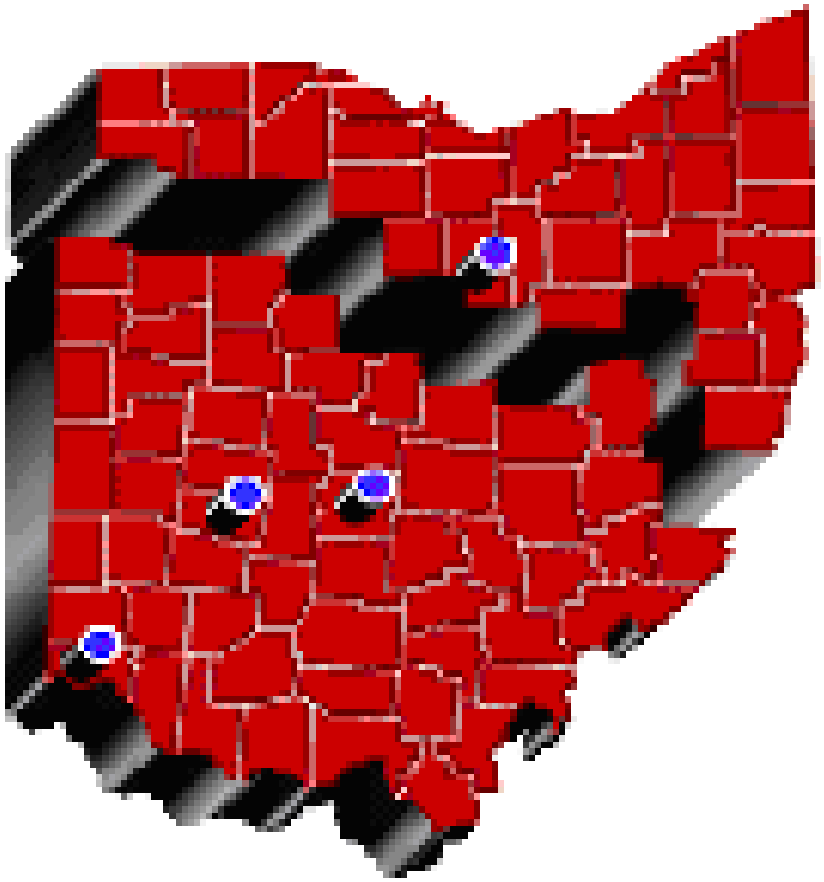
Central & Southern Ohio Chapter

Living with ALS

January 22, 2015

Marlin Seymour – Executive Director
Peggy Clary, RN, MHA, CCM – Care Services

The ALS Association – Ohio Chapters



Northern Ohio Chapter

Central & Southern Ohio Chapter

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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

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Serving the ALS Community

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Fighting Lou Gehrig's Disease
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- ALS Information
  - Patients
  - Healthcare Professionals
- ALS Clinic Partners
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- Equipment Loan Program
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- Bereavement Program

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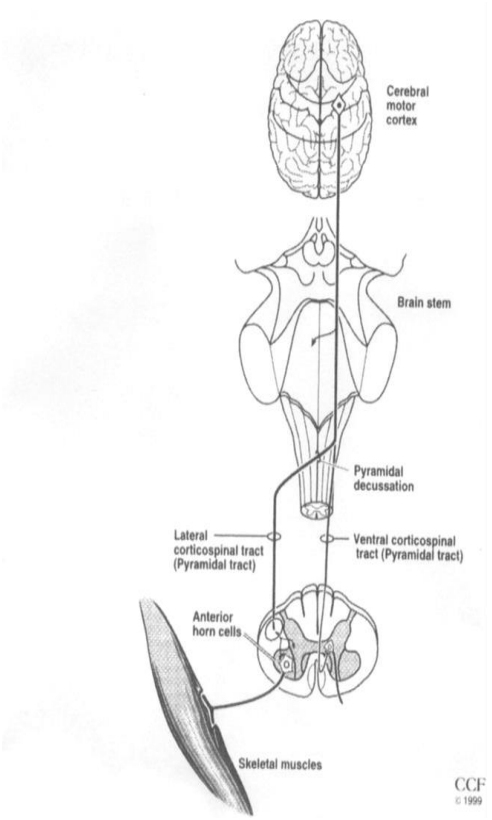
Amyotrophic Lateral Sclerosis



