

# Amyotrophic Lateral Sclerosis: Management Across the Disease Continuum

Live Interactive Webinar  
Presented By

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## Course Overview

- “Amyotrophic Lateral Sclerosis” is a live (real-time) interactive webinar for rehabilitation professionals presenting contemporary knowledge on this progressive neurodegenerative disease. The course addresses pathophysiology, clinical presentation, and disease progression with emphasis on motor neuron loss, respiratory compromise, and bulbar involvement. Participants will learn strategies for managing functional decline and promoting quality of life across all stages of the disease.

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## Course Rationale

- The purpose of this course is to enhance clinical understanding of the unique and evolving needs of individuals living with ALS. The evidence-based strategies presented will guide the development of individualized treatment programs that optimize independence and support functional preservation, safety, and quality of life.

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## Goals and Objectives

- Identify genetic mutations in familial and sporadic types of ALS.
- Identify relevant biomarkers and imaging findings associated with diagnosis.
- Recognize the stages of disease progression.
- Identify assessment tools to track disease progression.
- List the motor, non-motor, and bulbar components of clinical presentation.
- Identify symptom management and psychosocial care strategies.
- Distinguish the primary and secondary mechanisms contributing to pain.
- Define respiratory compromise and recognize ventilation support options.
- Identify dysphagia concerns and nutritional support strategies.
- Identify contemporary options to facilitate communication.

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## Disclaimer

- Application of concepts presented in this webinar is at the discretion of the individual participant in accordance with federal, state, and professional regulations.
- No conflict of interest exists for the presenter or provider of this course.

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3-Hour  
Live Interactive  
Webinar

| Topic                                                  | Time               |
|--------------------------------------------------------|--------------------|
| Overview                                               | 0:00 - 0:15        |
| Genetic and Environmental Factors                      | 0:16 - 0:30        |
| Pathogenesis                                           | 0:31 - 0:40        |
| Neuroimaging and Biomarkers                            | 0:41 - 0:50        |
| <b>Interactive Discussion of Clinical Applications</b> | <b>0:51 - 1:00</b> |
| Disease Progression                                    | 1:00 - 1:20        |
| Motor Impairment                                       | 1:21 - 1:50        |
| <b>Interactive Discussion of Clinical Applications</b> | <b>1:51 - 2:00</b> |
| Respiratory Compromise                                 | 2:00 - 2:15        |
| Bulbar Involvement, Nutrition, and Communication       | 2:16 - 2:31        |
| Fatigue, Pain, Cognitive and Behavioral Changes        | 2:31 - 2:40        |
| Pharmacotherapy                                        | 2:41 - 2:45        |
| Patient Preferences and End of Life                    | 2:46 - 2:50        |
| <b>Interactive Discussion of Clinical Applications</b> | <b>2:51 - 3:00</b> |

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### How To Obtain CEUs For This Course

- Course review and summary for post test at the end of the webinar.
- After the live interactive webinar and prior to 11:59 pm TONIGHT go to [cheapceus.com](https://cheapceus.com)
- Complete the post test with score of at least 70%
  - May be retaken multiple times
- Submit online payment for course
- Print certificate



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### Course Post Test

- Slides with "Consider This" icon in bottom right corner will be helpful in completing the post-test.



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### Overview

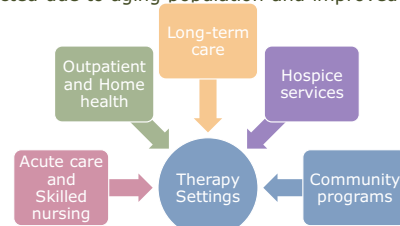
- A rare and progressive neurodegenerative disorder of the central and peripheral nervous system leading to advancing weakness, loss of voluntary movement, and ultimately life-limiting respiratory decline.
- Amyotrophic Lateral Sclerosis (ALS)
- Lou Gehrig's Disease



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### Incidence and Prevalence

- Steady increase in people living with ALS world-wide is expected due to aging population and improved survival.



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### Genetics

- Etiology not fully understood, likely involves genetic susceptibility and environmental influences.

Sporadic sALS  
• 90%  
• Not inherited  
• No specific cause

Familial fALS  
• 10%  
• Genetic  
• Several genes identified

C9ORF72  
SOD1  
TARDBP  
FUS



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### Environmental Risk Factors

- Associations correlate with epigenetic alterations, but direct causality is not established.
- DNA methylation silences genes essential for synaptic integrity, axonal transport, and neuronal viability.

