Accommodation and Compliance Series: Employees with Amyotrophic Lateral Sclerosis (ALS)/Lou Gehrig's Disease

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Preface

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Introduction

JAN’s Accommodation and Compliance Series is designed to help employers determine effective accommodations and comply with Title I of the Americans with Disabilities Act (ADA). Each publication in the series addresses a specific medical condition and provides information about the condition, ADA information, accommodation ideas, and resources for additional information.

The Accommodation and Compliance Series is a starting point in the accommodation process and may not address every situation. Accommodations should be made on a case by case basis, considering each employee’s individual limitations and accommodation needs. Employers are encouraged to contact JAN to discuss specific situations in more detail.

For information on assistive technology and other accommodation ideas, visit JAN’s Searchable Online Accommodation Resource (SOAR) at https://askjan.org/soar.

Information about ALS/Lou Gehrig's Disease

Amyotrophic lateral sclerosis (ALS), often referred to as "Lou Gehrig's disease," is a progressive neurodegenerative disease that attacks nerve cells in the brain and the spinal cord. ALS is a progressive neurodegenerative disease affecting the nerve cells of the spinal cord and brain. As ALS progresses, the motor neurons that span from the brain to the spinal cord to the muscles are destroyed, leading to loss of muscle control. This can lead to involuntary muscle movements as well as the inability to speak, swallow, and breathe. Two types of ALS are known: Familial (which is inherited) and Sporadic. Sporadic is the most common, comprising almost 95% of ALS cases. Around 20,000 people in the US have ALS and most are diagnosed between the ages of 40 and 70.

ALS/Lou Gehrig's Disease and the Americans with Disabilities Act

The ADA does not contain a list of medical conditions that constitute disabilities. Instead, the ADA has a general definition of disability that each person must meet. A person has a disability if he/she has a physical or mental impairment that substantially limits one or more major life activities, a record of such an impairment, or is regarded as having an impairment. For more information about how to determine whether a person has a disability under the ADA, see How to Determine Whether a Person Has a Disability under the Americans with Disabilities Act Amendments Act (ADAAA).
Accommodating Employees with ALS/Lou Gehrig's Disease

People with limitations from ALS may develop some of the limitations discussed below, but seldom develop all of them. Also, the degree of limitation will vary among individuals. Be aware that not all people with ALS will need accommodations to perform their jobs and many others may only need a few accommodations. The following is only a sample of the possibilities available. Numerous other accommodation solutions may exist.

Questions to Consider:

1. What limitations is the employee experiencing?
2. How do these limitations affect the employee and the employee’s job performance?
3. What specific job tasks are problematic as a result of these limitations?
4. What accommodations are available to reduce or eliminate these problems? Are all possible resources being used to determine possible accommodations?
5. Has the employee been consulted regarding possible accommodations?
6. Once accommodations are in place, would it be useful to meet with the employee to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
7. Do supervisory personnel and employees need training?

Accommodation Ideas:

Limitations

Decreased Stamina/Fatigue
- Aide/Assistant/Attendant
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic Assessments
- Ergonomic Equipment
- Flexible Schedule
- Job Restructuring
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchairs
- Worksite Redesign / Modified Workspace

**Overall Body Coordination**

- Canes
- Personal Transportation and Mobility Products
- Rollators and Rolling Walkers
- Scooters
- Walkers
- Walkers with Seats

**Overall Body Weakness/Strength**

- Independent Living
  - Aide/Assistant/Attendant
  - Grab Bars
  - Independent Living Aids
  - Personal Safety and Fall Alert Devices
  - Toileting Aids

- Mobility Aids
  - Scooters
  - Walkers
  - Wheelchairs

- Office Equipment
  - Anti-fatigue Matting
  - Compact Material Handling
  - Ergonomic and Adjustable Office Chairs
  - Forearm Supports
  - Multi-Purpose Carts
- Stair Lifts
- Stand-lean Stools
- Wearable Anti-fatigue Matting
- Worksite Redesign / Modified Workspace
- Other
  - Modified Break Schedule
  - Periodic Rest Breaks
  - Telework, Work from Home, Working Remotely

