Accommodation and Compliance Series: Ehlers-Danlos Syndrome

Job Accommodation Network
PO Box 6080
Morgantown, WV 26506-6080
(800)526-7234 (V)
(877)781-9403 (TTY)
jan@askjan.org
AskJAN.org

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

The Job Accommodation Network (JAN) is funded by a contract with the Office of Disability Employment Policy, U.S. Department of Labor. JAN makes documents available with the understanding that the information be used solely for educational purposes. The information is not intended to be legal or medical advice. If legal or medical advice is needed, appropriate legal or medical services should be contacted.

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.

The following document is not copyrighted and reproduction is encouraged. Section 105 of the Copyright Law provides that no copyright protection is available for works created by the U.S. Government. Therefore, all works created by JAN fall under this provision. While individuals may use such work with impunity, individuals may not claim copyright in the original government work, only in the original material added. Individuals may access the full text of the law from the U.S. Copyright Office https://www.loc.gov/copyright. Please note that specific information cited by JAN may be copyrighted from other sources. Citing secondary sources from a JAN publication may violate another organization's or individual's copyright. Permission must be obtained from these sources on a case-by-case basis. When using JAN materials, JAN asks that the materials not be reproduced for profit, that the tone and substance of the information are not altered, and that proper credit is given to JAN as the source of the information. For further information regarding this or any other document provided by JAN, please contact JAN.

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

Commutte
• 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
PO Box 6080
Morgantown, WV 26506-6080
Toll Free: (800) 526-7234
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.

**Genetics Home Reference**

Genetics Home Reference provides consumer-friendly information about the effects of genetic variation on human health.
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).
This document was developed by the Job Accommodation Network, funded by a contract from the U.S. Department of Labor, Office of Disability Employment Policy (#1605DC-17-C-0038). The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Labor. Nor does mention of tradenames, commercial products, or organizations imply endorsement by the U.S. Department of Labor.