Newell, M. E., et al. (2025). Epigenetic Biomarkers Driven by Environmental Toxins Associated with Alzheimer's Disease, Parkinson's Disease, and Amyotrophic Lateral Sclerosis in the United States: A Systematic Review. *Toxics*, 13(2), 114.  
Benatar, M., Helman-Patterson, T. D., Cooper-Knock, J., Brickman, D., et al. (2025). Guidance for clinical management of pathogenic variant carriers at elevated genetic risk for ALS/FTD. *Journal of Neurology, Neurosurgery & Psychiatry*, 96(3), 205-218.

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### Head Injury (HI) and Earlier Age of ALS Diagnosis

- Not an absolute risk factor or cause.

**Associated with Diagnosis before age 60**

- Childhood or early adulthood HI
- Hospital visit or loss of consciousness
- Five or more HIs

**Reverse Causation**

- Mid to late adult HI and CTE
- Short interval between injury and diagnosis
- Prodromal ALS

Raymond, J., et al. (2025). Head Injury and Amyotrophic Lateral Sclerosis: Population-Based Study from the National ALS Registry. *Brain Sciences*, 15(2), 143.

Consider This

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### Presumption of Military Service Connection

- Some occupational and environmental deployment exposures are associated with increased ALS risk, but no single exposure has been definitively proven as causal.

Environmental and Chemical Exposures

Traumatic Brain Injury

Physical and Operational Stressors

Congressionally Directed Medical Research Programs. (2024). Amyotrophic Lateral Sclerosis Research Program (ALSRP). U.S. Department of Defense.

14

### Pathogenesis

- Mechanisms develop in parallel and reinforce one another over time.

Faller, K. M., et al. (2025). Targeting common disease pathomechanisms to treat amyotrophic lateral sclerosis. *Nature Reviews Neurology*, 1-17.  
González-Sánchez, M., et al. (2025). Pathophysiology, Clinical Heterogeneity, and Therapeutic Advances in Amyotrophic Lateral Sclerosis: A Comprehensive Review of Molecular Mechanisms, Diagnostic Challenges, and Multidisciplinary Management Strategies. *Life*, 15(4), 647.

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### Cell Stress and Toxic Buildup

**Key Factors**

- Misfolded proteins (TDP-43)
- RNA processing errors

**Consequences**

- Proteins in the wrong place
- Disrupted cell functions
- Neuron becomes unstable
- Sets the stage for neurodegeneration

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### Signal Loss

**Key Factors**

- Axonal transport failure
- Cytoskeleton breakdown
- Blocked movement of cellular materials

**Consequences**

- Neurotransmitter depletion
- Mitochondrial dysfunction
- Axon retraction
- Loss of synaptic connections

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### Cell Damage

**Key Factors**

- Neurotransmitter imbalance
- Glutamate excitotoxicity
- Calcium overload
- Mitochondrial stress
- Diminished astrocyte clearance

**Consequences**

- Reduced neuronal efficiency
- Energy failure
- Inflammation
- Slower recovery

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### Neuron Degeneration

|                                                                                                                                                                                                                                                                   |                                                                                                                                                                                                   |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Key Factors</b> <ul style="list-style-type: none"> <li>Persistent calcium stress</li> <li>Chronic neurotransmitter dysregulation</li> <li>Sustained glial and astrocyte activation</li> <li>Failure of cellular repair</li> <li>Ongoing signal loss</li> </ul> | <b>Consequences</b> <ul style="list-style-type: none"> <li>Motor neuron death</li> <li>Ongoing muscle denervation</li> <li>Progressive weakness</li> <li>Declining functional capacity</li> </ul> |
|-------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------|

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### Upper and Motor Neuron Involvement

- Disrupts the motor network linking the primary motor cortex, lateral corticospinal tracts, anterior horn cells, and neuromuscular junctions in voluntary muscles.
- Brainstem involvement of bulbar motor cranial nerve nuclei.

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### Diagnosis Challenges

- Variable presentation and late symptom emergence lead to delayed diagnosis.
- No single diagnostic tool.

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### thinkALS™ tool

- This tool cannot be substituted as a diagnostic instrument but used only as a diagnostic guide.

