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

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Preface

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JAN does not endorse or recommend any products or services mentioned in this publication. Although every effort is made to update resources, JAN encourages contacting product manufacturers/vendors and service providers directly to ensure that they meet the intended purposes. This guarantees that the most up-to-date information is obtained.

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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 definitive list of medical conditions that constitute disabilities. Instead, the ADA defines a person with a disability as someone who (1) has a physical or mental impairment that substantially limits one or more "major life activities," (2) has a record of such an impairment, or (3) is regarded as having such 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. 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?
6. Do supervisory personnel and employees need training?

Accommodation Ideas:

Limitations

Decreased Stamina/Fatigue

- Accessories for Scooters
- Aide/Assistant/Attendant
- All-Terrain Scooters
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic and Pneumatic Tools
- Ergonomic Assessments
- Ergonomic Equipment
- Examination and Procedures Chair
- Flexible Schedule
- Head Support for Wheelchairs
- Job Restructuring
- Low Task Chair
- Mechanic's Seats and Creepers
- Multi-Purpose Carts
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Overall Body Coordination
- Canes
- Convex Mirrors
- Ergonomic and Pneumatic Tools
- Long-Handled Mirrors
- Personal Transportation and Mobility Products
- Rollators and Rolling Walkers
- Scooters
- Telescoping Cameras
- 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 Support
  • 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 Support
  • 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
  • Interpreter
  • 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

Practical Solutions • Workplace Success
• 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
• Van Conversion

Manipulate Items
• Adjustable Drafting Tables
• Adjustable Massage Tables
• Aerial Lifts
• Anti-vibration Gloves
• Anti-vibration Tool Wraps
• Auto-dialers
• Automated Filing Systems
• Automatic Door Openers
• Cake Decorating and Baking Equipment
• Compact Mobile Cranes
• Deburring Tools
• Electric Scissors
• Electric Stapler
• Electronic Organizers
• Ergonomic and Pneumatic Tools
• Folding Steps
- Graphics Design Software
- Grip Aids
- Hair Scissors
- Height Adjustable Table Legs
- Large-Rated Small Step Ladders
- Light Switch Extension Handles
- Mechanic’s Seats and Creepers
- Pickups, Semis, and Heavy Equipment
- Pipettes
- Professional Organizers
- Proper Sitting / Standing Techniques
- Rolling Safety Ladders
- Sewing Aids for Individuals with Vision Impairment
- Stair Assists
- Stools for Cutting Hair
- Talking Bar Code Scanner/Reader
- Talking Money Identifier
- Test Tube Holders
- Tool Balancers
- Vacuum Lifts
- Vacuum Pickup Tools
- Wheelchair Trays

Move Items/People
- Adjustable Exam Tables
- Aerial Lifts
- Animal Lift Tables
- Ball Transfer Tables
- Battery Powered Lift Tables
- Cake Decorating and Baking Equipment
- Carts
- Compact Material Handling
• Compact Mobile Cranes
• Engine Lifts and Lift Plates
• Ergonomic and Pneumatic Tools
• Grab Bars - Toilet Hinged Arm Support
• Hair Scissors
• Large-Rated Small Step Ladders
• Lifting Aids
• Light Switch Extension Handles
• Manhole Cover Lifts
• Multi-Purpose Carts
• Pickups, Semis, and Heavy Equipment
• Pipettes
• Pool Lifts
• Proper Lifting Techniques
• Rolling Safety Ladders
• Spring-Loaded Carts
• Stainless Steel Carts and Worktables
• Swing Away Grab Bars
• Tire Handling
• Transfer Aids
• Transfer Sheets
• Trashcans
• Vacuum Lifts
• Vacuum Pickup Tools
• Walk-up Changing Tables

Off Site Access
• Accessible Vehicles
• Accessories for Scooters
• All-Terrain Scooters
• All-Terrain Wheelchairs
• Examination and Procedures Chair
• Flexible Schedule
• Head Support for Wheelchairs
• Low Task Chair
• Personal Transportation and Mobility Products
• Scooters
• Stair Assists
• Telework, Work from Home, Working Remotely
• Transportation Assistance
• Van Conversion
• Wheelchair Accessible Scales
• Wheelchair Carts/Trailers
• Wheelchair Mounts

