

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Muscular Dystrophy

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ODEP
Office of Disability
Employment Policy

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 grant from 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.

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Updated 02/07/2024.

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 Muscular Dystrophy

Muscular dystrophy 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. Individuals with muscular dystrophy 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 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 is generally inherited but in some cases no family history of the disease may exist. It 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 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 Muscular Dystrophy

People with muscular dystrophy 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 muscular dystrophy 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

Decreased Stamina/Fatigue

- Accessories for Scooters
- Aide/Assistant/Attendant
- All-Terrain Scooters
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic and Pneumatic Tools
- Ergonomic Assessments

- Ergonomic Equipment
- Examination and Procedures Chair
- Flexible Schedule
- Head Support for Wheelchairs
- Job Restructuring
- Low Task Chair
- Mechanic's Seats and Creepers
- Multi-Purpose Carts
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Mounts
- Wheelchairs
- Worksite Redesign / Modified Workspace

Effect of/Receive Medical Treatment

- Augmentative and Alternative Communication (AAC) Device
- Flexible Schedule
- Outgoing Voice Amplification - Telephone
- Personal On-Site Paging Devices
- Protective Eyewear
- Telework, Work from Home, Working Remotely
- Voice Amplification

Feeling/Sensing

- Aide/Assistant/Attendant
- Periodic Rest Breaks

- Task Rotation

Stress Intolerance

- Apps for Anxiety and Stress
- Behavior Modification Techniques
- Counseling/Therapy
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Supervisory Methods
- Support Animal
- Support Person

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
- Transfer Sheets
- Worksite Redesign / Modified Workspace

Walking

- Accessories for Scooters
- Aide/Assistant/Attendant

- All-Terrain Scooters
- All-Terrain Wheelchairs
- Anti-fatigue Matting
- Boat Access
- Ergonomic and Pneumatic Tools
- Examination and Procedures Chair
- Foldable / Transport Wheelchairs
- Head Support for Wheelchairs
- Large-Rated Scooters
- Large-Rated Wheelchairs
- Low Task Chair
- Personal Transportation and Mobility Products
- Reclining Wheelchairs
- Rollators and Rolling Walkers
- Scooters
- Scooters for Small Stature
- Stair Assists
- Stools for Cutting Hair
- Telework, Work from Home, Working Remotely
- Van Conversion
- Walkers
- Walkers for Tall Individuals
- Walkers with Seats
- Wearable Anti-fatigue Matting
- Wheelchair Accessible Scales
- Wheelchair Carts/Trailers
- Wheelchair Mounts
- 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
- Van Conversion

Parking

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

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

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.

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

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

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

A technical writer with muscular dystrophy 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 staff employee with muscular dystrophy 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 student with muscular dystrophy was limited in her use of the computer.
She was accommodated with a miniature computer keyboard and mouse. The keyboard worked with the slightest touch and no force was needed to activate the keys.

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

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 Occupational Therapy Association

6116 Executive Boulevard, Suite 200
North Bethesda, MD 20852-4929
Direct: (301) 652-6611
members@aota.org
<https://www.aota.org/>

The American Occupational Therapy Association (AOTA) is the national professional association established in 1917 to represent the interests and concerns of occupational therapy practitioners and students of occupational therapy and to improve the quality of occupational therapy services.

American Physical Therapy Association

<http://www.moveforwardpt.com/Default.aspx>

MoveForwardPT.com is the official consumer information website of the American Physical Therapy Association.

Centers for Disease Control and Prevention

1600 Clifton Rd

Atlanta, GA 30333

Toll Free: (800) 232-4636

<https://www.cdc.gov/>

The Centers for Disease Control and Prevention are dedicated to protecting the health and safety of people - at home and abroad, providing credible information to enhance health decisions, and promoting health through strong partnerships.

Christopher & Dana Reeve Foundation

636 Morris Turnpike

Suite 3A

Short Hills, NJ 07078

Toll Free: (800) 225-0292

Direct: (973) 379-2690

TeamReeve@ChristopherReeve.org

http://www.christopherreeve.org/site/c.ddJFKRNoFiG/b.4048063/k.67BA/The_Christopher_amp_Dana_Reeve_Foundation_Paralysis_amp_Spinal_Cord_Injury.htm

The Reeve Foundation is dedicated to curing spinal cord injury by funding innovative research, and improving the quality of life for people living with paralysis through grants, information and advocacy.