Progressive Neurodegenerative Disease

- Catastrophic
- Unpredictable
- Terminal

- Affects upper & lower motor neurons
  - Brain
  - Brain Stem
  - Spinal Cord
- Sensory neurons not affected

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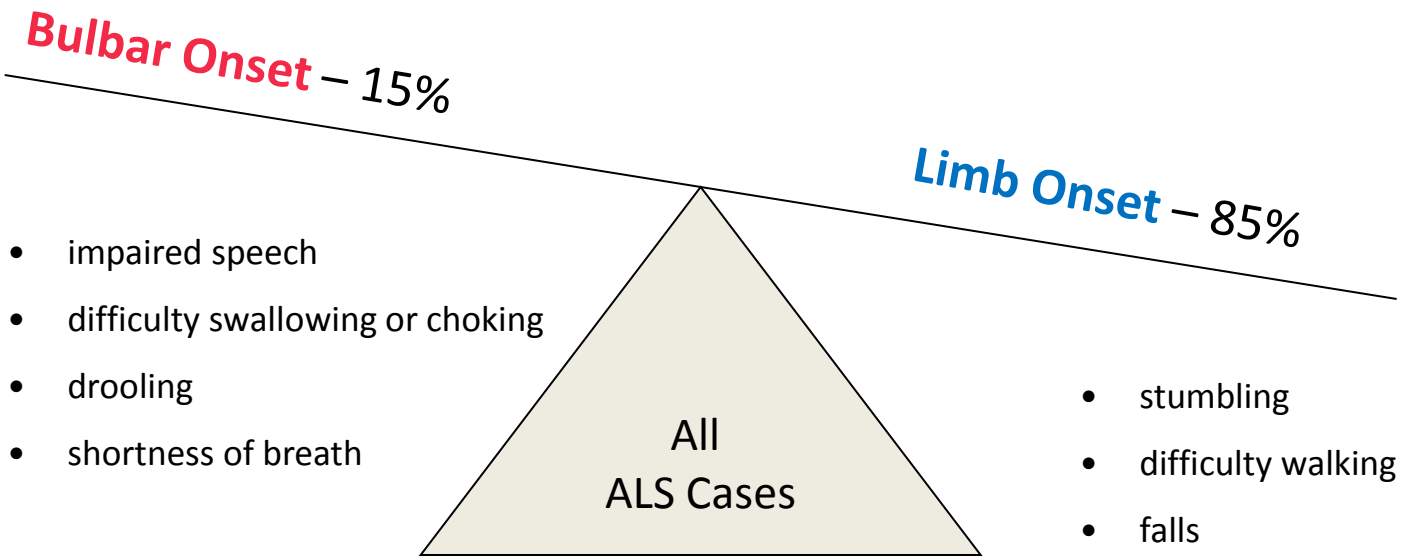
What Are the Symptoms?



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

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

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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

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How Does ALS Progress?

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

1937	
Batting Avg.	**.351**
RBI	**159**
HR	**37**
Hits	**200**

1938	
Batting Avg.	**.295**
RBI	**114**
HR	**29**
Hits	**170**

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Lou Gehrig - 1939 Season

Spring, 1939

Batting Avg.	**.143**
RBI	**1**
HR	**0**

- **Decreased coordination & speed**
- **June – Diagnosed with ALS**
- **Lou Gehrig 1903-1941**

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Disease Progression – Limb Onset

2003

2010

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Disease Progression – Bulbar Onset