Spasm/Tic/Tremor/Blinking
  - Access Information
    - Alternative Input Devices
    - Alternative Keyboards
    - Alternative Mice
    - Ergonomic Equipment
    - Expanded Keyboards
    - Forearm Supports
    - Keyguards
    - On-Screen Keyboards
    - One-Handed Keyboards
    - Speech Recognition Software
    - Switches
    - Tongue Touch Keyboards/Mice
    - Typing / Keyboarding Aids
    - Word Prediction/Completion and Macro Software
  - Gripping and Grasping
    - Book Holders
    - Door Knob Grips and Handles
    - Eating Aids
    - Ergonomic and Pneumatic Tools
    - Extra Grip Gloves
    - Grip Aids
• Money Handling Products
• Page Turners
• Scribe/Notetaker
• Tool Balancers
• Writing Aids

• Lifting
  • Compact Material Handling
  • Vacuum Lifts
  • Vacuum Pickup Tools

• Other
  • Aide/Assistant/Attendant
  • Job Restructuring
  • Padded Edging

• Phone
  • Auto-dialers
  • Hands-free Telephones
  • Outgoing Voice Amplification - Telephone

Stress Intolerance
• Apps for Anxiety and Stress
• Behavior Modification Techniques
• Counseling/Therapy
• Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
• Flexible Schedule
• Job Restructuring
• Marginal Functions
• Modified Break Schedule
• Supervisory Methods
• Support Animal
• Support Person
**Work-Related Functions**

**Access Information**

- Accessible Mobile Phones
- Accessible Telephones
- Adjustable Desk Top Workstations for Office Settings
- Aide/Assistant/Attendant
- Alternative Input Devices
- Alternative Keyboards
- Alternative Mice
- Alternative Mice - Limiting Tremors
- Breath and Mouth Controlled Alternative Computer Input Devices
- Eye Controlled Alternative Computer Input Devices
- Head Controlled Alternative Computer Input Devices
- Keyguards
- Large Button Phones
- On-Screen Keyboards
- One-Handed Keyboards
- Prism Glasses/Bed Spectacles
- Screen Reading Software and Training

**Communicate**

- In-Person/Remote
  - Aide/Assistant/Attendant
  - Assistive Listening Devices (personal)
  - Assistive Listening Devices and Sound Field System
  - Augmentative and Alternative Communication (AAC) Device
  - Bone Conduction Technology
  - CART Services - Remote
  - CART Services
  - Interpreters
  - Neckloops
• On-site Mentoring
• Verbal Responses
• Video Remote Interpreting Services (VRI)

• Other
• Word Prediction/Completion and Macro Software
• Writing/Editing Software

• Phone
• Accessible Telephones
• Bluetooth Products
• Braille Telephones
• Braille TTY
• Captioned Telephone Calls
• Cellular Telephone Technology: Deaf & Hard of Hearing
• Hands-free Telephones
• Headsets - Computer (USB, VOIP etc.)
• Headsets - Hearing Aid Compatible, Amplification
• Outgoing Voice Amplification - Telephone
• Hearing Carry Over (HCO) TTYs
• Telecoil Compatible Headsets
• Talking Telephones
• Telephone Amplification
• TTYs (Text Telephones)
• Voice Amplification
• Voice-Carry-Over (VCO) Telephones
• Video Relay Services (VRS)

Commute
• Flexible Schedule
• Ridesharing/Carpooling
• Telework, Work from Home, Working Remotely
• Transportation Assistance
Manipulate Items

- Aerial Lifts
- Anti-vibration Gloves
- Anti-vibration Tool Wraps
- Auto-dialers
- Automatic Door Openers
- Compact Mobile Cranes
- Ergonomic and Pneumatic Tools
- Grip Aids
- Tool Balancers
- Vacuum Lifts
- Vacuum Pickup Tools