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### Neuroimaging and Biomarkers

- No single confirmatory test
- Clinical criteria (El Escorial, Awaji, Gold Coast) identify a consistent pattern of progressive upper and lower motor neuron involvement.
- Electromyography (EMG)
- Magnetic Resonance Imaging (MRI)
- Positron Emission Tomography (PET)
- Diffusion Tensor Imaging (DTI)
- Fluid biomarkers, including neurofilament light chain (NfL)

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### Diffusion Tensor Imaging (DTI)

- A specialized type of MRI that measures how water molecules move inside brain tissue, especially along white-matter nerve fibers.
- Provides information about microstructural damage earlier than standard imaging.
- Decreased Fractional Anisotropy (FA)
- Increased Mean Diffusivity (MD)
- Confirms UMN involvement

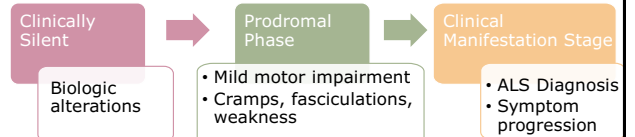
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### Neurofilament Light Chain (NfL) Levels

- NfL is a structural axonal protein that is released with motor neuron injury.
- Elevated serum and cerebrospinal fluid levels are indicative of disease severity and progression.
- Can support early diagnosis in high-risk individuals.

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### Disease Onset



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### Symptom Onset Patterns

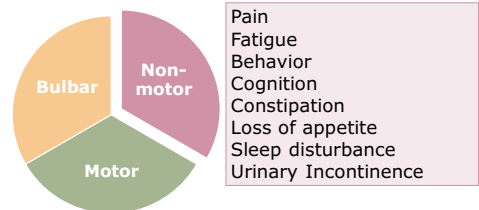
- Variable early clinical signs
- Limb Onset
  - Asymmetrical upper or lower extremity weakness
  - Muscle fasciculations, decreased dexterity
- Bulbar Onset
  - Speech and/or difficulties, hoarse voice
- Respiratory Onset



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### Multisystem Disorder

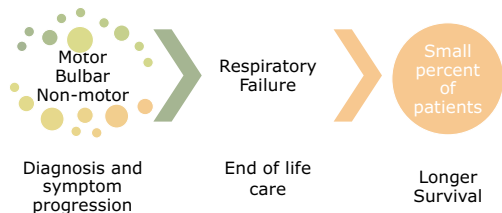
- Sensation and eye muscle control is typically retained.



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### Disease Progression

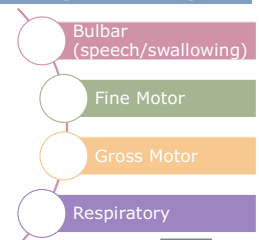
- No cure with treatment goals is to delay disease progression and manage symptoms as they emerge.



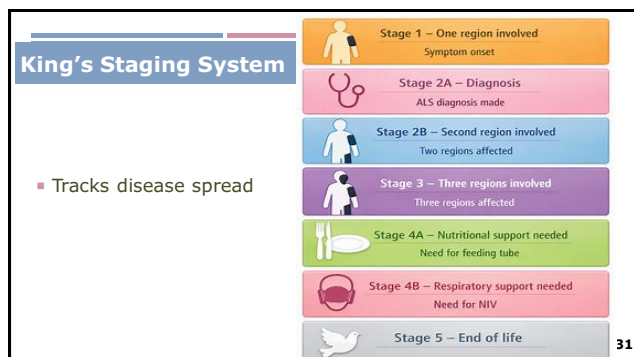
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### ALS Functional Rating Scale (ALSFRS-R)

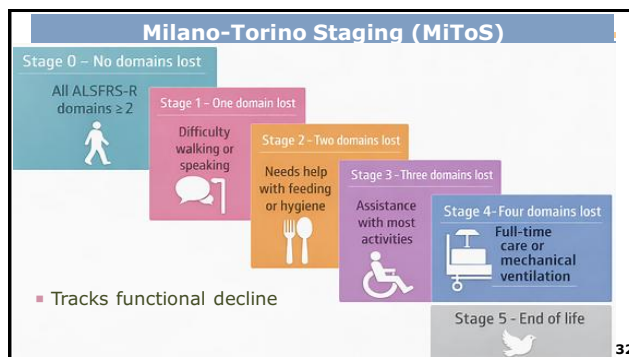
- Measures functional decline across several domains.
- Higher scores indicate better function with lower scores reflecting greater disability.



