

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Employees with Muscular Dystrophy

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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 Linda Carter Batiste, J.D. Updated 03/23/10.

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://askjan.org/soar>.

Information about Muscular Dystrophy (MD)

What is MD?

MD refers to a group of genetic diseases marked by progressive weakness and degeneration of the skeletal, or voluntary, muscles, which control movement. The muscles of the heart and some other involuntary muscles are also affected in some forms of muscular dystrophy, and a few forms involve other organs as well. The major forms of muscular dystrophy are myotonic, Duchenne, Becker, limb-girdle, facioscapulohumeral, congenital, oculopharyngeal, distal, and Emery-Dreifuss. All forms of muscular dystrophy are caused by gene defects (Muscular Dystrophy Association, 2001).

What are the symptoms of MD?

Individuals with MD usually exhibit contractures, a condition often associated with shortened muscles around the joints. Due to the abnormal and sometimes painful positioning of the joints, most individuals with MD have extreme fatigue and weakness as well as speech, mobility, and fine motor limitations. In addition, scoliosis, or curvature of the spine, is common (Muscular Dystrophy Association, 2001).

Who gets MD?

MD is generally inherited but in some cases no family history of the disease may exist. MD can affect people of all ages. While some forms first become apparent in infancy or childhood, others may not appear until middle age or later (Muscular Dystrophy Association, 2001).

How is MD treated?

Moderate exercise programs and physical therapy can minimize contractures, and certain exercises may prevent or delay scoliosis. Surgery can sometimes be helpful in relieving muscle shortening. In addition, respiratory care for some individuals with MD may also help. Medications known as corticosteroids have been found to slow muscle destruction in some forms of MD, but can have serious side effects. Researchers are testing new corticosteroids that may have fewer side effects. The prognosis of MD varies according to the type of MD and the progression of the disorder (Muscular Dystrophy Association, 2001).

MD and the Americans with Disabilities Act

Is MD 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 MD 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://askjan.org/corner/vol02iss04.htm>.

Accommodating Employees with MD

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

Accommodation Ideas:

Activities of Daily Living:

- Allow use of a personal attendant at work
- Allow use of a service animal at work
- Make sure the facility is accessible
- Move workstation closer to the restroom
- Allow longer breaks
- Refer to appropriate community services

Fatigue/Weakness:

- Reduce or eliminate physical exertion and workplace stress
- Schedule periodic rest breaks away from the workstation
- Allow a flexible work schedule and flexible use of leave time
- Allow work from home
- Implement ergonomic workstation design

Fine Motor Impairment:

- Provide alternative computer access
- Provide alternative telephone access
- Provide arm supports
- Provide writing and grip aids
- Provide a page turner and a book holder
- Provide a note taker

Gross Motor:

- Provide a scooter or other mobility aid if walking cannot be reduced
- Provide parking close to the work-site
- Provide an accessible entrance
- Install automatic door openers
- Provide an accessible route of travel to other work areas used by the employee
- Make sure materials and equipment are within reach range
- Move workstation close to other work areas, office equipment, and break rooms

Medical Treatment Allowances:

- Provide flexible schedules
- Allow a self-paced workload with flexible hours
- Allow employee to work from home
- Provide part-time work schedules

Speech Impairment:

- Provide speech amplification, speech enhancement, or other communication device
- Use written communication, such as email or fax
- Transfer to a position that does not require a lot of communication
- Allow periodic rest breaks

Stress Intolerance:

- Develop strategies to deal with work problems before they arise
- Provide sensitivity training to coworkers
- Allow telephone calls during work hours to doctors and others for support
- Provide information on counseling and employee assistance programs

Situations and Solutions:

An engineer with MD had difficulty grasping frequently used files. He was accommodated with a desktop carousel.

A student with MD was limited in her use of the computer. She was accommodated with the Magic Wand Keyboard, a miniature computer keyboard and mouse. The keyboard worked with the slightest touch of a wand and no force was needed to activate the keys.

A staff employee with MD who operated a power chair with a joystick was having difficulty opening doors. The individual could not grasp door handles and was accommodated with automatic door openers.

A physician with MD was having problems getting up from a seated position after consulting with patients. The individual was accommodated with a lift cushion for his chair.

A counselor was having difficulty performing psychological evaluations due to cognitive limitations. Her manager agreed to provide written job instructions when possible, and make memory aids such as schedulers or organizers readily available.

A service worker was having difficulty maintaining a full workday due to fatigue. The individual was accommodated with periodic rest breaks away from the workstation, a flexible work schedule, flexible use of leave time, parking close to the work-site, and periodic work from home.

A technical writer with MD was having difficulty reaching her workstation. The individual was accommodated with a flat screen monitor, monitor arm, keyboard tray, footrest, headset, and strategically placed filing racks.