Operate Equipment/Vehicles
• Adjustable Drafting Tables
• Adjustable Massage Tables
• Anti-vibration Gloves
• Anti-vibration Seats
• Anti-vibration Tool Wraps
• Breath and Mouth Controlled Alternative Computer Input Devices
• Convex Mirrors
• Deburring Tools
• Ergonomic and Pneumatic Tools
• Ergonomic Equipment
• Gear Shift Adapter/Extension
• Hand Controls
• Head Controlled Alternative Computer Input Devices
• Height Adjustable Table Legs
• Joystick Driving Systems
• Long-Handled Mirrors
• Mechanic's Seats and Creepers
• Pickups, Semis, and Heavy Equipment
- Proper Sitting / Standing Techniques
- Seat Belts & Seat Belt Extenders
- Swivel Seats and Seat Extenders
- Talking Cash Register
- Talking Coin Counter/Sorter
- Talking Credit Card Terminal
- Telephone Flasher
- Telescoping Cameras
- Van Conversion
- 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
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Marginal Functions
- Modified Break Schedule
- Periodic Rest Breaks
- Physical/Social Distancing Signage
- Policy Modification
- Reassignment
- Service Animal
- Sleep Alerting Devices
- Strobe Lights
• Supervisory Methods
• Support Animal
• Telework, Work from Home, Working Remotely
• Touchless Faucets

Stress
• Apps for Anxiety and Stress
• Behavior Modification Techniques
• Counseling/Therapy
• Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
• Flexible Schedule
• Job Coaches
• Job Restructuring
• Marginal Functions
• Modified Break Schedule
• Monitor Mirrors
• Odor Control
• On-site Mentoring
• Service Animal
• Simulated Skylights and Windows
• Strobe Lights
• Supervisory Methods
• Support Animal
• Support Person
• Telework, Work from Home, Working Remotely
• Uninterrupted Work Time

Work Site Access
• Accessible Toilets and Toilet Seats
• Accessories for Scooters
• Adjustable Workstations for Industrial Settings
• Adjustable Workstations for Office Settings
• All-Terrain Scooters
• Anti-fatigue Matting
• Automatic Door Openers
• Boat Access
• Braille and/or ADA Signage
• Door Knob Grips and Handles
• Examination and Procedures Chair
• Flexible Schedule
• Head Support for Wheelchairs
• High Visibility Floor Tape and Paint
• Low Task Chair
• Portable Ramps
• Ramps
• Scooters
• Service Animal
• Smart Locks/Keyless Entry Locks
• Stair Assists
• Stair Tread/Textured Tape
• Support Animal
• Telework, Work from Home, Working Remotely
• Van Conversion
• Walkers
• Wearable Anti-fatigue Matting
• Wheelchair Accessible Scales
• Wheelchair Carts/Trailers
• Wheelchair Lifts
• Wheelchair Mounts
• Wheelchairs
• Worksite Redesign / Modified Workspace

Work Station Access
• Accessories for Scooters
• Adjustable and Ergonomic School Desks and Equipment
• Adjustable Desk Top Workstations for Office Settings
• Adjustable Workstations for Industrial Settings
• All-Terrain Scooters
• Anti-fatigue Matting
• Articulating Keyboard Trays
• Assist Lift Cushions
• Automatic Door Openers
• 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
• Examination and Procedures Chair
• Expanded Keyboards
• Forearm Support
• Forward Leaning Chairs
• Head Support for Wheelchairs
• Large-Rated Chairs
• Low Task Chair
• Monitor Mirrors
• Monitor Risers
• Mousing Surfaces
• Proper Sitting / Standing Techniques
• Stair Assists
• Stand-lean Stools
• Supine Workstations
• Van Conversion
• Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs
- Work Platforms
- Zero Gravity (reclining) Chairs
Situations and Solutions:

The following situations and solutions are real-life examples of accommodations that were made by JAN customers. Because accommodations are made on a case-by-case basis, these examples may not be effective for every workplace but give you an idea about the types of accommodations that are possible.

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
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TTY: (304) 293-7186
Fax: (304) 293-5407
jan@askjan.org
https://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
https://www.dol.gov/agencies/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.

**ALS Association**
1275 K Street NW
Suite 250
Washington, DC 20005
Toll Free: (800) 782-4747
Fax: (202) 289-6801
alsinfo@alsa-national.org
http://www.alsa.org
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.

**Centers for Disease Control and Prevention**
1600 Clifton Rd
Atlanta, GA 30333
Toll Free: (800) 232-4636
https://www.cdc.gov/

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.

**Charlie Foundation for Ketogenic Therapies**
515 Ocean Ave.
#602N
Santa Monica, CA 90402
Direct: (310) 393-2347
http://www.charliefoundation.org/

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.
Christopher & Dana Reeve Foundation
636 Morris Turnpike
Suite 3A
Short Hills, NJ 07078
Toll Free: (800) 225-0292
Direct: (973) 379-2690
TeamReeve@ChristopherReeve.org
http://www.christopherreeve.org/site/c.ddJFKRNoiFiG/b.4048063/k.67BA/The_Christopher_amp_Dana_Reeve_Foundation__Paralysis_amp_Spinal_Cord_Injury.htm

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://medlineplus.gov

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.

**National Center for Biotechnology Information**
8600 Rockville Pike
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pubmedcentral@ncbi.nlm.nih.gov

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

**National Institute of Neurological Disorders and Stroke**
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http://www.ninds.nih.gov

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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