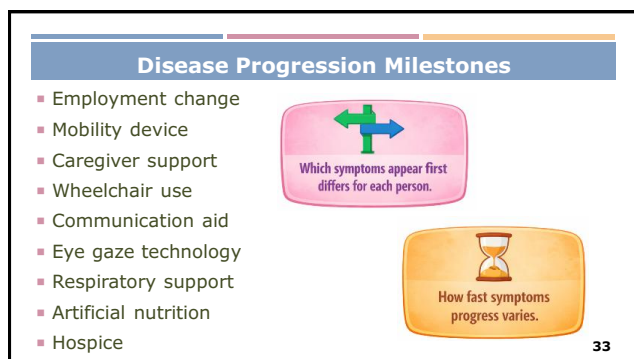
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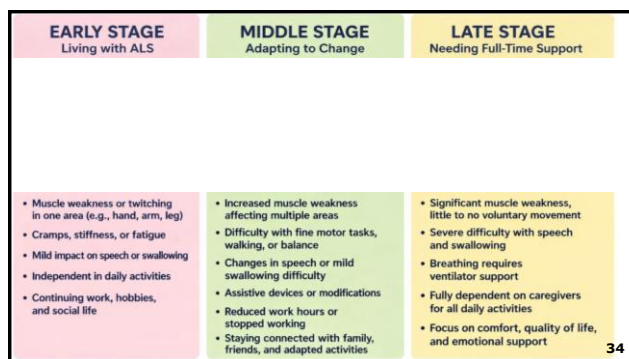
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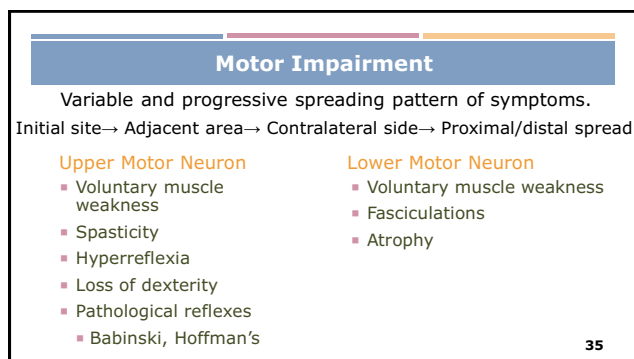
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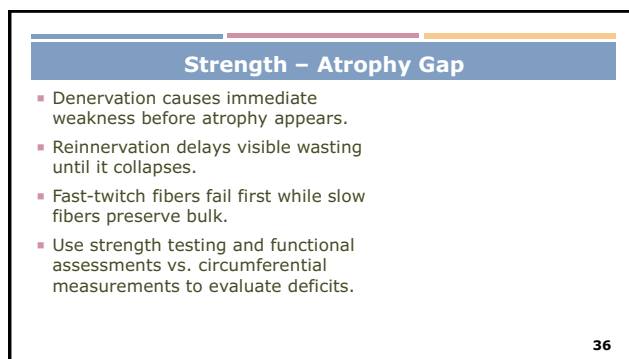
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Split Hand Index

- Disproportionate wasting of thenar and first dorsal interosseous muscles with relative sparing of hypothenar muscles.
  - Abductor pollicis brevis (APB)
  - First dorsal interosseous (FDI)
- Loss of precision/pincer grip.
  - Avoid high load isolation exercises.
- Use lateral or palmar grasp, two hand strategies, thumb opposition support splinting and adaptive equipment.

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Motor Impairment Interventions

- Stretching and orthotics
- Balance training and fall assessment
- Activity modification
- Energy conservation and adaptive equipment
- Home modifications and emergency egress
- Caregiver training and social engagement
- Mobility aids, transfer equipment, wheelchair customization



Gratzer, A., et al. (2025). Rehabilitation in Amyotrophic Lateral Sclerosis: Recommendations for Clinical Practice and Further Research. Journal of Clinical Medicine, 14(23), 8590.

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EARLY STAGE

MIDDLE STAGE

LATE STAGE

| FOCUS                                                                                                          | FOCUS                                                                                                                | FOCUS                                                                                                           |
|----------------------------------------------------------------------------------------------------------------|----------------------------------------------------------------------------------------------------------------------|-----------------------------------------------------------------------------------------------------------------|
| Maintain strength, function, and independence                                                                  | Adapt, conserve energy, and maintain quality of life                                                                 | Maximize comfort, safety, and quality of life                                                                   |
|  Exercise and Strengthening |  Mobility and Transfers           |  Respiratory Management      |
|  Balance and Coordination   |  Stretching and Range of Motion   |  Positioning and Comfort     |
|  Breathing Exercises        |  Respiratory Support              |  Caregiver Training          |
|  Energy Conservation        |  Home and Daily Activity Training |  Pain and Symptom Management |
|  Stay Active and Engaged    |  Support and Education            |  Emotional Support           |

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Exercise Guidelines

- Moderate resistance and aerobic training
- Appropriate for muscles that can move against gravity.

