



Accommodation and Compliance Series

Employees with Dystonia

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A service of the U.S. Department of Labor's Office of Disability Employment Policy

Preface

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Authored by Eddie Whidden. Updated 09/05/08.



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 <http://www.jan.wvu.edu/soar>.

Information about Dystonia

What is 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. Symptoms may be presented during childhood, adolescence, or adulthood (Dystonia Medical Research Foundation, 2006).

How prevalent is dystonia?

According to the Dystonia Medical Research Foundation, dystonia is the third most common movement disorder after Parkinsons Disease and Tremor. It affects more than 300,000 people in North America and is not limited by race or ethnicity (Dystonia Medical Research Foundation, 2006).

What types of dystonias are there?

There are several classifications of dystonias based on the body parts affected as listed by the National Institute of Neurological Disorders and Stroke. 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 (National Institute of Neurological Disorders and Stroke, 2007).

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 (National Institute of Neurological Disorders and Stroke, 2007).

Blepharospasm, the second most common form of focal dystonia results in closure of the eyelids or rapid eye blinking causing obvious vision problems (National Institute of Neurological Disorders and Stroke, 2007).

Cranial dystonia affects the muscles of the head, face, and neck. Spasmodic 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 (National Institute of Neurological Disorders and Stroke, 2007).

Writer's cramp is a form of dystonia many people have experienced temporarily. This condition is task specific, but can eventually affect other tasks such as eating (National Institute of Neurological Disorders and Stroke, 2007).

Dopa-responsive dystonia (DRD) manifests symptoms in childhood or adolescence and affects walking with progression worsening during the day (National Institute of Neurological Disorders and Stroke, 2007).

How is dystonia treated?

There is no cure for dystonia, but various treatments are available including medications on an individual basis; botulinum toxin injections; surgery; and therapies such as speech or physical therapy, splinting, and biofeedback. Because dystonic spasms increase during periods of stress, emotionality, or fatigue and often decrease during periods of rest or sleep, many patients use temporary techniques to decrease or suppress movements by touching the affected parts of the body and by applying some pressure to those areas (National Institute of Neurological Disorders and Stroke, 2007).

Dystonia and the Americans with Disabilities Act

Is dystonia a disability under the ADA?

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 (EEOC, 1992). Therefore, some people with dystonia will have a disability under the ADA and some will not.

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 such an impairment (EEOC, 1992). For more information about how to determine whether a person has a disability under the ADA, visit <http://www.jan.wvu.edu/corner/vol02iss04.htm>.

Accommodating Employees with Dystonia

(Note: 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 with dystonia 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 with dystonia been consulted regarding possible accommodations?
6. Once accommodations are in place, would it be useful to meet with the employee with dystonia to evaluate the effectiveness of the accommodations and to determine whether additional accommodations are needed?
7. Do supervisory personnel and employees need training regarding dystonia?

Accommodation Ideas:

General Accommodation Considerations:

- Accessible work-site
- Parking close to the work-site
- Accessible entrance
- Automatic door openers
- Accessible restroom and break area
- Accessible route of travel to other work areas used by the employee
- Accessible workstation
- Materials and equipment within reach
- Workstation close to restrooms, break areas, and other common use areas
- Alternative computer, phone, writing aids, and other assistive devices
- Ergonomic workstation design
- Sensitivity training to coworkers and supervisors



Keyboarding and Mousing:

- Speech recognition software
- Large-key keyboards and on-screen keyboard software used in conjunction with a mouse
- Alternative mice including trackballs, touchpads, foot mice, head pointers, and programmable mice
- Word prediction and alternative mouse software

Writing:

- Grip aids
- Weighted pens
- Writing cuffs
- Orthotic devices
- Soft grasp build-ups
- Portable recording products
- Clipboards
- Desk slants

Using the Telephone:

- Speaker-phones
- Telephones with programmable number storage
- Phone holders
- Telephone headsets

Using Tools:

- Grasping cuffs
- Ergonomically designed tools and handles
- Vibration dampening wraps and gloves
- Vises
- Work positioners
- Foot controls
- Pistol grip attachments
- Orthotic devices

Lifting:

- Portable lift equipment
- Hoists
- Tilt-tables
- Tailgate lifts

Carrying:

- Lightweight carts
- Shoulder bags
- Backpacks
- Electrically powered carts or scooters with baskets

Standing:

- Sit/stand stools
- Standing frames
- Lumbar support stands
- Anti-fatigue matting
- Rest breaks as needed

Climbing:

- Stair-lifts
- Wheelchair platform lifts
- Rolling safety ladders with handrails
- Work platforms
- Step-stands
- Hydraulic personnel lifts

Walking:

- Canes
- Crutches
- Rolling walkers with seats
- Wheelchairs
- Powered wheelchairs or scooters

Driving:

- Hand controls
- Steering wheel knobs
- Powered steering
- Automatic transmission vehicles
- Designated parking

Housekeeping/Cleaning:

- Lightweight vacuum cleaners
- Back-pack vacuums
- Grasping cuffs



Speech:

- Augmentative and alternative communication devices
- Voice amplifiers

Vision:

- Task lighting
- Dark glasses
- Anti-glare monitor filters for the computer

Situations and Solutions:

A student who has dystonia affecting the eyelids was having trouble in the classroom. JAN suggested the avoidance of bright lights, the use of sunglasses, stress reduction techniques, a good night's sleep, and concentration on specific tasks.

An office worker with neck and shoulder limitations was having difficulty using the PC while seated. JAN suggested the use of speech recognition software, rest breaks as needed, and the use of a supine workstation that allows computer use while in a reclined posture.

An assembly worker was not able to meet production standards due to cervical dystonia resulting in head movement and pain. JAN suggested the use of a tilt-table and ergonomic seating featuring neck support.

Products:

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource (SOAR) at <http://www.jan.wvu.edu/soar> is designed to let users explore various accommodation options. Many product vendor lists are accessible through this system; however, upon request JAN provides these lists and many more that are not available on the Web site. 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: (877)781-9403
Fax: (304)293-5407
jan@jan.wvu.edu
<http://www.jan.wvu.edu>

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)633-7635
TTY: (877)889-5627
Fax: (202)693-7888
<http://www.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.

Benign Essential Blepharospasm Research Foundation

BEBRF
P. O. Box 12468
Beaumont, TX 77726-2468
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 Medical Research Foundation

Dystonia Dialogue
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
<http://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.

NIH Neurological Institute

P. O. Box 5801
Bethesda, MD 20824
Toll Free: (800)352-9424
<http://www.ninds.nih.gov>

The mission of NINDS is to reduce the burden of neurological disease - a burden borne by every age group, by every segment of society, by people all over the world.

National Spasmodic Torticollis Association

9920 Talbert Avenue
Fountain Valley, CA 92708
Toll Free: (800)487-8385
NSTAmail@aol.com
<http://www.torticollis.org>

NSTA provides information on research, treatments, and support groups available to spasmodic torticollis.

Worldwide Education & Awareness for Movement Disorders

204 West 84th Street
New York, NY 10024
wemove@wemove.org
<http://www.wemove.org>

WE MOVE is the Internet's most comprehensive resource for movement disorder information and education and the only organization of its kind.

References

- Dystonia Medical Research Foundation. (2006). *Dystonia defined*. Retrieved September 5, 2008, from http://www.dystonia-foundation.org/pages/dystonia_defined/2.php
- Equal Employment Opportunity Commission. (1992). *A technical assistance manual on the employment provisions (title I) of the Americans with Disabilities Act*. Retrieved September 5, 2008, from <http://www.jan.wvu.edu/links/ADAtam1.html>
- National Institute of Neurological Disorders and Stroke. (2007). *Dystonias information page*. Retrieved September 5, 2008, from <http://www.ninds.nih.gov/disorders/dystonias/dystonias.htm>



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