Move Items/People

- Adjustable Exam Tables
- Aerial Lifts
- Animal Lift Tables
- Ball Transfer Tables
- Battery Powered Lift Tables
- Carts
- Compact Material Handling
- Compact Mobile Cranes
- Lifting Aids
- Multi-Purpose Carts
- Proper Lifting Techniques
- Vacuum Lifts
- Vacuum Pickup Tools
- Walk-up Changing Tables

Off Site Access

- Accessible Vehicles
- All-Terrain Scooters
- All-Terrain Wheelchairs
- Flexible Schedule
- Personal Transportation and Mobility Products
- Scooters
- Telework, Work from Home, Working Remotely
- Transportation Assistance

**Operate Equipment/Vehicles**
- Anti-vibration Gloves
- Anti-vibration Seats
- Anti-vibration Tool Wraps
- Ergonomic Equipment
- Gear Shift Adapter/Extension
- Hand Controls
- Swivel Seats and Seat Extenders
- Vehicle Rear Vision System
- Wheelchair Lifts

**Parking**
- Accessible Parking Space
- Flexible Schedule
- Telework, Work from Home, Working Remotely
- Wheelchairs

**Policies**
- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Flexible Schedule
- Marginal Functions
- Modified Break Schedule
- Periodic Rest Breaks
- Policy Modification
- Reassignment
• Service Animal
• Supervisory Methods
• Support Animal
• Telework, Work from Home, Working Remotely

Stress
• Apps for Anxiety and Stress
• Behavior Modification Techniques
• Counseling/Therapy
• Flexible Schedule
• Job Restructuring
• Marginal Functions
• Modified Break Schedule
• Monitor Mirrors
• On-site Mentoring
• Service Animal
• Simulated Skylights and Windows
• Supervisory Methods
• Support Animal
• Support Person
• Telework, Work from Home, Working Remotely
• Uninterrupted Work Time

Work Site Access
• Accessible Toilets and Toilet Seats
• Adjustable Workstations for Industrial Settings
• Adjustable Workstations for Office Settings
• Alternative Locks
• Anti-fatigue Matting
• Braille and/or ADA Signage
• Building Accessibility Products
• Door Knob Grips and Handles
• Flexible Schedule
• Portable Ramps
• Ramps
• Scooters
• Service Animal
• Support Animal
• Telework, Work from Home, Working Remotely
• Wearable Anti-fatigue Matting
• Wheelchair Lifts
• Wheelchairs
• Worksite Redesign / Modified Workspace

Work Station Access
• Adjustable and Ergonomic School Desks and Equipment
• Adjustable Desk Top Workstations for Office Settings
• Adjustable Workstations for Industrial Settings
• Anti-fatigue Matting
• Articulating Keyboard Trays
• Assist Lift Cushions
• Chair Mats
• Chairs for Little People
• Chairs for People who are Tall
• Dual Monitors
• Elevating Lift and Office Chairs
• Ergonomic and Adjustable Office Chairs
• Ergonomic Equipment
• Expanded Keyboards
• Forearm Supports
• Forward Leaning Chairs
• Large-Rated Chairs
• Monitor Mirrors
• Monitor Risers
- Mousing Surfaces
- Stand-lean Stools
- Supine Workstations
- Work Platforms
- Zero Gravity (reclining) Chairs
Situations and Solutions:

A customer service representative for a financial institution had ALS and his symptoms were being exacerbated by stress.
The noisy work environment and commute to work brought on additional stress to the employee. After calling JAN and better understanding its obligation to accommodate, the employer permitted this employee to work at home. The employee was able to continue working without exacerbating his condition.

A clerk at a local government was experiencing weakening speech due to Lou Gehrig’s disease.
Her job required her to communicate to coworkers and the public. Following a JAN consultation, the employer ended up providing the employee with a portable text communication device along with an Augmentative and Alternative Communication (AAC) Device which enabled her to communicate effectively in the workplace.