Safe. Effective. Sustainable.

AVOID ECCENTRIC LOADING

AVOID VIGOROUS INTENSITY

AVOID OVER EXERTION

 FOCUS INSTEAD ON:

 Concentric contractions

 Low to moderate intensity

 Energy conservation and pacing

Li, Z., & Kang, H. (2024). Efficacy of non-pharmacological interventions for individuals with amyotrophic lateral sclerosis: Systematic review and network meta-analysis of randomized control trials. Scientific reports, 14(1), 11365.

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Exercise Outcomes

| Intervention              | Outcome                                                                                                                                     |
|---------------------------|---------------------------------------------------------------------------------------------------------------------------------------------|
| Animal study treadmill    | High-intensity consistently worsened outcomes. Moderate delayed onset or improved survival in some cases. Swimming most consistent benefit. |
| Human resistance training | Beneficial effects on strength, function, quality of life. No evidence of slowing disease progression.                                      |
| Human aerobic training    | Beneficial effects on endurance, gait, work capacity, quality of life.                                                                      |

Fenili, G., et al. (2024). Physical exercise in amyotrophic lateral sclerosis: a potential co-adjutant therapeutic option to counteract disease progression. Frontiers in Cell and Developmental Biology, 12, 1421566.  
Ren, S., et al. (2025). The effect of exercise intervention on amyotrophic lateral sclerosis: A systematic review and meta-analysis. Frontiers in Neurology, 16, 1499407.

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Targeted Regions

- Bracing for foot drop, wrist/hand weakness, neck extensor weakness and shoulder subluxation
- Stretching and positioning for shoulder girdle, hamstring and gastrocnemius tightness and/or spasticity
- Massage and stretching for cramps

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### Adaptive Equipment

- Bendable utensils, nosey cup, long flexible straws, one way straw, universal cuff, mobile arm support
- Bath mitt, hairdryer stand, grooming station, portable showers
- Suspenders, zipper shoes
- Leisure and pleasure activity adaptations

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### Mobility Equipment

- Cane, rollator walker
- Transfer vest, lift belt
- Gliding transfer boards, pivot disks, sliding bed sheets, swivel seat cushion, mechanical lift, track lift
- Raised seat, seat lift cushion, sit to stand lift
- Seat-lift recliner

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### Wheelchair Features

- Power tilt, power recline, elevating height power wheelchair
- Power articulating leg rests
- Vent tray
- Drive control -joystick, sip & puff, switch, chin, head-array, foot pedal, eye gaze, infrared, attendant control
- Seating system
- Home modifications

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### Integumentary Care

- Patient and family training in skin inspection, pressure relief positioning, deep vein thrombosis monitoring.
- Edema positioning, compression garments and massage

Sensation assessment

Elevate entire leg or arm above heart

Manage tight gastroc and hamstring

Tilt & recline wheelchair with articulating leg rests

Seat lift recliner

Sequential compression device (SCD)

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### Bowel and Bladder

- Constipation due to non-neurological factors
  - Managed with medication, diet, and exercise
- Urinary urgency, incontinence, and retention
  - Managed with medication, pelvic floor strengthening, and catheter
- Mobility, adaptive equipment, and sleep disturbance considerations
  - Lift commode, magnetic/velcro clothing closures, split seams, female urinal, wireless doorbell with gumball/buddy button

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### Respiratory Involvement

- Assess respiratory insufficiency.
  - Dyspnea, fatigue, yawning, orthopnea, accessory muscle use, cough strength, morning headaches, daytime sleepiness
- Nocturnal hypoventilation and obstructive sleep apnea
  - Modify sleep position and contributors to fragmented sleep
- Pulmonary complications and weakness become life limiting.

Macpherson, C. E., et al. (2026). Physical Therapist Interventions for People With Amyotrophic Lateral Sclerosis Across Disease Stages: A Systematic Review of Efficacy. *Physical Therapy*, 106(1), para4-5.

