

Accommodation and Compliance Series

Accommodation and Compliance Series: Huntington's Disease

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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 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 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 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. 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

Attentiveness/Concentration

- Alerting Devices
- Alternative Lighting
- Applications (apps)
- Apps for Memory
- Behavior Modification Techniques
- Calendars and Planners
- Cubicle Doors, Shields, and Shades
- Electronic Organizers
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines

- Flexible Schedule
- Full Spectrum or Natural Lighting Products
- Job Coaches
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Noise Canceling Headsets
- Personal On-Site Paging Devices
- Professional Organizers
- Sound Absorption and Sound Proof Panels
- Task Separation
- Telework, Work from Home, Working Remotely
- Timers and Watches
- Uninterrupted "Off" Work Time
- Verbal Cues
- Visual Schedulers
- Worksite Redesign / Modified Workspace
- Written Instructions

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

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

Practical Solutions • Workplace Success

- 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

Memory Loss

- Additional Training Time / Training Refreshers
- Apps for Memory
- · Calendars and Planners
- Electronic Organizers
- Job Coaches
- Professional Organizers
- Recorded Directives, Messages, Materials
- Reminders
- Social Skill Builders
- Support Person
- Verbal Cues
- Visual Schedulers
- Written Instructions

Organizing/Planning/Prioritizing

- Applications (apps)
- Apps for Organization/ Time Management
- Calendars and Planners
- Color-coded Manuals, Outlines, and Maps
- Electronic Organizers
- Ergonomic Equipment
- Job Coaches
- Job Restructuring
- On-site Mentoring
- Organization Software
- Personal On-Site Paging Devices
- Professional Organizers
- Reminders
- Supervisory Methods
- Task Identification
- Task Separation
- Timers and Watches
- Visual Schedulers
- 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

Communicate

- Accessible Telephones
- Additional Training Time / Training Refreshers
- Aide/Assistant/Attendant
- Apps for Individuals Who are Deaf or Hard of Hearing
- Assistive Listening Devices (personal)
- Assistive Listening Devices and Sound Field System
- Augmentative and Alternative Communication (AAC) Device
- Behavior Modification Techniques
- Bluetooth Products
- Bone Conduction Technology
- Braille Telephones
- Braille TTY
- Captioned Telephone Calls
- CART Services
- CART Services Remote
- Cellular Telephone Technology: Deaf & Hard of Hearing
- Communication Access Technologies
- Electronic Organizers
- Graphics Design Software
- Handheld Computers (General)
- Hands-free Telephones
- Headsets Computer (USB, VOIP etc.)
- Headsets Hearing Aid Compatible, Amplification
- Hearing Carry Over (HCO) TTYs
- Interpreter
- Job Coaches

- Large Visual Display for TTY
- Literacy Skills Development
- Neckloops
- On-site Mentoring
- Outgoing Voice Amplification Telephone
- Paging Products & Services
- Personal On-Site Paging Devices
- Professional Organizers
- Real-time and Off-line Captioning Services
- Scribe/Notetaker
- Service Animal
- Social Skill Builders
- Speech Recognition Software
- Talking Telephones
- Telecoil Compatible Headsets
- Telephone Amplification
- Telephone Flasher
- Test Tube Holders
- TTY Software
- TTYs (Text Telephones)
- Verbal Responses
- Video Relay Services (VRS)
- Video Remote Interpreting Services (VRI)
- Voice Amplification
- Voice-Carry-Over (VCO) Telephones
- Word Prediction/Completion and Macro Software
- Word Processing Software
- Writing/Editing Software

Stress

- Apps for Anxiety and Stress
- Behavior Modification Techniques

- Counseling/Therapy
- Environmental Sound Machines / Tinnitus Maskers / White Noise Machines
- Flexible Schedule
- Job Coaches
- Job Restructuring
- Marginal Functions
- Modified Break Schedule
- Monitor Mirrors
- Odor Control
- On-site Mentoring
- Service Animal
- Simulated Skylights and Windows
- Strobe Lights
- 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
- Fractional, Decimal, Statistical, or Scientific Calculators
- Job Coaches
- Line Guides
- Marginal Functions

- Modified Break Schedule
- On-site Mentoring
- Personal On-Site Paging Devices
- Professional Organizers
- Reassignment
- Reminders
- Service Animal
- Social Skill Builders
- Support Person
- Training Modifications
- Uninterrupted Work Time

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 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 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.

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.vgvh.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 <u>custserv@nlm.nih.gov</u> 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.

National Center for Biotechnology Information

8600 Rockville Pike Bethesda, MD 20894 <u>pubmedcentral@ncbi.nlm.nih.gov</u> 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 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 Communites

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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