2007

2009

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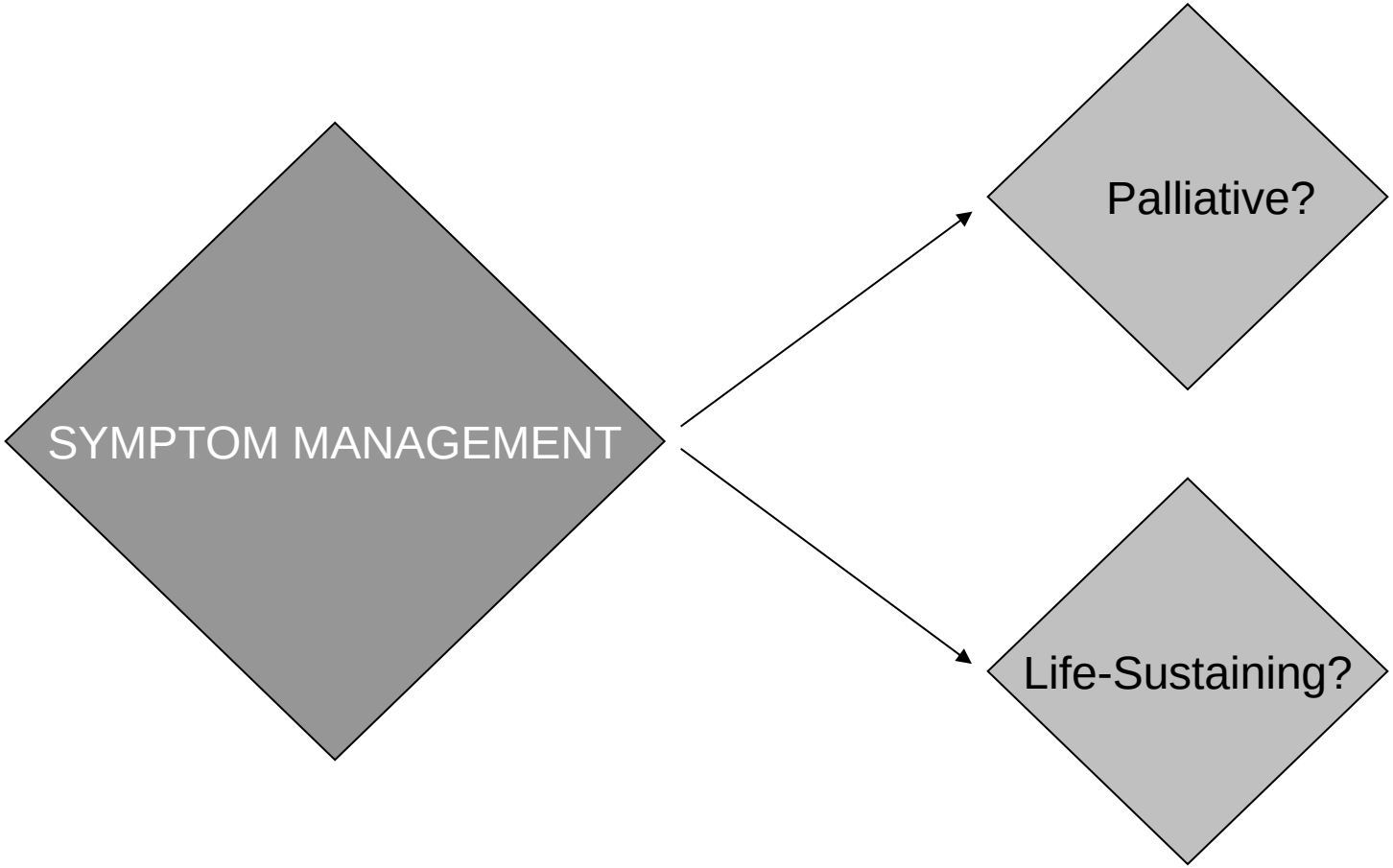
ALS Management

- Slow Disease Progression
  - Rilutek
  - Nutritional Support
  - Respiratory care
- Manage Symptoms
  - Physical
  - Emotional

ALS – Treatment Options



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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

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Case 2 - Bulbar Onset with FTD

- 49 y/o right handed woman
- PMH: Smoker, endometriosis, Grave's disease
- Social history: spouse very supportive. Spouse and son provide 24 hour supervision/assist. Lives in 1 story home . Walk-in shower with standard height toilet.

- 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

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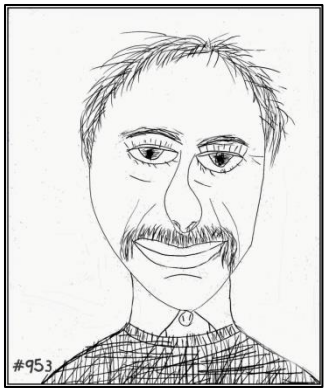
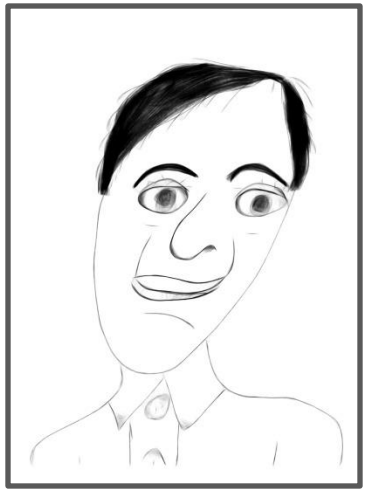
Important Decisions Facing Patients and Their Families