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Respiratory Training

- Forced Vital Capacity (FVC) is a predictor of survival.
- Maximum Inspiratory Pressure (MIP) and Sniff Nasal Inspiratory Pressure (SNIP) measure muscle strength.
- Goal of interventions is to delay progression to ventilatory failure.
- Breathing exercises
  - Inspiratory muscle training
  - Posture training and bracing
- Airway clearance

Consider This

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Airway Clearance Techniques

- Peak Cough Flow (PCF) measures cough strength.
- Manually assisted cough
- Mechanical insufflation/exsufflation
- Postural drainage
- Expiratory muscle training
- Portable suction
- Oral care

Impaired Cough in ALS

Glottis Dysfunction

Inspiratory Weakness

Expiratory Weakness

Ineffective Cough

- Retained Secretions
- Aspiration Risk

Magni, E., et al. (2024). Effects of Respiratory Training on Pulmonary Function, Cough, and Functional Independence in Patients with Amyotrophic Lateral Sclerosis. *Neurology International*, 16(6), 1332-1342.

Richerry, A. L. (2024). Airway clearance strategies and secretion management in amyotrophic lateral sclerosis. *Respiratory Care*, 69(2), 227-237.

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Breath Stacking

- Assists with oxygenation, secretion clearance, and thoracic mobility.

Khan, A., et al. (2023). Respiratory management of patients with neuromuscular weakness: American college of chest physicians clinical practice guideline and expert panel report. *Chest*, 164(2), 394-413.

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Lung Volume Recruitment (LVR)

- Incorporates manual bagging during inspirations of breath stacking.
- Establish patient signal gesture of full lungs to STOP inflation.
- Do NOT use bag for resuscitation emergencies.

Khan, A., et al. (2023). Respiratory management of patients with neuromuscular weakness: American college of chest physicians clinical practice guideline and expert panel report. *Chest*, 164(2), 394-413.

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Respiratory Outcomes

| Study                       | Outcome                                                                                                                                |
|-----------------------------|----------------------------------------------------------------------------------------------------------------------------------------|
| Fatigue prevalence          | Higher fatigue frequency with ALSFRS-R $\leq 30$ . Correlated to lower functional status and poorer quality of life.                   |
| Respiratory muscle training | MEP and swallow function most consistent improvement.<br>MIP inconsistent improvement.<br>ALSFRS-R and FVC no significant improvement. |

Hamad, A. A., et al. (2024). Prevalence and correlates of fatigue in amyotrophic lateral sclerosis: A systematic review and meta-analysis. *Neurological Sciences*, 45(2), 485-493.

Ansari, U., et al. (2025). Analysis of Respiratory Muscle Strength Training in Amyotrophic Lateral Sclerosis (ALS) Patients: A Systematic Review. *Cureus*, 17(2).

Bentz-Iglesias, M. J., et al. (2023). Efficacy of respiratory muscle training in improving pulmonary function and survival in patients with amyotrophic lateral sclerosis: a systematic review and meta-analysis. *Therapeutic advances in respiratory disease*, 19, 17534666231346095.

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Ventilation Support

- Noninvasive ventilation(NIV)
  - Bi-level Positive Airway Pressure (BiPAP)
  - Home ventilator
- Invasive ventilation
  - Tracheostomy

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Bulbar Involvement

- Facial muscle weakness and temporal muscle wasting
- Palmonental Reflex
  - Thenar eminence stroke elicits chin twitch
- Jaw Jerk Reflex
  - Tapping chin elicits jaw clonus
- Sialorrhea

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Malnutrition

- Weight stability is a prognostic factor for overall survival.

Metabolic Factors

- Hypermetabolism
- Increased energy expenditure

Swallowing & Intake Factors

- Dysphagia
- Appetite loss

Cognitive & Emotional Factors

- Depression
- Cognitive impairment

Functional & Practical Factors

- Meal preparation difficulty
- Feeding ability decline
- Polypharmacy

Bjelica, B., et al. (2024). Non-motor symptoms in patients with amyotrophic lateral sclerosis: current state and future directions. *Journal of neurology*, 271(7), 3953-3977.

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Dysphagia

- Early screening minimizes risk of pneumonia due to aspiration.
- EAT-10 Screening Tool
- Assess bathroom accessibility
- Posture and expiratory muscle training
- Oral hygiene

Cramps

Constipation

Thick mucus

Saliva lubrication

DEHYDRATION

Consider This

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Diet and Eating Modifications

- Texture modified diet
- Eating efficiency
  - Meal preparation, feeding technique, and mealtime length
- Safe feeding techniques
  - Swallowing maneuvers
  - Breath stacking
  - Adaptive equipment
- Alleviate stress on diaphragm after eating

de Carvalho Vilar, M. D., et al. (2025). Evidence-Based Nutritional Recommendations for Maintaining or Restoring Nutritional Status in Patients with Amyotrophic Lateral Sclerosis: A Systematic Review. *Nutrients*, 17(5), 782.