A university had offered a nursing instructor position to an applicant with ALS who used a wheelchair.
The university called JAN to better understand what modifications they needed to make to the physical work-site and learn what products could be used for the new hire. JAN suggested automatic door openers, a height adjustable table to teach from, and explained parking as a reasonable accommodation under the ADA.

An office worker in a hospital was experiencing muscle weakness in his neck and arms due to ALS
His employer called JAN looking for product ideas, specifically information on ergonomic chairs with a high back, neck rest, and arm rests. JAN was able to e-mail a vendor list for equipment so the employer could make an informed decision.

An insurance underwriter with ALS had general body weakness, he was no longer able to work in the standard office workstation.
The employer purchased a supine workstation which enabled the employee to continue to do his job from the reclined position. This permitted the employer to retain a qualified employee and helped maintain productivity.

Products

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource at https://askjan.org/soar is designed to let users explore various accommodation options. Many product vendor lists are accessible through this system; however, JAN provides these lists and many more that are not available on the Web site upon request. Contact JAN directly if you have specific accommodation situations, are looking for products, need vendor information, or are seeking a referral.
Resources

Job Accommodation Network
West Virginia University
PO Box 6080
Morgantown, WV 26506-6080
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TTY: (304) 293-7186
Fax: (304) 293-5407
jan@askjan.org
http://AskJAN.org

The Job Accommodation Network (JAN) is a free consulting service that provides information about job accommodations, the Americans with Disabilities Act (ADA), and the employability of people with disabilities.

Office of Disability Employment Policy
200 Constitution Avenue,
NW, Room S-1303
Washington, DC 20210
Toll Free: (866) 633-7365
odep@dol.gov
http://dol.gov/odep

The Office of Disability Employment Policy (ODEP) is an agency within the U.S. Department of Labor. ODEP provides national leadership to increase employment opportunities for adults and youth with disabilities while striving to eliminate barriers to employment.
The ALS Association is the only national non-profit organization fighting Lou Gehrig’s Disease on every front. By leading the way in global research, providing assistance for people with ALS through a nationwide network of chapters, coordinating multidisciplinary care through certified clinical care centers, and fostering government partnerships, The Association builds hope and enhances quality of life while aggressively searching for new treatments and a cure.

The Centers for Disease Control and Prevention are dedicated to protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

The Charlie Foundation for Ketogenic Therapies was founded in 1994 to provide information about diet therapies for people with epilepsy, other neurological disorders and tumorous cancers.
The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

Genetic and Rare Diseases Information Center (GARD)
P.O. Box 8126
Gaithersburg, MD 20898-8126
Toll Free: (888) 205-2311
Fax: (301) 251-4911
https://rarediseases.info.nih.gov/

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences (NCATS) and funded by two parts of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

MedlinePlus
8600 Rockville Pike
Bethesda, MD 20894
custserv@nlm.nih.gov
https://www.nlm.nih.gov/medlineplus/

MedlinePlus is the National Institutes of Health’s Web site for patients and their families and friends. Produced by the National Library of Medicine, the world’s largest medical library, it brings you information about diseases, conditions, and wellness issues in
language you can understand. MedlinePlus offers reliable, up-to-date health information, anytime, anywhere, for free.

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The NINDS, an agency of the U.S. Federal Government and a component of the National Institutes of Health and the U.S. Public Health Service, is a lead agency for the congressionally designated Decade of the Brain, and the leading supporter of biomedical research on disorders of the brain and nervous system.

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National Jewish Health is known worldwide for treatment of patients with respiratory, cardiac, immune and related disorders, and for groundbreaking medical research. Founded in 1899 as a nonprofit hospital, National Jewish Health remains the only facility in the world dedicated exclusively to these disorders. *U.S. News & World Report* has ranked National Jewish Health as the number one or number two hospital in pulmonology on its Best Hospitals list ever since pulmonology was included in the rankings.
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