

JAN

Job Accommodation Network

Practical Solutions • Workplace Success

Accommodation and Compliance Series

Accommodation and Compliance Series: Employees with Huntington's Disease

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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.

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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 <http://askjan.org/soar>.

Information about Huntington's Disease

Huntington's disease (HD) is a hereditary, degenerative brain disorder for which there is, at present, no treatment to slow the progression of symptoms and no cure. Most individuals with HD begin to exhibit symptoms between the ages of 30 to 50, and are likely to be employed when first diagnosed. As this genetic disease progresses, it will affect cognitive, motor, and behavioral functioning.

Motor issues often include involuntary movements, difficulty with speech and swallowing, lack of coordination, and fatigue and weakness. Many cognitive functions become limited, such as memory, decision making, critical thinking, multitasking and concentration. Behavioral issues include anxiety, depression, mood swings, and stress intolerance, as well as irritability and impulsivity.

Huntington's Disease 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 Huntington's Disease

People with Huntington's disease 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 Huntington's disease 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

Attentiveness/Concentration

- Applications (apps)
- Behavior Modification Techniques
- Cubicle Doors, Shields, and Shades
- Electronic Organizers
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Coaches
- Modified Break Schedule

- Noise Canceling Headsets
- Sound Absorption and Sound Proof Panels
- Telework, Work from Home, Working Remotely
- Timers and Watches
- Worksite Redesign / Modified Workspace
- Written Instructions

Decreased Stamina/Fatigue

- Aide/Assistant/Attendant
- Anti-fatigue Matting
- Elevating Wheelchairs
- Ergonomic Assessments
- Ergonomic Equipment
- Job Restructuring
- Periodic Rest Breaks
- Scooters
- Stand-lean Stools
- Telework, Work from Home, Working Remotely
- Walkers
- Wearable Anti-fatigue Matting
- Wheelchairs
- Worksite Redesign / Modified Workspace

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 Supports
 - 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

Memory Loss

- Additional Training Time / Training Refreshers
- Apps for Memory
- Electronic Organizers
- Memory Software
- Recorded Directives, Messages, Materials

- Reminders
- Support Person
- Verbal Cues
- Wall Calendars and Planners
- Written Instructions

Organizing/Planning/Prioritizing

- Applications (apps)
- Apps for Organization/ Time Management
- Color-coded Manuals, Outlines, and Maps
- Electronic Organizers
- Ergonomic Equipment
- Job Coaches
- Job Restructuring
- On-site Mentoring
- Organization Software
- Professional Organizers
- Reminders
- Supervisory Methods
- Timers and Watches
- Wall Calendars and Planners
- Written Instructions

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

Work-Related Functions

Stress

- Apps for Anxiety and Stress
- Behavior Modification Techniques
- Counseling/Therapy
- Flexible Schedule
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Monitor Mirrors
- On-site Mentoring
- Service Animal
- Simulated Skylights and Windows
- Supervisory Methods
- Support Animal
- Support Person
- Telework, Work from Home, Working Remotely
- Uninterrupted Work Time

Use Cognitive Function

- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Color Coded System
- Counting/Measuring Aids
- Electronic Dictionaries
- Electronic Organizers
- Extra Time
- Job Coaches

- Line Guides
- Marginal Functions
- Modified Break Schedule
- On-site Mentoring
- Reassignment
- Reminders
- Service Animal
- Support Person
- Training Modifications
- Uninterrupted Work Time

Work Site Access

- Accessible Toilets and Toilet Seats
- 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

Situations and Solutions:

An aircraft mechanic had to bond hardware on mechanisms, but when he was hungry his tremors that stemmed from Huntington's would flare.

His employer offered a modified schedule so the employee could eat throughout the day and also offered weighted gloves, wristbands, and an arm stabilizer for the tremor symptoms.

A JAN customer was losing her ability to speak due to Huntington's disease.

JAN suggested a range of accommodations, from high tech speech augmentation devices to low tech communication boards.

An employee of a mortgage company wasn't meeting production standards because of typing limitations due to his Huntington's.

The employer purchased word prediction software and looked into speech recognition software he may be able to use in the future.

A bill and account collector had trouble concentrating due to Huntington's disease.

JAN suggested and the employer ended up moving the employee's cubical, using higher cube walls, providing noise absorbing paneling and noise canceling headphones, designating time that is phone-free and visitor-free, changing work hours to quieter times of day, and permitting telework.

A construction worker had Huntington's disease related depression.

He requested ADA leave to get treatment and a reduced work schedule when he returned back to work, he was accommodated with leave and a modified schedule.

A medical assistant who worked at a hospital had trouble walking because of Huntington's disease.

JAN explained restructuring the shift so the employee was working in one specific area at a time and reducing walking around the work-site. JAN also discussed mobility devices, sitting while working, handrails along the paths she uses, and portable charts. The employee requested these accommodations, and was accommodated.

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: (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.

Alzheimer's Association

225 N. Michigan Avenue
Floor 17
Chicago, IL 60601-7633
Toll Free: (800) 272-3900
info@alz.org
<http://www.alz.org>

The Alzheimer's Association is the leading, global voluntary health organization in Alzheimer's care and support, and the largest private, nonprofit funder of Alzheimer's research.

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.

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.

Genetic and Rare Diseases Information Center (GARD)

P.O. Box 8126
Gaithersburg, MD 20898-8126
Toll Free: (888) 205-2311
Fax: (301) 251-4911
<https://rarediseases.info.nih.gov/>

The Genetic and Rare Diseases (GARD) Information Center is a program of the National Center for Advancing Translational Sciences (NCATS) and funded by two parts

of the National Institutes of Health (NIH): NCATS and the National Human Genome Research Institute (NHGRI). GARD provides the public with access to current, reliable, and easy to understand information about rare or genetic diseases in English or Spanish.

Huntington's Disease Foundation (HDFI)

P.O. Box 912
Salado, TX
HDArmy@HDFI-usa.org
<http://www.huntingtonsdiseasefoundation.org/>

The HDFI mission is to help researchers find a cure, bring public awareness about the disease, provide education, information and news to the public, and support individuals and their families who suffer from this deadly disease.

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://www.nlm.nih.gov/medlineplus/>

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.

Created by the U.S. National Library of Medicine

National Center for Biotechnology Information

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

MISSION: IMS brings together an international community of health care professionals, researchers, educators, and others to improve care and transform delivery of treatment to those suffering from soft tissue pain through the promotion and exchange of globally recognized research, education, and innovation in patient care.

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 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.

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.

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