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Nutritional Support

Weight loss

Preference

Fatigue & Stress

Dehydration

Respiratory status

Choking & Aspiration

PEG G-tube

- Hypercaloric nutrition to maintain nutritional status, support body weight, and mitigate catabolic muscle loss leading to muscle wasting.
- Artificial nutrition

Consider This

Foad, A. I., et al. (2025). Evolution of Wheelchair Technology: A Comprehensive Overview of History, Disabilities, Types and Control Mechanisms. *Advanced Sciences and Technology Journal*, 2(2), 1-20.

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Dysarthria

- Muscle spasticity and weakness
- Hypernasality
- Compensatory speech strategies
- Palatal lift
- Lung function and respiratory muscle strength
  - Expiratory muscle training
  - Lung volume recruitment

Pesqualucci, E., et al. (2025). Management of dysarthria in amyotrophic lateral sclerosis. *Cells*, 14(14), 1048.

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Alternative and Augmentative Communication

- Communication board
- Alerting system
- Voice amplifier, microphone
- Eye-gaze technology
- Speech synthesizers
- Message banking
- Voice banking

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Non-Motor Symptoms

- Sleep disturbance
- Autonomic function
- Fatigue
- Pain
- Cognition
- Behavior

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Fatigue

- Contributors to fatigue should be identified and managed.
  - Respiratory insufficiency, disrupted sleep, insufficient nutrition, prolonged mealtime, muscle weakness, depression, medication side effects
- Screen for comorbidities
- Prioritize energy conservation, positioning and mobility efficiency.

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Pain

- Common later stage non-motor symptom that may be difficult for patient to report.

Primary Neuropathic

Burning, tingling Dysesthesia

Sleep disturbance

Secondary Mechanical **More Prevalent**

Joint and soft tissue pain

Limits mobility Sleep Disturbance

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Pain Management

- Hydration, electrolytes and bowel regimen
- Early Stage**
  - Postural correction, ergonomic adjustments and activity pacing
  - Modalities and soft-tissue techniques
- Middle Stage**
  - Orthotics, bracing, and contracture prevention
  - Positioning schedule, sleep hygiene and seating optimization
- Late Stage**
  - Pressure relief, comfort positioning and palliative coordination

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Cognitive Changes

- Varying degrees of cognitive impairment to executive functioning.
  - Reduced verbal fluency
  - Mental inflexibility
  - Disinhibition
  - Impaired planning
- Some patients develop Frontotemporal Dementia (FTD).

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### Behavioral Changes

- Pseudobulbar affect
- Apathy, disinhibition, impaired social cognition, and depression

| Excess              | Absence             |
|---------------------|---------------------|
| Repetitive Actions  | Social Withdrawal   |
| Fixated Thoughts    | Apathy              |
| Anxiety             | No Motivation       |
| Emotional Outbursts | Poor Follow Through |
| Agitation           | Lack of Empathy     |

VS

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### Frontal Assessment Battery (FAB)

- Screens for frontal lobe executive dysfunction abilities.
- Requires spared verbal and motor abilities for completion.

|                             |                    |                          |
|-----------------------------|--------------------|--------------------------|
| Conceptualization           | Mental Flexibility | Motor Programming        |
| Sensitivity to Interference | Inhibitory Control | Environmental Monitoring |

Aliello, E. N., et al. (2023). Feasibility and diagnostics of the Frontal Assessment Battery (FAB) in amyotrophic lateral sclerosis. *Neurological Sciences*, 44(2), 587-592.

Consider This

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### ALS Specific Tools

#### Edinburgh Cognitive and Behavioral ALS Screen (ECAS)

- Executive functions, memory, language, visuospatial skills and social cognition
- Accounts for communication limitations to gather responses.

#### ALS Cognitive Behavioral Screen (ALS-CBS)

- Cognition assessment
- Attention, concentration, mental tracking, and verbal fluency
- Behavioral interview with caregiver
- Empathy, personality, judgment, language, and insight

Didcote, L., et al. (2024). What is the extent of reliability and validity evidence for screening tools for cognitive and behavioral change in people with ALS? A systematic review. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 25(5-6), 437-451.

