

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Ehlers- Danlos Syndrome

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Funded by a contract with the Office of Disability
Employment Policy, U.S. Department of Labor

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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Updated 08/14/2019.

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 <https://askjan.org/soar>.

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 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 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. 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

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
- Disability Awareness/Etiquette Training
- Job Restructuring
- Policy Modification

Standing

- Adjustable Workstations for Industrial Settings
- Adjustable Workstations for Office Settings
- Anti-fatigue Matting
- Assist Lift Cushions
- Elevating Lift and Office Chairs
- Flexible Schedule
- Grab Bars
- Periodic Rest Breaks
- Scooters
- Stand Aids
- Stand-lean Stools
- Stand-up Wheelchairs
- Wearable Anti-fatigue Matting

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
- Worksite Redesign / Modified Workspace

Walking

- Aide/Assistant/Attendant
- All-Terrain Scooters
- All-Terrain Wheelchairs
- Anti-fatigue Matting
- Foldable / Transport Wheelchairs
- Large-Rated Scooters
- Large-Rated Wheelchairs
- Personal Transportation and Mobility Products
- Reclining Wheelchairs
- Rollators and Rolling Walkers
- Scooters
- Scooters for Small Stature
- Telework, Work from Home, Working Remotely
- Walkers
- Walkers for Tall Individuals
- Walkers with Seats
- Wearable Anti-fatigue Matting
- 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

Parking

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

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

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
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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.

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

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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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