- How to tell the family
- When to stop work ing
- 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



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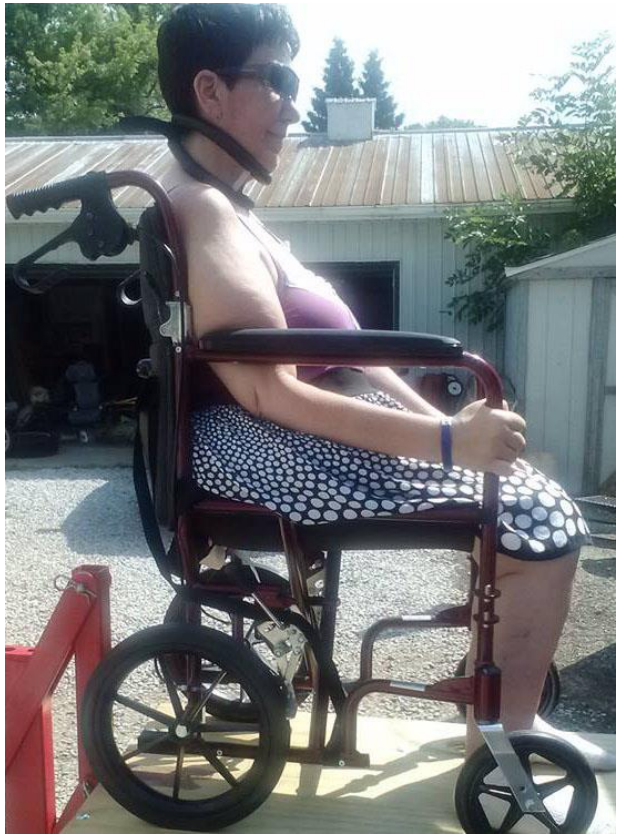
Mary Pat - RN - age 60
Onset – hand weakness
Diagnosis – 11/2011



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Brian - age 63
Onset – limb onset
Diagnosis – 11/1995 (age 48)

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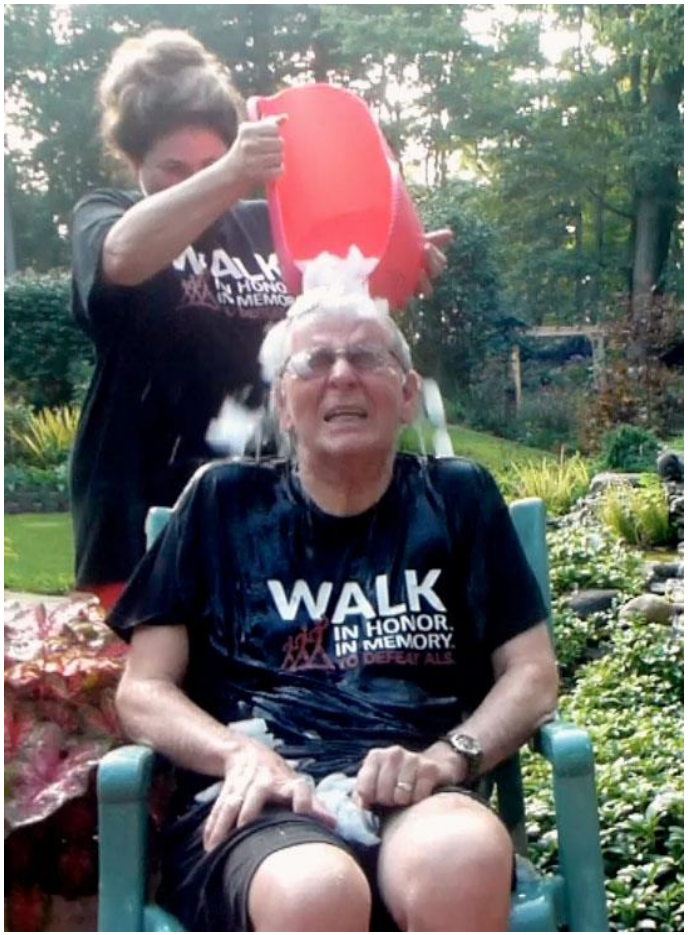
Roger – College Professor - age 70
Onset – lower extremity weakness
Diagnosed – 6/2003