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### Pharmacotherapy

- Disease-modifying therapies are intended to slow functional decline.
- Medications to manage symptoms.

|                    |                   |                  |
|--------------------|-------------------|------------------|
| Anxiety Depression | Sleep Disturbance | Sialorrhea Mucus |
| Cognition Behavior | Spasticity Cramps | Pain             |

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### Medication Side Effects

- Narcotics
  - Respiratory depression
- Diuretics
  - Dehydration, constipation
- Disease modifying medications
  - Taste changes
- Anticholinergics
  - Drowsiness, constipation

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### A-LS-PIKES Protocol

- Supports compassionate, clear communication for navigating complex and sensitive patient conversations.

|    |                       |
|----|-----------------------|
| A  | Advance preparation   |
| LS | Location and setting  |
| P  | Patient's perceptions |
| I  | Invitation            |
| K  | Knowledge             |
| E  | Emotion and empathy   |
| S  | Strategy and summary  |

O'Connell, C., et al. (2025). How to break the news in amyotrophic lateral sclerosis/motor neuron disease: practical guidelines from experts. *Amyotrophic Lateral Sclerosis and Frontotemporal Degeneration*, 26(1-2), 5-14.

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### Patient Preferences and End of Life

- Eating and Drinking with Acknowledged Risks (EDAR)
- Cognition may impact treatment decisions and compliance.
- Hospice care and dignity therapy

|                                                                                                                                                    |                                                                                                                                          |                                                                                                                                                   |                                                                                                                                            |                                                                                                                                                                    |
|----------------------------------------------------------------------------------------------------------------------------------------------------|------------------------------------------------------------------------------------------------------------------------------------------|---------------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------|--------------------------------------------------------------------------------------------------------------------------------------------------------------------|
| <b>Ease of Use</b><br><br>Simple, low physical / cognitive strain | <b>Accessibility</b><br><br>Affordable, easy, adaptable | <b>Making Life Easier</b><br><br>Symptom relief, reducing burden | <b>Autonomy</b><br><br>Loss of control, personal identity | <b>Safety &amp; Reliability</b><br><br>Low risk, security for unpredictable needs |
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Chir, A., et al. (2025). A Systematic Review of Attributes Influencing Preferences for Treatments and Interventions in People With Amyotrophic Lateral Sclerosis (ALS). Muscle & Nerve.

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### Conclusion

- While ALS remains a life-limiting disease, clinicians play a vital role in preserving dignity, prolonging function, and supporting meaningful participation for people living with ALS through compassionate, person-centered care.

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- Which of the following best describes Amyotrophic Lateral Sclerosis?
  - Autoimmune demyelinating disorder of the central nervous system
  - Progressive neurodegenerative disease of central and peripheral nervous system
  - Chronic inflammatory condition of the peripheral nerves
  - Reversible muscular disorder with episodic weakness

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- Approximately what percentage of the cases of ALS are familial/hereditary?
  - 10%
  - 30%
  - 60%
  - 90%

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- Which of the following environmental risk factors has been associated with the development of ALS?
  - Smoking
  - Microplastics
  - Head injury
  - Sedentary lifestyle

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- Which imaging modality measures water diffusion in the brain to identify white-matter microstructural damage?
  - DTI
  - Ultrasound
  - EMG
  - MRI

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5. Early clinical signs of ALS typically include:
- A. Sensory loss and paresthesia
  - B. Asymmetrical weakness and fasciculations
  - C. Seizures and myoclonus
  - D. Cognitive decline and apathy

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6. Which domain is not assessed on the ALS Functional Rating Scale (ALSF<sub>RS</sub>-R)?
- A. Emotional lability
  - B. Speech
  - C. Fine motor tasks
  - D. Respiratory function

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7. What is the primary goal of respiratory training?
- A. Prevent aspiration during meals
  - B. Improve oxygen saturation at rest
  - C. Eliminate the need for non-invasive ventilation
  - D. Delay the onset of ventilatory failure

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8. Why is early screening for dysphagia critical in ALS management?
- A. Avoids overuse jaw injuries
  - B. Ensures tongue strength for speech
  - C. Minimizes risk of pneumonia due to aspiration
  - D. Prevents TMJ dysfunction

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9. Why is hypercaloric nutrition often recommended?
- A. Offset increased cholesterol production
  - B. Support neural remyelination
  - C. Reduce oxidative muscle metabolism
  - D. Counteract muscle wasting and weight loss

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10. The FAB can help identify what type of cognitive deficits?
- A. Visual memory
  - B. Frontal executive function
  - C. Language comprehension
  - D. Procedural memory

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## Amyotrophic Lateral Sclerosis: Management Across the Disease Continuum

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