A to Z By Disability: Dystonia
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 https://AskJAN.org/soar.

Information about Dystonia

The term dystonia refers to movement disorders characterized by involuntary muscle contractions causing abnormal, often painful, movements or postures. Any part of the body can be affected including the arms, legs, neck, trunk, eyelids, face, or vocal cords. Dystonia can be diagnosed in childhood, adolescence, or adulthood. There are several classifications of dystonias based on the body parts affected. For example, generalized dystonia affects most or all of the body. Focal dystonia is localized to a specific part of the body. Multifocal dystonia involves two or more unrelated body parts. Segmental dystonia affects two or more adjacent parts of the body.

Hemidystonia involves the arm and leg on the same side of the body. Cervical dystonia is the most common of the focal dystonias and is sometimes referred to as spasmodic torticollis. The neck muscles that control the position of the head are affected resulting in pulling the head forward or backward or twisting from side to side. Blepharospasm, the second most common form of focal dystonia results in closure of the eyelids or rapid eye blinking causing vision problems. Cranial dystonia affects the muscles of the head, face, and neck. Spasmotic dystonia affects the muscles of the throat causing speech difficulty. Oromandibular dystonia causes speech and swallowing difficulties because the muscles of the jaw, lips, and tongue are affected. Writer's cramp is a form of dystonia many people have experienced temporarily. Dopa-responsive dystonia (DRD) manifests symptoms in childhood or adolescence and affects walking with progression worsening during the day.
Dystonia 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 Dystonia

People with dystonia 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 dystonia 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

Carrying

- Ball Transfer Tables
- Carts
- Compact Material Handling
• Vacuum Lifts
• Winches and Chain Hoists

Climbing
• Aerial Lifts
• Compact Ladders
• Elevators
• Evacuation Devices
• Extended Tractor Steps
• Folding Steps
• Ladders (General)
• Lightweight Ladders
• Rolling Safety Ladders
• Stair Assists
• Stair Lifts

Handling/Fingering
• Industrial
  • Anti-vibration Gloves
  • Anti-vibration Tool Wraps
  • Compact Material Handling
  • Ergonomic and Pneumatic Tools
  • Ergonomic Equipment
  • Extra Grip Gloves
  • Grip Aids
  • Vacuum Pickup Tools
• Office Equipment
  • Alternative Input Devices
  • Alternative Keyboards
  • Alternative Mice
  • Articulating Keyboard Trays
  • Book Holders
• Compact Material Handling
• Ergonomic Equipment
• Expanded Keyboards
• Forearm Support
• Grip Aids
• Keyguards
• Miniature Keyboards
• On-Screen Keyboards
• One-Handed Keyboards
• Page Turners
• Scribe/Notetaker
• Speech Recognition Software
• Typing / Keyboarding Aids
• Writing Aids

• Other

• Aide/Assistant/Attendant
• Money Handling Products
• Periodic Rest Breaks

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
• Lift Tables
• Rolling Safety Ladders
• Stairclimbing Handtrucks
• Truck Mounted Cranes
• Vacuum Lifts
• Vehicle Lifts and Manipulators

• 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
  • Height Adjustable Table Legs
  • Low Task Chair
  • Stairclimbing Handtrucks
  • 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
  • Adult Changing Tables
  • Adjustable Exam Tables
• Bath Chairs
• Evacuation Devices
• Large-Rated Wheelchair Lifts
• Patient Lifts (General)
• Pool Lifts
• Powered Bath Lifts
• Toileting Aids
• Transfer Aids
• Transfer Sheets
• Walk-up Changing Tables
• Wheelchair Lifts

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

Walking
• Scooters
• Walkers
• Wheelchairs

Weak Speech
• Flexible Schedule
• Job Restructuring
• Outgoing Voice Amplification - Telephone
• Voice Amplification

Work-Related Functions

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.

An applicant disclosed that he has dopa-responsive dystonia and stated that this causes his ability to walk to degrade throughout the day. The employer agreed to arrange the applicant’s schedule so that duties requiring extensive walking was done near the beginning of the shift and less physical duties were done near the end of the shift.

An employee diagnosed with cervical dystonia has reported difficulties holding the phone and using the keyboard at the same time. This was due to their uncontrollable head movements. The employer provided a phone headset as an accommodation.

An employee with spasmodic dystonia has been having trouble with clients hanging up when he calls them due to the speech difficulty he experiences. The employer allows the employee to correspond with his clients via e-mail, text messaging, and live chat rather than telephone as an accommodation.

An applicant with blepharospasm raised concerns about the on-the-job driving duties required for the position. The employer arranged for another employee to perform the driving duties as an accommodation. The employer felt this was a marginal function because the employee rarely traveled alone due to the nature of the job.

An employee with focal hand dystonia mentioned difficulty keeping up with prolonged writing tasks. The employer provided ergonomic writing aids as an accommodation.

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
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.

American Chronic Pain Association
P.O. Box 850
Rocklin, CA 95677-0850
Toll Free: (800) 533-3231
Fax: (916) 632-3208
ACPA@theacpa.org
http://www.theacpa.org
The purpose of the American Chronic Pain Association is to facilitate peer support and education for individuals with chronic pain and their families so that these individuals may live more fully in spite of their pain.