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Lori – Sales Manager – age 49
Onset – hand cramping
Diagnosis – 2/2004 (age 39)

2005

2014

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Greg – conveyor belt installer - age 52
Onset – hand weakness, cramping
Diagnosis – 11/2005 (age 43)

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Bill – Minister - age 66
Onset – fatigue with walking
Diagnosed – 8/2010

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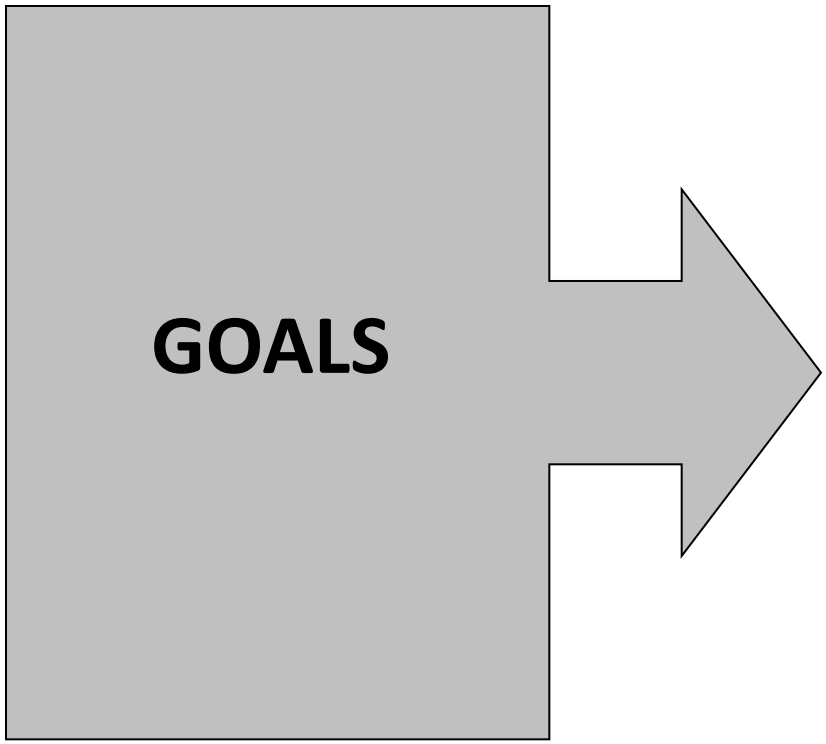
Working Together to Meet Patient Needs

The ALS Association



Treatment Team

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

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Meet the Care Services Team

Peggy Clary, RN
Leigh Reed, RN

Yvonne Dressman, LSW

Wilma Beckner, RN

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Support Group

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ALS Awareness

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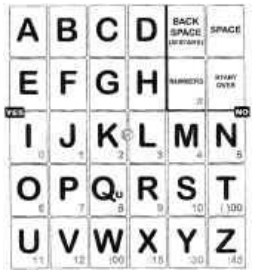
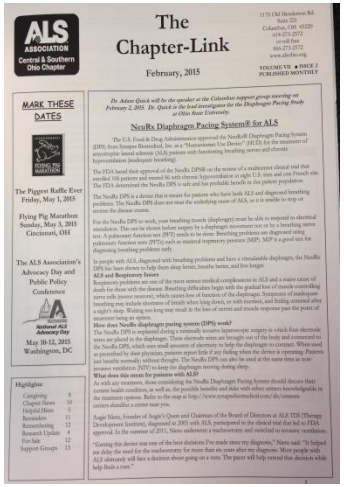
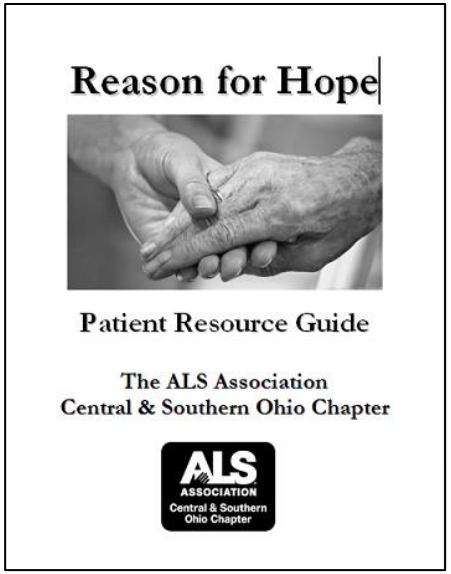
Equipment Needs



ALS Information





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