DNA Learning Center: Cold Spring Harbor Laboratory

Direct: (516) 367-5170

Fax: (516) 367-5182

<http://www.ygyh.org/index.htm>

Cold Spring Harbor Laboratory (CSHL) is a private, not-for-profit research and education institution at the forefront of molecular biology and genetics.

DNA Learning Centers's educate the public about genetics through the nation's first science centers dedicated to this purpose.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

31 Center Drive

Building 31, Room 2A32

Bethesda, MD 20892-2425

Toll Free: (800) 370-2943

Fax: (866) 760-5947

NICHDInformationResourceCenter@mail.nih.gov

<http://www.nichd.nih.gov/Pages/index.aspx>

The mission of the NICHD is to ensure that every person is born healthy and wanted, that women suffer no harmful effects from reproductive processes, and that all children have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

Eunice Kennedy Shriver National Institute of Child Health and Human Development

P.O. Box 3006

Rockville, MD 20847

Toll Free: (800) 370-2943

Fax: (866) 760-5947

NICHDInformationResourceCenter@mail.nih.gov

<http://www.nichd.nih.gov/Pages/index.aspx>

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have the chance to achieve their full potential for healthy and productive lives, free from disease or disability, and to ensure the health, productivity, independence, and well-being of all people through optimal rehabilitation.

Facioscapulohumeral Muscular Dystrophy Society

450 Bedford Street
Lexington, MA 02420
Direct: (781) 301-6060
Fax: (781) 862-1116
info@fshsociety.org
<http://askjan.org/media/PD.html>

The FSH Society is a nonprofit, patient-driven organization supporting research and education for facioscapulohumeral muscular dystrophy (FSHD), one of the most prevalent forms of muscular dystrophy. Progress on FSHD could benefit a wide range of other areas of medicine, from cancer and diabetes to muscle regeneration and repair.

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.

Muscular Dystrophy Association

222 S. Riverside Plaza,
Suite 1500
Chicago, IL 60606
Toll Free: (800) 572-1717
mda@mdausa.org
<http://www.mda.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
Toronto, Ontario M4P 2- 2E5
Toll Free: (866) 687-2538
Fax: (416) 488-7523
info@muscle.ca
<http://www.muscle.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.

P.O. Box 776
Carmel, IN 46082
Direct: (317) 615-9140
<http://mdff.org/>

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

Myotonic Dystrophy Foundation

1004A O'Reilly Avenue
San Francisco, CA 94129
Toll Free: (866) 968-6642
Direct: (415) 800-7777
info@myotonic.org
<http://www.myotonic.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' disease), which is a separate condition but in some cases having similar symptoms.

National Center for Biotechnology Information

8600 Rockville Pike
Bethesda, MD 20894
pubmedcentral@ncbi.nlm.nih.gov
<https://www.ncbi.nlm.nih.gov/>

The National Center for Biotechnology Information advances science and health by providing access to biomedical and genomic information.

National Human Genome Research Institute

31 Center Drive, MSC 2152
9000 Rockville Pike
Bethesda, MD 20892-2152
Direct: (301) 402-0911
Fax: (301) 402-2218
<https://www.genome.gov/>

NHGRI's mission has expanded to encompass a broad range of studies aimed at understanding the structure and function of the human genome and its role in health and disease. To that end NHGRI supports the development of resources and

technology that will accelerate genome research and its application to human health. A critical part of the NHGRI mission continues to be the study of the ethical, legal and social implications (ELSI) of genome research. NHGRI also supports the training of investigators and the dissemination of genome information to the public and to health professionals.

National Institute of Arthritis and Musculoskeletal and Skin Diseases

1 AMS Circle
Bethesda, MD 20892-3675
Toll Free: (877) 226-4267
Direct: (301) 495-4484
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 Institute of Neurological Disorders and Stroke

P.O. Box 5801
Bethesda, MD 20824
Toll Free: (800) 352-9424
Direct: (301) 496-5751
<http://www.ninds.nih.gov>

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.

National Organization for Rare Disorders

55 Kenosia Avenue
Danbury, CT 06813-1968
Toll Free: (800) 999-6673
Direct: (203) 744-0100
Fax: (203) 263-9938
<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 Muscular Dystrophy

401 Hackensack Avenue,
9th Floor
Hackensack, NJ 07601
Toll Free: (800) 714-5437
Direct: (201) 250-8440
Fax: (201) 250-8435
info@parentprojectmd.org
http://www.parentprojectmd.org/site/PageServer?pagename=s_index

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

This document was developed by the Job Accommodation Network (JAN), funded by a grant from the U.S. Department of Labor, Office of Disability Employment Policy (#OD-38028-22-75-4-54). 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.