American Dystonia Society
17 Suffolk Lane
Princeton Junction, NJ 08550
Direct: (310) 237-5478
Fax: (609) 275-5663
info@dystonia.us
http://www.dystonia.us/

ADS will push initiatives and programs that will promote awareness on every level of government and the general public. Awareness is the key for raising funds for research for a disorder that could affect at an estimated 300,000 Americans in recent epidemiology research. As Dystonia patients themselves, ADS's Board of Directors recognizes the need to provide support for Dystonians from the newly diagnosed to those who have long term Dystonia.

American Speech-Language-Hearing Association
2200 Research Blvd
Rockville, MD 20850-3289
Toll Free: (800) 638-8255
Direct: (301) 296-5700
Fax: (301) 296-8580
http://www.asha.org

ASHA promotes the interests of, and provide the highest quality services for, professions in audiology, speech-language pathology, and speech and hearing science; and an advocate for people with communication disabilities.
Benign Essential Blepharospasm Research Foundation
P. O. Box 12468
Beaumont, TX 77726
Direct: (409) 832-0788
Fax: (409) 832-0890
bebrf@blepharospasm.org
http://www.blepharospasm.org/

Informational page sponsored by the Benign Essential Blepharospasm Research Foundation, whose purpose is to undertake, promote, develop and carry on the search for the cause and a cure for benign essential blepharospasm and other related disorders and infirmities of the facial musculature.

Dystonia Advocacy Network
One East Wacker Drive
Suite 2810
Chicago, IL 60601
http://dystonia-advocacy.org/

The Dystonia Advocacy Network (DAN) is a grassroots organization that brings dystonia-affected individuals together to speak out with a single, powerful voice on legislative and public policy issues which impact the dystonia community.

Dystonia Medical Research Foundation
1 East Wacker Drive
Suite 2810
Chicago, IL 60601-1905
Toll Free: (800) 377-3978
Direct: (312) 755-0198
Fax: (312) 803-0138
dystonia@dystonia-foundation.org
https://www.dystonia-foundation.org/

Advances research into the causes and treatments for dystonia, builds awareness of dystonia in the medical and the lay communities, and sponsors patient and family support groups and programs.
International Parkinson and Movement Disorder Society
555 East Wells Street
Suite 1100
Milwaukee, WI 53202
Direct: (414) 276-2145
Fax: (414) 276-3349
info@movementdisorders.org
http://www.movementdisorders.org/MDS.htm

The International Parkinson and Movement Disorder Society (MDS) is a professional society of over 4,500 clinicians, scientists and other healthcare professionals dedicated to improving the care of patients with movement disorders through education and research.

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.

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.
**Michael J. Fox Foundation for Parkinson’s Research**
Grand Central Station  
PO Box 4777  
New York, NY 10163-4777  
Toll Free: (800) 708-7644  
[https://www.michaeljfox.org/](https://www.michaeljfox.org/)

The Michael J. Fox Foundation is dedicated to finding a cure for Parkinson’s disease through an aggressively funded research agenda and to ensuring the development of improved therapies for those living with Parkinson's today.

**National Center for Biotechnology Information**
8600 Rockville Pike  
Bethesda, MD 20894  
[pubmedcentral@ncbi.nlm.nih.gov](mailto: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**
P.O. Box 5801  
Bethesda, MD 20824  
Toll Free: (800) 352-9424  
Direct: (301) 496-5751  

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.
NORD is a unique federation of voluntary health organizations dedicated to helping people with rare "orphan" diseases and assisting the organizations that serve them. NORD is committed to the identification, treatment, and cure of rare disorders through programs of education, advocacy, research, and service.

The National Spasmodic Dysphonia Association (NSDA) is a not-for-profit 501c(3) organization dedicated to advancing medical research into the causes of and treatments for SD, promoting physician and public awareness of the disorder, and providing support to those affected by SD through symposiums, support groups, and on-line resources.

The mission of the National Spasmodic Torticollis Association is to support the needs and well being of affected individuals and families; to promote awareness and education; to advance research for more treatments and ultimately a cure.
Remedy's Health Communities
http://www.healthcommunities.com

Remedy Health Media is America’s fastest growing health information and technology company. We are a leading provider of clinical resources and wellness tools that help millions of patients and caregivers live healthier, more fulfilled lives.

Our mission is to empower patients and caregivers with the information and applications needed to efficiently navigate the healthcare landscape and as a result, to permit better health outcomes through use of our products and services.

ST Dystonia, Inc.
PO Box 28
Mukwonago, WI 53149
Toll Free: (888) 445-4588
info@spasmodictorticollis.org
http://www.spasmodictorticollis.org/

ST Dystonia was founded on the premise to be there for our members...like one big family. We’re about the positive and want to mix this site up with education, fun, humor, treatments, trivia and whatever comes to our/your mind. We’re wide open to listening and please remember, YOU ARE NOT ALONE.

The Bachmann-Strauss Dystonia & Parkinson Foundation, Inc.
P.O. Box 38016
Albany, NY 12203
Direct: (212) 509-0995
lfreeman@michaeljfox.org
http://www.dystonia-parkinsons.org/

The Bachmann-Strauss Dystonia & Parkinson Foundation ("BSDPF") is a 501(c)(3) nonprofit organization dedicated to finding better treatments and cures for the movement disorders dystonia and Parkinson's disease.
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