A secretary with MD was restricted from typing information into her computer due to fine motor limitations. She was accommodated with speech recognition.

A manager with MD was having difficulty with daily living needs. The individual was allowed to bring her service animal to work and provided an accessible restroom.

A lawyer with MD was having difficulty climbing stairs. He was accommodated with a stair lift.

An office worker with MD who distributed mail was having difficulty carrying mail to workstations. He was accommodated with a cart.

A writer with MD had severe hand weakness and was limited in her ability to use the keyboard. The individual was accommodated with a miniature keyboard with light touch features.

Products:

There are numerous products that can be used to accommodate people with limitations. JAN's Searchable Online Accommodation Resource at <http://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: (877)781-9403
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)633-7635
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.

Facioscapulohumeral Dystrophy Society

3 Westwood Road
Lexington, MA 02420
Direct: (781)860-0501
Fax: (781)860-0599
Phone: (781)275-7781
<http://www.fshsociety.org>

Encourages and promotes scientific and clinical research and development through education of the general public, governmental bodies, and the medical profession.

International Myotonic Dystrophy Organization

PO Box 1121
Sunland, CA 91041-1121
Toll Free: (866)679-7954
Direct: (818)951-2311
info@myotonicdystrophy.org

<http://www.myotonicdystrophy.org>

This site is devoted to information about Myotonic Dystrophy (MD) and Congenital Myotonic Dystrophy (CMyD), both forms of muscular dystrophy. Also contained in this site is information on Congenital Muscular Dystrophy (Thompsons's disease), which is a separate condition but in some cases having similar symptoms.

Muscular Dystrophy Association

3300 East Sunrise Drive
Tucson, AZ 85718
Toll Free: (800)572-1717
mda@mdausa.org
<http://www.mdausa.org>

MDA provides comprehensive medical services to tens of thousands of people with neuromuscular diseases at some 240 hospital-affiliated clinics across the country. The Association's worldwide research program, which funds over 400 individual scientific investigations annually, represents the largest single effort to advance knowledge of neuromuscular diseases and to find cures and treatments for them. In addition, MDA conducts far-reaching educational programs for the public and professionals.

Muscular Dystrophy Association of Canada

2345 Yonge Street
Suite 900
866MUSCLE8
Toronto, ON M4P 2-E5
Toll Free: (866)MUS-CLE8
Direct: (416)488-0300
Fax: (416)488-7523
<http://www.mdac.ca>

MDA of Canada is a national voluntary agency that is committed to funding leading research to find the causes, treatments, preventions, and cures for MD.

Muscular Dystrophy Family Foundation, Inc.

3951 N. Meridian Street, Suite 100
Indianapolis, IN 46208
Toll Free: (800)544-1213
Direct: (317)923-6333
Fax: (317)923-6334
<http://www.mdff.org>

The Muscular Dystrophy Family Foundation, Inc. provides services, resources, home medical equipment, and adaptive devices to help people with MD.

National Institute of Arthritis and Musculoskeletal and Skin Diseases

National Institutes of Health
1 AMS Circle
Bethesda, MD 20892-3675
Toll Free: (877)22N-IAMS
Direct: (301)495-4484
TTY: (301)565-2966
Fax: (301)718-6366
niamsinfo@mail.nih.gov
<http://www.niams.nih.gov>

The mission of the National Institute of Arthritis and Musculoskeletal and Skin Diseases is to support research into the causes, treatment, and prevention of arthritis and musculoskeletal and skin diseases, the training of basic and clinical scientists to carry out this research, and the dissemination of information on research progress in these diseases.

National Organization for Rare Disorders

55 Kenosia Avenue
PO Box 1968
Danbury, CT 06813-1968
Toll Free: (800)999-6673
Direct: (203)744-0100
TTY: (203)797-9590
Fax: (203)798-2291
orphan@rarediseases.org
<http://www.rarediseases.org/>

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.

Parent Project for Muscular Dystrophy Research

1012 North University Boulevard
Middletown, OH 45042
Toll Free: (800)714-5437
Direct: (513)424-0696
Fax: (513)425-9907
info@parentprojectmd.org
<http://www.parentdmd.org>

The Parent Project for Muscular Dystrophy Research, Inc. is committed to expedite a treatment and cure for Duchenne and Becker Muscular Dystrophy.

References

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://askjan.org/links/ADAтам1.html>

Muscular Dystrophy Association. (2001). *Facts about Muscular Dystrophy (MD).*

Retrieved July 6, 2005, from <http://www.mdausa.org/publications/fa-md.html>

This document was developed by the Job Accommodation Network, funded by a contract agreement from the U.S. Department of Labor, Office of Disability Employment Policy (DOL079RP20426). The opinions expressed herein do not necessarily reflect the position or policy of the U.S. Department of Labor. Nor does mention of trade names, commercial products, or organizations imply endorsement by the U.S. Department of Labor.