

# **Accommodation and Compliance Series**

# Accommodation and Compliance Series: Ehlers-Danlos Syndrome

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# Preface

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## JAN'S Accommodation and Compliance Series

# 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 <a href="https://askJAN.org/soar">https://askJAN.org/soar</a>.

# Information about Ehlers-Danlos Syndrome

Ehlers-Danlos syndrome is a rare genetic disorder that affects connective tissues and results in flexible joints, elastic skin, and fragile tissues. There are several variations of the syndrome with each affecting a different gene and producing different signs and symptoms. Joint hypermobility is the dominant clinical manifestation. Some types of EDS are characterized by weaknesses in the walls of the hollow organs of the gastrointestinal tract, in the esophagus, the cardiovascular system, uterus, bladder, blood vessels, and the arteries. Ehlers-Danlos syndrome can alter the body's response to injury. Complications such as joint dislocations, early-onset arthritis, and damaged skin can result. Although there is no cure for Ehlers-Danlos syndrome, injuries can be treated and preventative measure can be taken to mitigate chances of injury. Ehlers-Danlos syndrome is a lifelong condition and for those working, accommodations may be needed.

# Ehlers-Danlos Syndrome 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 <u>How to Determine Whether a Person Has a Disability</u> under the Americans with Disabilities Act Amendments Act (ADAAA).

# Accommodating Employees with Ehlers-Danlos Syndrome

People with Ehlers-Danlos syndrome 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 Ehlers-Danlos syndrome 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

Lifting

- Agriculture/Farm
  - Animal Lift Tables
  - Carts
  - Compact Mobile Cranes
- Industrial
- Aerial Lifts
- Ball Transfer Tables
- Battery Powered Lift Tables
- Drum Handling
- Engine Lifts and Lift Plates

- Lift Gates
- Rolling Safety Ladders
- Stairclimbing Handtrucks
- Truck Mounted Cranes
- Vacuum Lifts
- Vehicle Lifts and Manipulators
- Winches and Chain Hoists
- Work Platforms
- Office or Retail Goods
  - Carts
  - Compact Material Handling
  - Ergonomic Assessments
  - Ergonomic Equipment
  - Height Adjustable Table Legs
  - Low Task Chair
  - Stairclimbing Handtrucks
- Other
- Drywall and Wallboard Lifts
- Ergonomic Equipment
- Independent Living Aids
- Job Restructuring
- Lifters and Carriers for Mobility Aids
- Lifting Aids
- Manhole Cover Lifts
- Periodic Rest Breaks
- Power Lift IV Stands
- Proper Lifting Techniques
- People
- Accessible Baby Changing Stations
- Adjustable Exam Tables
- Adult Changing Tables

- Bath Chairs
- Evacuation Devices
- Large-Rated Wheelchair Lifts
- Powered Bath Lifts
- Patient Lifts (General)
- Pool Lifts
- Transfer Aids
- Transfer Sheets
- Wheelchair Lifts

## Skin Rash/Blisters/Sores

- Alternative Cleaning Supplies
- Augmentative and Alternative Communication (AAC) Device
- Disability Awareness/Etiquette Training
- Job Restructuring
- Odor Control
- Outgoing Voice Amplification Telephone
- Policy Modification
- Touchless Faucets
- Voice Amplification

## Standing

- Accessories for Scooters
- Adjustable Drafting Tables
- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- All-Terrain Scooters
- Anti-fatigue Matting
- Assist Lift Cushions
- Elevating Lift and Office Chairs
- Ergonomic and Pneumatic Tools
- Examination and Procedures Chair

- Flexible Schedule
- Grab Bars
- Handheld Computers (General)
- Head Support for Wheelchairs
- Low Task Chair
- Periodic Rest Breaks
- Proper Sitting / Standing Techniques
- Scooters
- Stair Assists
- Stand Aids
- Stand-lean Stools
- Stand-up Wheelchairs
- Stools for Cutting Hair
- Van Conversion
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- Wheelchairs

Toileting/Grooming Issue

- Accessible Toilets and Toilet Seats
- Aide/Assistant/Attendant
- Flexible Schedule
- Grab Bars Toilet Hinged Arm Support
- Grooming and Dressing Aids
- Independent Living Aids
- Modified Break Schedule
- Swing Away Grab Bars
- Telework, Work from Home, Working Remotely
- Toileting Aids
- Transfer Aids

- Transfer Sheets
- Worksite Redesign / Modified Workspace

#### Walking

- Accessories for Scooters
- Aide/Assistant/Attendant
- All-Terrain Scooters
- All-Terrain Wheelchairs
- Anti-fatigue Matting
- Boat Access
- Ergonomic and Pneumatic Tools
- Examination and Procedures Chair
- Foldable / Transport Wheelchairs
- Head Support for Wheelchairs
- Large-Rated Scooters
- Large-Rated Wheelchairs
- Low Task Chair
- Personal Transportation and Mobility Products
- Reclining Wheelchairs
- Rollators and Rolling Walkers
- Scooters
- Scooters for Small Stature
- Stair Assists
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Van Conversion
- Walkers
- Walkers for Tall Individuals
- Walkers with Seats
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers

- Wheelchair Mounts
- Wheelchairs
- Wheelchairs for Small Stature
- Worksite Redesign / Modified Workspace

### **Work-Related Functions**

## Commute

- Flexible Schedule
- Ridesharing/Carpooling
- Telework, Work from Home, Working Remotely
- Transportation Assistance
- Van Conversion

#### Parking

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

#### 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.

# **Products**

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource at <a href="https://AskJAN.org/soar">https://AskJAN.org/soar</a> 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 Toll Free: (800) 526-7234 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.

#### **Genetics Home Reference**

https://ghr.nlm.nih.gov/

Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health.

Mayo Clinic 13400 E. Shea Blvd. Scottsdale, AZ 85259 Direct: (480) 301-8000 http://www.mayoclinic.org/

The Mayo Clinic's mission to inspire hope and contribute to health and well-being by providing the best care to every patient through integrated clinical practice, education and research.

The Ehlers-Danlos Society P.O. Box 87463 Montgomery Village, MD 20886 info@ehlers-danlos.com https://www.ehlers-danlos.com/

The Ehlers-Danlos Society is a global community of patients, caregivers, health care professionals, and supporters, dedicated to saving and improving the lives of those affected by the Ehlers-Danlos syndromes, hypermobility spectrum disorders, and related conditions.

We support collaborative research and education initiatives, awareness campaigns, advocacy, community-building, and care for the EDS and HSD population.

Our goals are world-wide awareness—and a better quality of life for all who suffer from these conditions. Research is at the center of what we do, so that one day we will have a cure. Our strength begins with hope.

The Ehlers-Danlos Society was originally established as a nonprofit organization in 1985 as the Ehlers-Danlos National Foundation (EDNF) by Nancy Hanna Rogowski (1957–1995).

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